The Spaces Between Us

A Qualitative Exploratory Study of Perinatal Death, Burial & Bereavement in 20th century Ireland

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Summary

Background: a preliminary review of perinatal death literature established there was a paucity of research examining the cultural context of perinatal mortuary ritual, and its relevance to grief theory

Aims: to learn about perinatal mortuary rituals and see what effect their absence or presence has over a lifetime with regard to disenfranchised grief and continuing bonds theory

Methodology: a social constructionist approach was used in this interdisciplinary qualitative exploratory study

Methods: the dataset was comprised of historic and contemporary qualitative data. The date range for the study was 1900 – 2000. A qualitative survey of bereaved parents whose baby died prior to 2000, or adult children of bereaved parents, were convenience sampled (n=20). The National Folklore Collection, an Irish oral history archive of 1930s life was purposefully sampled for relevant records (n=1200). The data was analysed using a framework adapted from Howarth (2007a).

Findings: three forms of mortuary ritual were identified as prevalent in Ireland in the 19th century, these coalesce towards the start of the 20th century, and were affected by social class and place of death. Evidence of traditional mortuary rituals for perinatal infants is described, these rituals were comparable to those for adults, including burial. Irish mortuary rituals were social rather than religious. The purpose of rituals was sociological rather than psychological meaning in collectivist societies such as Ireland, mortuary rituals were the ties that bind the community. This was also true for perinatal deaths. A key finding is that parental grief lasted a lifetime. Adult mortuary rituals incorporated remembrance activities for babies who died. End of life visions which reunited parents with their dead children in the afterlife were commonly recorded. Parental distress at time of birth was noted – this remains constant across time, social class, and frequency of death.

The biggest difference in Irish mortuary ritual was found between hospital and non-hospital birth. The recommendation of funeral as a hospital intervention for perinatal death was traced. It discovered the intervention was introduced without the benefit of adequate evidence, was predicated on psychotherapeutic models popular in the 1970s, and originated in Anglo-American individualist cultures. By recommending funeral as an

intervention, this created an ethnocentric one-size-fits-all biomedical policy, which overstepped from the medical to the social world. The policy overlooked the significance of culture in the exercise of mortuary rituals, ignored the presence of birth related trauma and insisted on confronting reality. The policy became part of best practice guidelines in 1985. This has relevance as the same policies continue to be used today. This may have implications for collectivist cultures or low resource communities who continue to experience high rates of perinatal mortality. Western psychological models may create a form of culture clash which result in disenfranchised grief or disrupt continuing bonds to the dead, in collectivist cultures.

Conclusions: interdisciplinary research is challenging but offers benefits, retrospective data can be an asset in social research. Hospital birth may lead to disenfranchised grief. Continuing bonds exists regardless of whether mortuary rituals are performed. Funeral as an intervention may not be appropriate and oversteps from the medical to the cultural world. Parents continue to have strong emotions about their birth experiences, these can last a lifetime. Caregiver interactions and respectful care remain important. This thesis argues that more research on the plasticity of grief and the cultural expression of emotions is essential, and that midwives reconsider the current domain of practice.

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Dedication

for

Josephine

who would have been so proud

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Glossary

Cillín / *Cillíní (plural)*	Anglicised as Killeen, it refers to a type of folk burial ground in Ireland commonly believed to be unconsecrated and for the burial of unbaptised infants.
Great Famine	Ireland's most notorious famine occurred during the mid-1800s resulting in mass death and displacement of its population. Known in Irish as *Gorta Mór* or the Great Hunger
Hagart	A section on a farm used for drying of hay or other domestic type functions. Also known as a haggard.
Intervention	An action taken by a healthcare professional. During birth, these are known as birth interventions. When one intervention creates the need for another intervention, this is known as cascading intervention.
Limbo	*Limbus Patrum* or *Limbus Inferni,* meaning edges of hell. Commonly known as Purgatory, a place of suffering for souls of the dead prior to entry to heaven. *Limbus Infantum* was a version for unbaptised children who remained in purgatory but without suffering.
Meitheal	*Meitheal* is an Irish word for a mutual and communal exchange of labour within a specific social network. It applied to agricultural activities but also the care of the dead.
Poor Laws	The Irish Poor Law Act 1838 (the 'Poor Law') was introduced to combat the destitution of the largely impoverished population, remaining in place until the 1920s. It governed the introduction of the workhouses
Unbaptised	A person who has not received the Christian sacrament of baptism. Lay baptism (*baiste an úrlair* (baptism of the floor)) was widely practised in Ireland

List of Abbreviations

ADC	After Death Communication
AML	Active Management of Labour
ARRG	Annual Report of the Registrar General
CMS	Clinical Midwife Specialist
CSO	Central Statistics Office
GRO	General Registrar's Office
ELV	End of Life Vision
HSE	Health Service Executive
ICM	International Confederation of Midwives
IFC	Irish Folklore Commission / *Coimisiún Béaloideasa Éireann*
NBS	National Bereavement Standards
NFC	National Folklore Collection
NMBI	Nursing and Midwifery Board of Ireland / *Bord Altranais agus Cnáimhseachais na hÉireann*
RCM	Royal College of Midwives
RCOG	Royal College of Obstetricians and Gynaecologists
WHO	World Health Organisation

1 Introduction

1.1 Overview of Perinatal Death

Globally, each year approx. five million babies die at or around the time of birth. This figure is comprised of 2.6 million babies, over 28 weeks gestation, who are stillborn (Blencowe *et al.* 2016; Lawn *et al.* 2016) and approx. 2.4 million neonatal deaths (Hug *et al.* 2019). Of these neonatal deaths, that is deaths under 28 days, one million infants survive for less than 24 hours and 75% die within the first week of life (Hug *et al.* 2019). Startling as these figures are, they represent a 51% decline of the global neonatal deaths recorded in 1990 (Hug *et al.* 2019). More stark, is that 42% of stillborn babies die during labour (intrapartum) meaning 1.4 million stillbirths are preventable (Lawn *et al.* 2016; Hug *et al.* 2021).

Perinatal deaths, meaning deaths around the time of birth, are a statistical category defined by causes of death, constituting stillbirths over 28 weeks gestation, and early neonatal deaths (within the first seven days) (Peller 1948; Blencowe *et al.* 2016).[1] In Ireland, approx. 400 families experience a perinatal death (National Perinatal Epidemiology Centre 2018; 2022) annually.[2] An estimate for Ireland in the 1950s, indicates approximately 3,500 mothers lost a baby in the perinatal period.[3] These perinatal deaths received little attention historically and parental grief went largely unacknowledged within and outside of hospitals. Though a considerable psychological literature has since developed regarding the impact of perinatal death, few studies examine the long-term impact of perinatal grief on bereaved parents (Smart 2003) or the significance of funerary ritual (Wijngaards-de Meij *et al.* 2008).

[1] Perinatal incorporates ante, intra and post partum, or around the time of birth, defined by Peller (1948) who argued that as the causes of death were different in the first week of life versus the following three weeks, the first month of life, biologically speaking, is not a unit at all. The Centres for Disease Control (CDC) now follow two definitions: the first is Peller's (1948), Perinatal Definition I, which includes foetal deaths over 28 weeks gestation plus neonatal deaths under seven days. Perinatal Definition II being the more inclusive definition includes foetal deaths of 20 weeks gestation to 28 days post birth (MacDorman & Gregory 2015).

[2] In Ireland, a perinatal death includes the death of an infant from 24 weeks gestation to seven days post-birth and/or weighing more than 500g. This definition has changed in Ireland – before 1995, the definition for stillbirth used a gestational age of 28 weeks.

[3] Perinatal Mortality rate for Ireland in 1953 was estimated at 53.7 per 1,000 live births, translating into 3,360 estimated perinatal deaths – this estimate was based on recorded stillbirths in the three Dublin maternity hospitals, no estimate is offered prior to 1946 (CSO 1960; Deeny 1995).

1.2 Rationale for Research

When analysing aspects of pregnancy loss, it is important to situate them in the broader conceptual debates and sociocultural contexts in which they occur (Šmídová 2019a). The move to hospital births represents perhaps the greatest sociological change not just of the twentieth century but of humankind (Nash 2015a). In Ireland, the migration from home to hospital birth took place from the late 1930s, accelerating to 66% of births in hospitals by the mid-1950s – by the early 1970s less than 1% of births were domiciliary.[4] This shift in place of birth changed the place of perinatal death, moving it from the domestic sphere into a medicolegal bureaucracy. Hospital protocols for perinatal death became a rallying point for social reform in the mid-1960s (see Chapters 2 and 5). When a baby died at that time, parents did not get to see, hold, or care for their baby before baby was hastily taken away (Bourne 1968). As healthcare professionals provide care to women through all phases of their lives, it is essential to understand the long term impact of perinatal bereavement, particularly in older women who may be at higher risk for unresolved grief given hospital practice at the time of their loss (Cecil 1996; Dyson & While 1998).

Perinatal death is still (predominantly) contained within the hospital setting and so due to its relative invisibility, perinatal loss remains an abstract concept for general society, though painfully personal for parents (Malacrida 1999; Kobler & Kavanaugh 2007; Cacciatore 2009; Yamazaki 2010; Cacciatore & Flint 2012). The National Bereavement Standards (Browne 2016) for hospitals were developed as part of Ireland's first cohesive National Maternity Strategy (Langford 2016). This highlighted the importance of providing unified and empathic care pathways to bereaved parents in hospital in the wake of loss. The follow-on report from the National Bereavement Standards, *On the Implementation of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death*, (O'Donoghue & Cotter 2021) emphasises the impact of historic practices pertaining to perinatal death and burial. The report quotes Nuzum & O'Donoghue (2021) who say

> as a nation, the legacy of how we responded to the loss of a pregnancy or the death of a baby casts a long shadow over the individual, familial and communal experience of perinatal loss. The experience of this shadow continues to be felt today

[4] In 1955, almost 34% of births were at home, by 1965 this figure dropped to 10% and by 1975 domiciliary births account for just 0.7% of births (compiled from *Vital Reports* (CSO 1955; 1965; 1975))

This is an imperfect characterisation of historic perinatal death due to the paucity of social history relating to it. It demonstrates, however, that a comprehensive social context to perinatal death and burial is required, as it reveals perinatal death as both a personal, and societal event. It means that there is a need to reassess the role of rituals for families relating to birth and death, and the broader social response to perinatal death and how maternity hospitals may have shaped and changed these perspectives.

Though the National Bereavement Standards is a major step forward in the provision of universal best practice among Irish hospitals, it does not adequately address the ongoing needs of already bereaved parents in the community and how those needs may change over the long term. The numbers of parents who experience perinatal death have declined significantly in Ireland over the last twenty years, yet the ongoing lifetime impact of perinatal death has not been adequately researched either in an Irish or global context. Little is known of the long term mourning processes involved following perinatal bereavement (Dyson & While 1998). This phenomenon is not rare, is of national and international significance and has consequences for the mental health and wellbeing of women and their families. Additionally, despite the changes in how hospitals have started to manage perinatal death, parents still experience stigma, social isolation, and disenfranchised grief (Mulvihill & Walsh 2014; Miller *et al.* 2019; Pollock *et al.* 2020). This points to a gap in our understanding of perinatal bereavement and underpins the need for further research into the nature of long-term mourning, specifically an exploration of the value of socially expressed rituals regarding death.

This project thus provides insights into the cultural heritage and social history of perinatal funerary ritual. In addition it provides insights which may influence future provision of health care supports and inform future research. This study is a significant contribution to the scholarship on death, burial, and bereavement.

1.3 Research Aims & Questions

This research started with one basic question - ‘when a baby died a long time ago, what happened next?’ I was curious as to how we have ended up with a culture where, after the death of a baby you are expected to, as Jalland (2013) says, ‘do your grieving like your praying’ that is, silently. A preliminary review of the literature relating to perinatal death established there was a paucity of research examining the cultural context and existence of perinatal mortuary ritual, and their relevance to grief theory.

The overall aim of the study is to understand more about the significance of Irish mortuary rituals in the context of perinatal deaths, and whether ritual had any discernible effect on two grief theories, disenfranchised grief, and continuing bonds, over time. Disenfranchised Grief (Doka 1989) is a grief that is not socially recognised, sometimes through the absence of rituals. Alongside this sits the theory of Continuing Bonds (Klass *et al.* 2014), a theoretical perspective which posits that people define and continue relationships with their deceased loved ones. The connection between the two primary theories of Disenfranchised Grief and Continuing Bonds are linked to the performance of ritual, or its absence.

The rapid transition from the social to medical model of childbirth, from the 1930s, resulted in the gradual containment of infant birth into the Irish maternity hospital system. The maternity hospital represents the intersection of the public and private space, moving perinatal death from the home and into the public domain, and a bureaucracy in which it must be managed. How might these changes affect burial practices, social customs, and parental grief? How might families respond whether with or without ritual to guide them? When linked with the literature, the questions that emerged were:

- Is there evidence of social rituals relating to perinatal death in the past?
- What significance does ritual play in family experiences of perinatal loss?
- What effect did hospital birth have on social rituals (baptism, naming, burial, funeral) following baby loss?
- How do families remember their infants, particularly in the absence of social rituals?
- Does the absence or presence of ritual influence Disenfranchised Grief or Continuing Bonds?

1.4 Choosing to Study Death

The topic of death is not new to me. Perinatal death was the subject of my master's research in 2013, which coincided with the breaking news regarding burials at Tuam Mother & Baby Home, which then affected the progression of that study. Over the ten years since, I have accumulated a myriad of stories that are sometimes fascinating and often heartbreaking, each in a small way contributing to how I think about this topic – these stories linger in my memory, perhaps another time I will get a chance to tell them.

Following from my prior research, I was curious as to how Ireland with such a rich death tradition appeared to have none for the deaths of infants, particularly as even a cursory look at early twentieth registration data indicates 20% of all deaths were to children under ten years old (CSO 1930). As a social scientist, rather than a midwife or historian, this disparity suggested there was an important story to be told about the intersection of life and death.

At the start of this project, I had intended to do oral histories, and it was at an oral history conference, I heard for the first time, the indigenous Australian Wiradjuri term *yindyamarra*. It is a concept that means to live a life well, to go slowly. It is a holistic way of thinking and being in the world, and represents concepts of respect, honour, and responsibility. These seem like humanistic principles which should form the basis of respectful research, particularly for this topic, and guided the way in which I approached the study. However, it also made me evaluate the role of culture – and not just contemporary Irish culture but our own ancient heritage and the role it plays in shaping our language, traditions, and rituals.

1.5 Structure of Thesis

As this is an interdisciplinary research study, using multiple data sources and methods of analysis, this thesis is structured to reflect this dimension of the project.

Chapter 1 introduces the topic and outlines the structure of the thesis.

Chapter 2 forms the theoretical backbone of the study and examines the multidisciplinary scholarship of death studies, focusing on mortuary ritual. The chapter briefly explores cultural ritual responses to perinatal death, including socioreligious rituals.

Chapter 3 confines itself to the philosophical, ontological, and epistemological elements of the study. It includes a discussion on the challenges of using interdisciplinary approaches to research and how different disciplines approach knowledge. The chapter finishes with an overview of generic approaches to qualitative research as the research design, and how it has value.

Chapter 4 continues the methodological discussion, discussing the changes to the project as a consequence of the pandemic and the step by step approach taken to ensure completion of the study. The rest of the chapter describes the research methods that were used to ensure this.

Chapter 5 explains the historic background to the topic of infant death and burial in Ireland and the contemporary interest to Irish society. The chapter continues with the historical development of midwifery practices and psychological theories which culminated in the social reform of perinatal death in hospital in the late twentieth century.

Chapter 6 is the first of three findings chapters. This chapter is restricted to the contemporary accounts gathered from bereaved parents and adult children of bereaved parents. These personal accounts cover the period 1945 – 1999 and show some similarities and differences among parents experiences of perinatal death in this time period.

Chapter 7 is dedicated to discussion of the contemporary personal accounts presented in chapter six and relates this discussion to the five research questions posed in the introduction.

Chapter 8 is the second of three findings chapters. This chapter takes a macro perspective and traces key developments through the nineteenth century, which shaped Ireland's mortuary rituals, some of which persist into the twentieth century. Summarising what the main mortuary customs were in Ireland enables a comparison between adult and perinatal mortuary rituals, and to assess to what degree they differed. The discussion of this complex history closes the chapter.

Chapter 9 is the final of three findings chapters. This chapter explores social responses to perinatal death prior to 1950. Despite the belief there were no ritual responses to perinatal death in the past, this chapter disputes that view. This chapter provides evidence of perinatal mortuary ritual preceding the mid-twentieth century and finishes with a discussion of these customs in the context of the research questions.

Chapter 10 integrates the total findings into a cohesive discussion. This chapter clarifies the chronology of rituals and the relevance of funeral as an intervention. The usefulness of interdisciplinarity is summarised and the implications for research are outlined. The chapter closes with the conclusions drawn from the study and recommendations for future research.

2 Literature Review

2.1 Introduction

Perinatal death, perhaps more than any other research topic, is the pinnacle of complex research, a juxtaposition of the only two sureties in life – birth and death. As such, it represents the intersection of class, gender, parenthood, identity, personhood, kinship, politics, healthcare, and power, as non-exhaustive examples. By extension, the topic is peppered across many disciplinary fields of reference. To borrow from the field of technology, the term 'hairball' is applied to enmeshed, entangled, jumbled, or confusing technological problems which are difficult if not impossible to simplify (Techopedia 2017). This is a useful analogy for the study of death, with its interconnecting webs of meaning, cultural embeddedness, and scholarly divisions.

Death is a social rather than a medical event, with its own ecosystem (Sallnow *et al.* 2022; Murray 2015; Mamo 1999). Similarly, perinatal death, poised at the juncture between birth and death, is also a social rather than medical event (McCreight 2008; Van der Sijpt 2010; Murphy 2019). Though rituals after stillbirth are recommended to help women 'recover' from grief and hope for subsequent successful pregnancies (Tseng et al. 2018), there had until the mid-twentieth century been little interest in understanding the significance of mortuary rituals.

The long term impact of perinatal bereavement on parent's lives has been neglected (Lang *et al.* 2005; Bennett *et al.* 2008; O'Leary & Warland 2013). Longitudinal studies of perinatal bereavement have typically been confined to two years post death (Boyle 1997; Dyson & While 1998). Given the growth in nonsequential models of adaptation to loss, Saltzman (2019) suggests dispensing with longitudinal psychological models that control for time in favour of "subjective, meaningful and cyclical time" to more closely align with the lived experiences of the bereaved. Perinatal grief is described as unique, intense, complicated, and long lasting with recovery taking on average two to four years (Bennett *et al.* 2008; O'Connell *et al.* 2016). This contradicts the few retrospective qualitative studies undertaken which have clearly identified the ongoing emotional impact of loss many years later (Rosenblatt & Burns 1986; Cecil 1996; William 1996; Dyregrov & Dyregrov 1999; Smart 2003; O'Leary & Warland, 2013; Gravensteen *et al.*, 2013; Christiansen *et al.* 2013). However, these retrospective studies include participants who may fall outside the parameters of perinatal death (i.e. include early miscarriage, or deaths of older babies and toddlers), and/or are typically

limited to less than twenty years post loss. For example, Smart (2003) included participants who gave birth fifty years earlier but included a range of reproductive losses including infant and toddler death; and Rosenblatt & Burns (1986) study though spanning a time period of two to 46 years post death, also included early miscarriages, and ectopic pregnancies. O'Leary & Warland (2013) completed a secondary data analysis, the original data included a subset of parents (n=9) who experienced perinatal deaths between 1948 and 1975. Whilst these authors justify the reasons for their samples, none of them look explicitly at perinatal death and ritual, or the lifetime impact of both. The reason why this becomes important is, in the context of ritual, most perinatal deaths occur within the first hours of birth meaning babies and their parents are isolated within hospital walls and opportunities to meet others are limited, historically resulting in an absence of rituals.

2.2 Defining the Literature

2.2.1 Disenfranchised Grief & Continuing Bonds

By the late twentieth century, two models of grief theory which emphasise aspects of social rather than psychological behaviour had been published. The first model, Doka's (1989) theory of Disenfranchised Grief, meaning a grief that is not socially recognised, explores situations in which the right to grieve is not socially sanctioned (i.e. socially acknowledged, validated, or supported). In the context of perinatal death, this relates to the absence of defined funerary ritual and/or the social minimisation of parental grief (Lang *et al.* 2011). The second model, Continuing Bonds (Klass *et al.* 2014), published in 1996, explored the ongoing relationship between the bereaved and their dead – this was quite a revolutionary idea in the context of grief theory, which to this point had emphasised severing ties to the dead (breaking bonds) for the healthy resolution of grief (Worden 2015). These two models represent the duality of the bereavement experience – the external world relying on public recognition, and the internal world which seeks an outer expression – both being socially experienced. However, for most of the twentieth century, the time period under review in this study, these theories did not yet exist. Instead, through the twentieth century, as discussed in Chapter 5, a focus on funeral develops within the psychological literature, conflating the experience of perinatal death with adult death.

Agreeing that psychological approaches fail to consider the broader social context which in turn distorts understanding of the experience of loss, other authors advocate for complementary sociological perspectives which incorporate historical and cultural

contexts of death and grief (Layne 2003; Neimeyer *et al.* 2014; Thompson *et al.* 2016; O'Mahony 2017; Murphy 2019; Šmídová 2019a). More recently, Sallnow *et al.* (2022) suggest that studies of death should include diverse disciplinarity, for example, highlighting that archaeological investigation of burial sites and graves, could generate insights into historical practices around death, dying, and bereavement and the death systems they were part of. This Sallnow *et al.* (2022) argue would provide a more holistic understanding of the death ecosystem, hence this study takes a multidisciplinary approach to the study of a complex topic, perinatal death. The umbrella term, Death Studies, incorporates this multidisciplinary approach to the study of death, dying, bereavement, and end of life care (Borgstrom & Ellis 2017).

2.2.2 Defining Perinatal Death

2.2.2.1 Conceptual Ambiguity

In the mid-1990s, Cecil (1996, p.179) remarked that the "everyday" experiences of women, including pregnancy losses, had "rarely been recorded" – which is extraordinary when considering up to 30% of all pregnancies (and up to 15% of clinically recognised pregnancies) result in miscarriage, most occurring within the first trimester (Linnakaari *et al.* 2019). McCreight (2008) and Murphy (2019) assert pregnancy loss is more than a medical event and the way in which loss is socially constructed affects parental experiences. These social constructions include statistical, legal, medical, and cultural terms which appear to have simple meanings but the use of the language regarding pregnancy outcomes assigns social value to these constructions (Jutel 2006). Though Jutel (2006) refers to the range of terms to describe a pregnancy not carried to term, this omits the category of deaths after birth (i.e., early neonatal deaths).

The scale of the challenge in researching perinatal death rests in the array of phrases used interchangeably to describe different reproductive experiences or 'generation' (Donaghy 2021). Quickening or ensoulment is an old term used to define signs of foetal life, occurring about the fifth month of pregnancy – common law up to the nineteenth century failed to apply criminal penalties to abortions before this time, though once quickening had occurred, abortion was punishable by death (Sauer, 1978). The Ellenborough Act of 1803 gave legal protection to the pregnancy from conception, and abortion of either a quickened or unquickened foetus was subject to criminal charge (Sauer, 1978). From 1869, the Roman Catholic Church *Apostolicae Sedis Moderationi* reflected this legal position and dismissed the distinction between

the quickened and unquickened foetus in canon law, applying immediate excommunication for any termination (Brind'Amour, 2007). Quickening was still being used clinically in the early twentieth century to define foetal maturity (Withycombe, 2018).

Further, historic explorations of generation have illustrated that within the eighteenth, nineteenth and twentieth centuries, clinicians used the terms abortion, miscarriage and stillbirth synonymously without necessarily defining gestation (Elliot 2014; Durbach 2020; Middlemiss 2020; Donaghy 2021) with a knock-on effect on civil registrations. Even up to the late 1950s, Durbach (2020) found that UK clinicians flouted the law and exercised individual clinical judgement regarding foetal viability, with babies born alive before 28 weeks gestation (even though living for some days after birth) neither having their birth or death registered, yet subsequently presented for burial as stillbirths.[5] Reflecting this ambiguity, the lack of clear definition appears as late as 1981 in the annual *Clinical Report of the Rotunda Hospital* (Henry 1982).[6] The report details that the hospital had 755 deliveries under 28 weeks gestation, of which three were moles, 679 were abortions, and 73 were miscarriages (of which 21 were live born); and it also uses interchangeably the terms stillborn and dead born, for foetal deaths over 28 weeks gestation (Henry 1982, p. 9.).[7] Foetal loss is defined in a variety of ways including gestation (over or under 28 weeks) and different weight classifications.[8] Further, when (second trimester) babies subsequently died it appears they were not included in perinatal statistics, being under 28 weeks gestation. Finally, despite the legal definition of viability (of 28 weeks gestation), babies under this threshold did survive and clearly medical interventions took place to ensure this. This reflects Durbach's (2020) assertion that doctors and midwives exercised their clinical judgement as to what constituted stillbirth and viability. The fluidity of 'generation' terms for the same event thus complicates the historical and social context of reproductive loss. This ambiguity persists in contemporary life, for example, in Ireland,

[5] One medic argued that registration only caused parents the trouble of a funeral and the *British Medical Journal* in 1954, remarked that abortion, stillbirth and live birth were matters of opinion (Durbach, 2020).
[6] The Rotunda Lying-In Hospital is a major maternity hospital in Dublin, established in 1745
[7] Abortion was not legal in Ireland in the 20th century so its usage here indicates the medical term spontaneous abortion, meaning the natural expulsion of the foetus from the mother
[8] This indicates that despite the legal definition of viability (28 weeks gestation) the babies born at the margins of viability (late second trimester) inhabit both the definitional category of miscarriage and living child. The distinction between abortion and miscarriage is not clarified in this report but can be understood as abortion referring to early pregnancy loss (first trimester) and miscarriage being applied to later pregnancy loss (second trimester).

a recent national survey found that 40% of respondents defined miscarriage as pregnancy loss after 24 weeks (National Care Experience Programme 2021).

Civil registration was initially introduced for the purposes of confirming inheritances and property rights of the landed gentry; being concerned with the status of legal persons, it only required the registration of live births (there was no provision for stillbirths) (Hemenway *et al.* 1928). Extrapolated data for public health, in the form of vital statistics, was an offshoot of this original purpose (Hemenway *et al.* 1928).[9] Infant mortality was only gradually introduced into vital statistics and over the course of the late nineteenth and early twentieth century statistical measurements continued to be refined and defined (Armstrong 2008) with considerable debate in the medical press regarding the definitions to be applied, in particular to international data regarding stillbirth (Lawson 1917; Sterling 1927; Hemenway *et al.* 1928). The issue with civil registration is that it is now interpreted as a threshold concept for personhood – yet this threshold is an ambiguous one, fluid and adaptable contingent on context (Ballantyne 1902; Durbach 2020; Middlemiss 2020); the lack of international uniformity as to what constitutes personhood or stillbirth still remains (Sanger 2012).[10] In 1948, the term Perinatal Mortality was coined to cover the overlapping medico-statistical categorisations of stillbirth and early neonatal death based on comparable causes of death (Peller 1948). It was the first attempt to create definitive clarity regarding stillbirth. Peller's definition, broadly in use still today, was predicated on the basis that causes of death for neonates under seven days occurred for different reasons than those between two and four weeks. Peller (1948) argued that by examining causes of death, third trimester stillbirths and early neonatal deaths constituted a singular category, worthy of clinical focus. He referred to these as perinatal, meaning around

[9] The Act for Registering Births, Deaths, and Marriages in England 1836 established the General Register Office (GRO) for recording of vital statistics (Cullen, 1974); in Ireland, marriages of non-Catholics were counted from 1845, followed by the introduction of Registration of Births, Deaths and Marriages Act 1864 which extended data collection nationally and resulted in the collation of vital statistics (National Archives of Ireland, 2022)

[10] In 1927, as statistical, legal and medical opinion consolidated, considerable confusion over the definition of stillbirth remained (Sterling 1927). The League of Nations proposed new international definitions which were rejected by the American authorities (in part over concern of concealment of infanticide) as it constituted 'misty theory' (Hemenway *et al* 1928, p.31). The Americans argued the proposed terms of stillbirth, dead birth, foetus, and miscarriage rendered the classifications of science out of step with the [American] law (Hemenway *et al.* 1928). Herein lay the problem then as now, and the need for multiple recording and reporting systems.

the time of birth.[11] The World Health Organisation (WHO) on Health Statistics (1950) recommended two parameters for the measurement of foetal demise, 20 and 28 weeks gestation, on the basis that babies were rarely born alive before 20 weeks, and that by 28 weeks three times more babies were born alive than stillborn, indicating that from a *clinical* perspective, this represented a measure of viability.[12] In essence, perinatal death, was defined statistically, in a specific, measurable way based on causes of death (largely attributed to prematurity), in order to mobilise medics to take concerted action – perinatal death then is a medico-statistical definition.

2.2.2.2 Perinatal Loss as a Social Event

Through to the late twentieth century, reproductive social sciences scholarship focused on psychological dimensions of pregnancy loss neglecting both cultural and historical context, whereas historians of birth had focused on death (Layne 2003).[13] By the early 1980s, anthropological studies trended away from a focus on death rituals towards emotions, and the experience of grief in everyday life (Layne 2003). This trend is reflected in the revival of expressive grieving,[14] led mainly by middle-class women from the 1970s, attributed to greater liberal attitudes and freedom of emotional expression, wrought by the counterculture of 1960s England (Walter 2000; Jalland 2013).[15] This contemporary trend towards the emotional aspect of grief ignored the intellectual dimension present in nineteenth century parental grief, however, thus reducing it to a

[11] Perinatal means ante, intra and post natal, or around the time of birth – Peller argued that the causes of death were different in the first week of life versus the following three weeks, maintaining the first month of life, biologically speaking, is not a unit at all (Peller 1948). Sutherland's (1949) work on the epidemiology of stillbirth, expanded the link between stillbirth and prematurity, quoting various studies that estimated 50% to 70% of stillbirths occurred before onset of labour. This figure is fairly consistent with contemporary accounts which estimate 42% of stillbirths are intrapartum, and thereby avoidable (Lawn *et al.*, 2016; Hug *et al.*, 2021).

[12] The World Health Organization (WHO) (2021) introduced a category in 2016, ICD-PM (the tenth International Statistical Classification of Diseases and Related Health Problems i.e. ICD-10), to capture specific causes of death, linked to maternal outcomes, to streamline international data collection and comparison. For international comparison, 28 weeks gestation is used as the defining feature for stillbirth (Blencowe *et al.* 2016) as there are difficulties in applying parameters of weight versus gestational age according to ICD-10 classification, see Lawn et al., (2016) for discussion

[13] Layne (2003) defines the social sciences as incorporating sociology, nursing, psychology, and anthropology. Layne (2003) asserts that scholarship focused on models of quantification, defining and refining measurements of grief, depression, and social support, ostensibly with the aim of improving care following pregnancy loss.

[14] Studies of grief in early twentieth century Britain and Australia, identified that post World War I, women grieved more like men, i.e. silently (Gorer 1965; Jalland 2006; 2013).

[15] Counterculture in this context refers to social, cultural, and intellectual changes in the post-modern anti-establishment social movements of the 1960s and 1970s. This included the rise of human and civil rights activism, and second wave feminism, which saw women enter prominent careers in media and gave them platforms for women's issues to gain public attention (Jalland 2013; Walter 2000, p.2)

temporary state of feelings which both marginalises and trivialises the experience, according to Simons & Rothman (1992), as cited by Klass (2013, p.599).

The medicalisation of maternity has frequently ignored that reproductive loss occurs within women's social lives (Cecil 1996; McCreight 2008; Van der Sijpt 2010), thus this research orients towards the social dimensions of perinatal death and the way in which parents socially experience loss, viewed through the use of mortuary rituals. Within the dominant psychiatric/psychological view of perinatal death, which overlooks stillbirth as a social event (Murphy 2019) and consistently refers to the role of funeral but neglects to study what actual benefit it offers (Wijngaards-de Meij *et al.* 2008), sociology can offer a different perspective. Whereas psychology focuses on individual experience within a biomedical framework, sociology explores the interactive dynamic of the individual *with* society, social context is not just a backdrop to individual experience but ultimately shapes and refines it (Howarth 2007a; Thompson *et al.* 2016). Thereby sociological studies which focus on the social context of death and burial, complement psychological theories (Thompson *et al.* 2016; Murphy 2019), and provide a more holistic consideration of perinatal death.

When it comes to research relating to women, often there is a lack of archival data and what is produced is frequently done so from a male perspective (Martin 1995; Perez 2019; Yow 2005). Marginalisation of experience as well as medicalisation of reproductive loss has led to a one-sided view of this 'socially complex and dynamic' event (Van der Sijpt 2010) with Cecil (1996, p.179) noting the everyday lives of ordinary women remain "uncollected, unanalysed and lost to documentation… pregnancy losses have rarely been recorded". Infant death studies are impeded by the dearth of general death, burial, and bereavement scholarship, particularly from an Irish perspective, which renders comparative analysis problematic. The reliance on formal registration data to study the broader category of infant mortality, masks analysis of a distinctive category of death, the perinatal infant.[16] As detailed above, the literature relating to perinatal death contains conceptual ambiguities and terms which are poorly defined, conflating miscarriage, stillbirth, abortion, neonatal (and sometimes child) death into a singular category, often referred to generically as 'pregnancy loss', thus making for what Murphy & Cacciatore (2017, p.129) refer to as an "imprecise" literature. Further, the unique characteristics of perinatal death (mainly stillbirth) are

[16] Historical studies of infant mortality focus on registration data, see for example Breathnach & Gurrin (2017); Breathnach (2017)

difficult to study due to their virtual invisibility in the historical record (Hart 1998), particularly in an Irish context.

Due to the 'imprecise' literature and the 'invisibility' of perinatal death in the historical record, in terms of interdisciplinary evaluation of the literature, this thesis relies on Howarth's (2007a, p.2) sociological approach to mortality

> …[whilst] no individual discipline or profession can justify a claim to privileged knowledge of mortality each offers insights into the relationship between life and death and furthers our understanding of the two.

2.2.3 Systematic Search Strategies

The biomedical literature tends towards intervention-based approaches to research, using models such as PICO (Population, Intervention, Comparison, Outcome) for quantification studies and a reliance on randomised controlled trials as the gold standard in evidence-based research (Booth 2006). For qualitative health research, SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) or SPIDER (Sample, Phenomenon, Design, Evaluation, Research Type) models are also suggested, however, as these models focus on interventions and/or synthesis, they are not useful for the kinds of research which seek to contextualise understanding or examine attitudes, such as exploratory studies (Booth 2006; Cooke *et al.* 2012; Korstjens & Moser 2017).

A review of relevant disciplinary databases yielded results far beyond the scope of this thesis to analyse (see Table 1 for search terms) e.g., a search of CINAHL yielded 15,983 results for stillbirth, and 242,031 for the term grief compared to MEDLINE which generated 58,244 and 619,693 results respectively. There is a notable increase in both these topics since the 1970s. Combining the search terms, stillbirth + grief, illustrates that 62% of related papers in CINAHL were published within the last ten years. Comparatively, in the same period, 37% of related papers were published in PSYCINFO, with only eleven papers published in that database until 1974. Searches for stillbirth + funeral yield twice as many studies in CINAHL compared to PSYCINFO, again with 60% (CINAHL) versus 44% (PSYCINFO) published in the last ten years. This reflects an increased interest in the care pathways relating to mortuary practice and the effect of such on psychological responses. Goldenberg *et al.* (2011) framed the global significance of stillbirth as an unrecognised public health issue in 2011; just one of a sequence of articles published in *The Lancet, Ending Preventable Stillbirths Series*, highlighting the need for stillbirth research, which may in part explain the surge

observed in the database searches.[17]

TABLE 1: DATABASE SEARCH RESULTS, UNFILTERED SPECIFIED SEARCH TERMS (EXCLUDES BOOKS)

ENTRIES PER SEARCH TERM PER DATABASE (UNFILTERED)	HISTORICAL ABSTRACTS	WILSON HUMANITIES	WILSON SOCIAL SCIENCE	CINAHL	MEDLINE	PSYCINFO	EMBASE	WEB OF SCIENCE
STILLBIRTH[1]	168	164	498	15983	58244	2041	64004	67036
STILLBORN OR STILLBIRTH	138	112	457	11152	38521	1622	26943	16404
GRIEF[2]	7906	9981	55278	242031	619693	458419	999759	1243975
GRIEF ONLY	545	2045	4514	12012	13511	20269	16282	15032
FUNERAL[3]	8898	15662	13412	13025	87224	16586	59975	136506
PREGNANCY LOSS	7	22	125	3022	10546	797	11670	9894
MISCARRIAGE	124	193	475	6639	24954	1605	21537	29784
PERINATAL DEATH	21	7	205	10028	7957	342	6620	2826
AMBIGUOUS* OR AMBIGUITY	4849	6089	7479	465	1815	3371	45685	129324
SILENCE[4]	3756	6904	5494	11926	72161	18748	96174	187685
STIGMA	529	427	5888	26480	32865	31140	45685	52485
SHAME	573	1627	2937	4981	7211	13862	9227	15624
STILLBIRTH[1] + GRIEF	5	13	125	1532	1820	876	2279	2056
STILLBIRTH[1] + FUNERAL[3]	12	8	30	140	175	70	152	0
MISCARRIAGE + FUNERAL[3]	2	18	11	35	53	39	27	81
STILLBIRTH[1] + STIGMA	2	1	7	80	64	18	81	84
STILLBIRTH[1] + AMBIGUITY*	0	1	7	0	0	0	110	98

1	"stillbirth*" or "still born" or "stillborn*" or "fetal death" or "foetal death" or "intrauterine death" or "dead born" or "dead birth*" or "perinatal death" or "intrauterine fetal death" or "intrauterine foetal death" or "fetal demise" or "foetal demise"
2	grief or bereavement or mourning or anxiety or depression or sorrow or melancho*
3	funeral or disposal or burial or rites
4	silence or silent or silenced

[17] *Ending Preventable Stillbirths Series* (2011), published 2011 https://www.thelancet.com/series/stillbirth; updated 2016, *Ending Preventable Stillbirths Series* (2016) https://www.thelancet.com/series/stillbirth

Though all databases have their usefulness and systematic search strategies have their place in research, such an approach was not a good fit for this study. Qualitative reviews encompass specified literature purposely chosen, critically appraised, and subject to deep reflection with attention to theoretical arguments, something not guaranteed by systematic searches (Newnham & Rothman 2022). Using systematic searches would narrow the field of inquiry which already limits itself with an overt focus on the psychological dimension of grief (Fenstermacher & Hupcey 2013) whereas this study is about expanding that scholarly view. This required drawing on multiple fields of scholarship which do not conform to the systematic style of searching used in health sciences. Further, due to the contention regarding this topic, this meant that the close reading of texts (see Chapter 5) applied to the collected data as well as the scholarship – it meant finding original publications, checking their data and conclusions, following the references quoted in these mid and early twentieth century texts, and reading those texts. This is an iterative system of inquiry more akin to a breadcrumb trail than systematic search, though it still retains a method of close deliberation and evaluation necessary to build context.

2.3 Sociocultural versus Psychosocial Research

The decision to focus on sociocultural aspects of perinatal death rather than psychosocial adaptation is made on the basis of two trends in the literature. Firstly, in the biomedical sphere there is an "artificial separation of mind and body, reason and emotion, nature and culture, and biology from society" (Mamo 1999, p.34). This renders the social psychological experiences of death, and its associated emotions and subjectivities, invisible (Mamo 1999). Thus the biomedical literature identifies an overt focus on psychological grief responses (Lofland 1985; Zeanah 1989; Fenstermacher & Hupcey 2013; Murphy 2019) and the effects of perinatal loss have been well documented (e.g. depression, anger, anxiety, guilt, grief (Burden *et al.* 2016; Christiansen *et al.* 2013)), with the exception of long-term grief. Secondly, the call from authors for the sociological studies of grief which consider time, historical and cultural context (Stroebe and Schut 1998; Layne 2003; Bleyen 2010; Neimeyer *et al.* 2014; Thompson *et al.* 2016; O'Mahony 2017; Rosenblatt 2017; Saltzman 2019; Šmídová 2019a).

2.4 Deviancy in the Scholarship

The contemporary interest in perinatal death, is the converse of Bourne's (1977, p.1157) experience, when writing in the *British Medical Journal* he says:

> the syndromes around stillbirth include the feature of extraordinary medical resistance to publishing anything about it… I was not able to find a single article on it [stillbirth] nor any mention of the topic in any index in the English language, even though more must presumably exist since the problem should be obvious to a blind man…

Whilst the medical journals had however published regularly on stillbirth, up to the late twentieth century these articles did not attend to the emotional management of stillbirth – the basis of Bourne's and his contemporaries' efforts.[18] The context of published articles was preoccupied, through the late nineteenth and early twentieth century, with stillbirth certifications, registrations, and perfection of statistical measurement of mortality,[19] and tied the public and medical debates on these topics to burial practices.[20] The introduction of UK stillbirth registration in 1926 was not due to concerns regarding public health but to social concerns that infanticide victims were being disposed of nefariously – only through proper medical surveillance could this practice be eliminated with the signing of death certificates and/or burial orders (Durbach 2020; Sanger 2012). This ran parallel to the medicalisation of reproduction which intertwined stillbirth with contraception, termination (abortion), and infanticide (Knight 1977; Elliot 2014; Durbach 2020). This connection between stillbirth and what were considered 'deviant' behaviours in the nineteenth and twentieth century, permeated the medical literature up to the mid-twentieth century, with miscarriage and abortion used interchangeably within the medical field, but abortion almost inevitably being used in public criminal cases (Elliot 2014). Any social history of stillbirth (or perinatal death) thus becomes entangled in social debates not just about the medicalisation or control of reproduction but also infant survival and motherhood (particularly impoverished motherhood), respectability, illegitimacy (the historical term

[18] See Seitz & Warrick (1974); Jolly (1976); Cohen et al. (1978); Lewis & Page (1978); Oakley (1980); Lovell (1983)

[19] See articles in the *British Medical Journal* - Rentoul (1890), Mullins (1895), Wall (1890), Woods (1895) as examples of discourse in the medical press

[20] See e.g. articles in the *British Medical Journal* (1863; 1889; BMJ, 1890; BMJ, 1897; 1890), the *Lancet* (1859), the *American Journal of Public Health* (1928) and *Public Health Reports* (Sterling 1927)

for children born outside of marriage) and consequently institutions providing for pregnant women, mothers, and children.[21]

The connection of stillbirth with deviancy extends beyond the medicolegal discourse, themes of illicitness permeate the biomedical, historical, and psychosocial literature. For example, O'Connor's (2005) seminal folkloric work titled *The Blessed and the Damned: Sinful Women and Unbaptised Children in Irish Folklore* reflects and reinforces the perception that stillbirth is linked to promiscuity and illegitimacy. Themes of concealment (Bourne 1968; Graham-George 2020), stigma (Murphy 2012; Omar *et al.* 2019; Pollock *et al.* 2019), shame (Murphy 2019), silence (Kelley & Trinidad 2012; Kiguli *et al.* 2015; Nuzum & O'Donoghue 2021) and social isolation (Quirk 1979; Yamazaki 2010; Pollock *et al.* 2020) underpin the perception that stillbirth, perinatal death, is something hidden and to be hidden. This 'furtive' characterisation has remained sticky in the scholarship, despite the development of medical and psychosocial bereavement interventions in clinical practice (including funeral planning and baptism e.g.) (Koopmans *et al.* 2013; Steen 2015). It forms the basis of Doka's (1989) theory of disenfranchised grief and characterises perinatal loss in a specific way. There remains a discussion as to the extent to which the scholarship perpetuates furtive themes. Markin & Zilcha-Mano (2018, p.21), for example, maintain that parental grief is a consequence of being "shunned" by society through absent rituals that "force" parents to grieve in a culture that "forbids" talking and "prohibits" public expressions of grief. This language reinforces a specific characterisation of perinatal bereavement. It focuses on ritual as a psychological salve for grief but simultaneously omits an understanding of the social context of mortuary rituals. This demonstrates the limitation of psychological models without a sociological appreciation.

2.5 The Influence of Anglo-American Theory

Cann & Troyer (2017) posit that over the last fifty years, death research in the US has privileged psychological and psychiatric perspectives, in contrast to the UK which has focused on sociocultural aspects of death.[22] This view is supported by Walter (2000) who maintains there is a clear link between psychiatric theories of grief and contemporary demands for the bereaved to tell their stories.

[21] For further explorations of motherhood and institutionalised motherhood see Kennedy (2001), Bolger, (2021), Laragy (2021); and Deeny (1955) for discussion of these issues in relation to perinatal mortality

[22] The result being sociocultural priorities have resulted in more effective policy making regarding end of life care as they are multidisciplinary (Cann & Troyer 2017)

Cann & Troyer (2017) further observe that American medical culture favours aggressive medical treatment and views death as failure, a legacy of its historic frontier past, a theme also found by Field & Cassel (1997). These culture specific variables are then exported in medical contexts as culturally agnostic and objective (Taylor 2003, quoted Cann & Troyer 2017). Similar observations can be made around birth, with more similarities than differences between American and British maternity practices (Loudon 1992).[23] Cameron *et al*. (2008) noted in their critique of twentieth century midwifery textbooks, that until the mid-twentieth century these were written by doctors. In relation to perinatal death, they found changing ideologies, rhetoric, and rituals over the decades, confirming that textbooks can reinforce cultural and professional norms. The British midwifery textbooks analysed by Cameron *et al*. (2008) were and still are used in undergraduate midwifery programmes in Ireland. Irish midwives who trained in Dublin's Rotunda Hospital could be included in the register of midwives in the UK, following the Midwives Act, 1902 (England and Wales) (Ó hÓgartaigh 2012), reinforcing professional standards that were expected in UK training. Equally, the Irish Institute of Obstetricians and Gynaecologists (IOG) was only established in 1968.[24] Up to this point, and beyond it, the UK Royal College of Obstetricians and Gynaecologists (RCOG) provided training for Irish obstetrics but with no regulatory oversight (Walsh, 2014). This illustrates how a dominant paradigm developed between the UK and America, but was implemented in Ireland via professional regulations, standards, and textbooks. In summary, what this means is the defining features of what purport to be clinically agnostic practices are in fact culturally specific.

2.6 Funeral Rituals

As with other conceptual ambiguities in death research, the terms mortuary, mourning, and funerary ritual tend to be used interchangeably, with multiple statements on what a funeral actually is, what benefits it offers, and to whom. Mortuary rituals encompass a range of behaviours and ceremonies, both public and private or a combination of both, some oriented towards the individual, others towards the social group – the funeral being a public ritual and just one component of mortuary rituals which can include pre

[23] For a comprehensive review of the development of maternity hospitals and maternity care through the 19th and 20th centuries, including the cross Atlantic relationship between the US and UK maternity systems, see Rogers (1889); Wertz & Wertz (1979); Loudon (1992); Richardson (2013) and for the parallels in the development of healthcare in Britain and Ireland in the 19th and 20th century see Stewart (2014)

[24] The IOG was established within the older institution of the Royal College of Physicians Ireland (RCPI) see https://www.rcpi.ie/faculties/obstetricians-and-gynaecologists/

and post-funeral activities such as defined mourning periods (Howarth 2007a).[25] Shimane (2018) noting the need for integrated disciplinary approaches to death studies research, suggests that funeral rites which embody collective human behaviour have been overlooked in sociological studies of death and thereby its importance deserves its own sub-field of research, 'funeralogy'. However, there is no agreement in the scholarship as to what constitutes a funeral. Bowman (1973) offers a definition for funerals as comprised of four steps, characterised here as follows: a wake (the time between death and disposal), a ceremony (meaning religious rites), the committal of remains (burial or cremation), and post-funeral activity (meaning a meal with family e.g.) – this definition however, excludes post death memorial activities, which are included in Howarth's (2007a) broader mortuary rituals description. Therefore, Howarth's (2007a) description is the one used in this research to explore mortuary rituals for perinatal death in Ireland.

Human societies have always used communal rituals to cope with "powerful and terrifying feelings" and yet there is little research on how collective ceremonies may alleviate or prevent trauma (Van der Kolk 2014 p.267). Funerals are such an example of communal ritual and collective behaviour (Shimane 2018; Sallnow *et al.* 2022); and investigating how people mourn their dead in both material and non-material ways creates an understanding of what it means to be human in a diverse, ever-changing world (Kuijt *et al.* 2021). Further, the slow pace of change with regard to funeral rituals means they are threads to our cultural heritage (Irion 1991; Hoy 2021) offering us ways back into the past.

As modernism advanced in the early twentieth century, the bonds with the dead changed, predominantly due to the outsourcing of funerary services to professionals and the decline in funeral attendance (Shimane 2018). By the mid-1950s, a view had emerged that contemporary responses to death were inadequate and that the "natural" way to cope with the psychological demands of death was to rely on the "therapeutic" value of older community-based rituals (Hockey 1996, p.9). This was the basis of Gorer's (1965) influential study which posited that resurrecting expressive Victorian mourning rituals would alleviate the distress of the bereaved - and their personal grief should be the focal point of both public and private responses to death (Hockey

[25] Mortuary ritual in this context can include the care of the dying and the preparation of the body for the funeral, as well as elaborate mourning rituals and burials customs

1996).[26] Gorer's (1965) nostalgia for Victorian mortuary ritual is flawed according to Cannadine ([1981] 2011), and assumes a therapeutic and supportive value for Victorian ritual which, though frequently alluded to in the broader scholarship, remains unproven. Victorian death rituals embodied strict social customs and blatant consumerism, across all social classes, yet this display of commercialism is not synonymous with any psychological resolution of grief (Cannadine [1981] 2011). This theme is picked up in Cannon & Cook's (2015) archaeological approach to infant death and grief. Cannon & Cook (2015) identify that an unfair social judgement is exercised in relation to burial mode, which assumes emotional indifference when disposal is perfunctory - and deep sorrow when disposal is ostentatious. Hockey (1996) questions the academic privileging of emotion within scholarship which she attributes to a populist quest for ancestral wisdom as a cure for grief, one which Cannadine ([1981] 2011) suggests contemporary death, dying and bereavement researchers dispense with. If Cannadine ([1981] 2011) is correct then the Victorian past offers no value in furthering theory or practice yet it is this time period – and these white Anglo-Saxon Protestant cultures of America and Britain - which have come to form the basis for perinatal funeral interventions.

2.7 Perinatal Mortuary Ritual

2.7.1 Rituals at Time of Death

Early twentieth century perinatal death had no clear funerary, commemorative or mourning rituals and parents were rarely encouraged towards them, depriving them of the "right to mourn", thus increasing their distress (Lang *et al.* 2011, p.189). This perception is common in the perinatal scholarship but as outlined earlier is embedded in a very specific view of the value of funerary ritual offering a resolution of grief; and the precise phrase 'right to mourn' suggests a demand for public rather than private expression of grief. This is reflected in Charrier & Clavandier's (2019) research of the evolution of French perinatal death care, which they describe as a three step process. The first step occurs at birth, where parents meet their baby and a "fiction" is performed which transforms the foetus into a baby, whether the foetus was viable or physiologically lived (Charrier & Clavandier 2019, p.197). To compensate for the short time parents have with their baby, midwives create tangible mementoes (memory-

[26] Summarising three phases of mourning drawn from earlier works in the psychology of grief, Gorer (1965) lists these as initial shock, followed by intense grief (including shame, guilt, sadness, dissociative behaviour, withdrawal and feeling lost), and then recovery – if recovery was not achieved it was deemed pathological.

making). This first step creates mortal remains which must be cared for, and which must then receive an appropriate funeral, which is the second step. The third step is memorialisation. These three steps are meant to soften the technical aspects of protocol administration and liken them to ritual funerary gestures, thus creating social recognition of 'children' who die at or before birth (Charrier & Clavandier 2019). Charrier & Clavandier (2019) acknowledge that the funerary and commemorative rituals they observe are not traditionally French but derive from Anglophone cultures which they maintain may be better matched to contemporary values and norms. The perinatal funeral ritual as exists today, however, is a forced construct of psychological theory in the 1970s social reform of hospital protocols for stillbirth management – what form these rituals take today are not organic but stem from this change.

Western practices regarding perinatal death have changed dramatically over the twentieth century, aimed at providing a social body and identity to the perinatal infant (Bleyen 2010; Charrier & Clavandier 2019). This process starts with hospital protocols that facilitate memory-making through encouraging parents to see, hold, touch, and name their child along with the creation of transitional or memorial items (footprints, photographs, locks of hair, memory boxes, etc) (Bleyen 2010; Bremborg & Rådestad 2017; Keeble *et al.* 2018; Riches & Dawson 1998). Transitional items common in Western hospital protocols, however, are taboo in some cultures and religions (Arshad *et al.* 2004; Popoola *et al.* 2022). Parents may also create memory and meaning from other activities including online memorials, the allocation and marking of individual graves, and private and public commemorative practices, (Mitchell *et al.* 2012; Sanger 2012; Bremborg & Rådestad 2017; Charrier & Clavandier 2019; Fuller & Kuberska 2022). In her study of the social economy of perinatal death, Malacrida (1999) records how cost influenced parents choices for funerals, coffins and headstones. Costs feature in parental decisions over burial too, as observed in Kenya, where hospital burials were appreciated by parents due to cost, travel distance, and family disagreements over burial location (Ayebare *et al.* 2021). Parental decisions regarding mortuary rituals are clearly both pragmatic *and* emotional. For some parents, creating memories that bonded them to their baby was important yet for others being tied to these memories was distressing, for example, some parents did not want to have a grave that would tether them to the memory of their baby (Littlemore & Turner 2019). For other parents, not wanting their baby to be on their own, combined with their emotional state at the time of death, affected funeral arrangements (Littlemore & Turner 2019).

2.7.2 Commemoration

Until the late 1990s, the dominant grief paradigm viewed death as final and relationships with the dead were to be severed (Silverman & Klass 1996). Ongoing attachment to the dead was viewed as pathological and problematic, referred to as unresolved grief, a grief model that was a creation of the twentieth century (Silverman & Klass 1996). Continuing Bonds theory challenged this dominant paradigm and recognised that enduring, even lifelong, mourning was normal rather than abnormal (Klass *et al.* 1996). Continuing Bonds however, manifests in both material and immaterial ways (Maddrell 2016).

Grave visiting and grave marking form part of commemorative practice which according to Flohr Sorensen (2011) is increasingly expressive and conspicuous. Communal mourning in both real and virtual spaces demonstrates a revival of mourning as a collective activity and public event, the media acting as a catalyst for this (Howarth 2007a). This is quite a change from the Buddhist public commemorative ritual of *Mizuko-Kuyō* for pregnancy and perinatal loss dismissed by Japanese media as a fad in the 1970s (Smith 2013). Nonetheless, this perinatal mortuary ritual practiced from the early twentieth century, has been adopted and adapted by Americans as part of a surge of interest in eastern philosophy at that time (Smith 2013).

The Buddhist intercession ritual of Mizuko-Kuyō takes place at temples or shrines, where parents pray to *Jizō* bodhisattva of Crossroads and Transitions, the deity who protects children and where parents decorate small *Jizō* statues in place of graves (Klass & Heath 1996; Smith 2013).[27] Mizuko-Kuyō rituals are a consequence of macro social changes in family structure, which reduced collective and kinship support and consequently increased the individual and silently borne burden of grief (Yamazaki 2010; Smith 2013).[28] The widespread adoption of the ritual illustrates the overlap of tradition with modernity, myth, symbol, doctrine and praxis (Smith 2013). Though these shrines are very public commemorations, parental grief remains private - parents sometimes travel to other shrines or temples where they can remain anonymous, parents remain silent at the temples and grieving is still highly personalised rather than

[27] Within Irish culture a similar figure exists, St Brigid or the pagan goddess Brigit, is the patron saint of childbirth, mothers, babies, and midwives. In Irish folklore she is known as *Cailleach Bheara*, representing death and rebirth (O'Riordan 1951; Sellner 1989; Magan 2020; Butler 2021)

[28] Mizuko-Kuyō is also a ritual of intercession where parents pray for protection of their child to *Jizō Bodhisattva* (bodhisattva is the equivalent of 'saint' in the Christian tradition). In Sanskrit *Jizō* is called Kshitigarbha; *kshiti* meaning 'the earth', and *garbha* translated as storehouse, treasure house, or womb (Klass & Heath 1996)

shared (Smith 2013). This Japanese parental response negates somewhat Markin & Zilcha-Mano's (2018) assertion that public rituals are beneficial and that the problem is a society which discourages and avoids such ritual responses.

Within Catholic Europe, a similar commemorative public response is occurring. Since the year 2000, 160 monuments for stillborn children have been erected in Dutch graveyards, a social movement that is attributed to the compassionate gesture of one local priest which has grown into a national phenomenon (Peelen 2009; Faro 2020). The erection of these monuments is seen as a tacit acknowledgement of past wrongdoing by the Catholic church for disenfranchising parents grief through the anonymous burial of unbaptised babies in unconsecrated ground within graveyards, and forcing Dutch parents to deny the existence of their child (Faro 2020). The experience of twentieth century Dutch Catholic parents, is described as broadly negative (Peelen 2009; Faro 2020). Catholic authorities determined what rituals would apply and where children could be buried.[29] The hospital or the father arranged an anonymous, sober burial, without a ceremony, in unconsecrated ground; and it was never spoken of again, often leaving parents uncertain as to where their children may be buried (Peelen 2009; Faro 2020). New French funerary customs reflect the 'promotion' of foetal remains to baby, humanising foetal bodies and ritualising 'almost-births' (Memmi (2011) as cited by Charrier & Clavandier 2019). Within French cemeteries, perinatal deaths are clustered together in segregated burial spaces, with renewable private plots for payment, or common plots that are used free of charge for five years (Charrier & Clavandier 2019). Segregated spaces are filled with decorative items and toys, butterflies featuring as intercessionary figures in place of angels (Charrier & Clavandier 2019).[30] Collective farewell ceremonies, first developed within hospitals, form part of the new way of commemorative remembrance; messages for the dead in the form of ribbons or drawings are tied to trees, a substitute for infant bodies (Charrier & Clavandier 2019).

2.8 Cultural Responses to Perinatal Death

Sociologists perceive mortality as a universal social issue but one in which individual societies differ in their cultural and social responses to death, dying, and bereavement

[29] Parents at Hertogenbosch hospital were told their stillborn infants were buried in coffins with other adults. At Roermond hospital, no burial records were kept and stillborn children were apparently cremated (Faro 2020).

[30] Charrier & Clavandier (2019) note that accumulated grave offerings are cleared by cemeteries as they deteriorate or there are an excess of items

(Howarth 2007a; Thompson *et al.* 2016; Rosenblatt 2017). These cultural responses however have been heavily shaped by the psychological literature, or what Walter (1996, p.21) refers to as the "clinical lore of bereavement", in essence, a trickle-down effect from scholarship has permeated everyday life. More specifically, perinatal death though increasingly the focus of social science research as identified earlier by Layne (2003), is left under explored from a cultural perspective (Rice-Liamputtong 2000).

For Cecil (1996) funeral rites are the formal expression of community loss, which affirms the social worth of the deceased as a member of that community, with wakes or visiting a less formal expression of the same behaviour - conversely, the absence of ceremony imparts the devaluing of the deceased, a view that Prior (1989) also supports. In Northern Ireland, Cecil (1996) notes how little is known of the rituals pertaining to perinatal deaths or how families and communities acknowledged these losses. The absence of defined mortuary rituals for perinatal deaths (or more specifically stillborn infants) are frequently attributed to the non-recognition of foetal personhood and the perception that these foetuses/infants are not fully human (Cecil 1996; Peelen 2009), or are human but less human than older children or adults (Scheper-Hughes 1985) thus creating ambiguity about what has been lost (Rosenblatt & Burns 1986). This ambiguity is reflected in the reform of mortuary rituals in the 1970s, which advocated funerals for *persons over 28 weeks* gestation (the legal and medical age of viability). This standard of viability is not the defining feature of personhood or barometer for full funeral rites in many cultures, however. Personhood is not automatically bestowed at biological birth and social personhood (represented by rituals of washing, naming, etc) may be acquired incrementally across the life course, with additional ritual processes marking these incremental changes (e.g. initiation rites at puberty) (Jackson 1977; Shaw 2014). Thus not only are full funeral rites or ceremonies not performed for perinatal deaths, they may be absent or reduced for toddlers or young children (Jackson 1977; Van der Sijpt 2018).

2.8.1 The Art of Resignation: Poverty & Emotions

In general, as Howarth (2007b) notes, sociologies of death and grief have neglected working-class cultures and focused on upper and middle-class appraisals of death and bereavement which purport to be representative of the majority (Howarth 2007b). As Earner-Byrne (2017) notes in her work on early twentieth century poverty in Ireland, the features that most impacted people's lives were not religion or gender but class and economics, a theme that recurs within the field of perinatal death and burial. One area where funerary ritual has been slow to change is within working-class communities

(Howarth 2007b). Murdoch (2015) notes that in nineteenth century working class London, it could take two weeks to raise enough money to bury a child. This in part may explain why older traditions remained resilient in to the late twentieth century, particularly with regard to the deaths of babies and children, which families accepted stoically (Jalland 2013). Stoicism refers to the ability to endure, this is at odds with the contemporary therapeutic goal which is towards personal growth (Klass 2013). Modern grief theory has tended to validate talk, over stoic silence (Howarth 2007b). In Rosenblatt & Burns (1986) study of long term perinatal grief, some parents felt no need or desire to talk, for others talking was too private or socially inappropriate. Strange (2002; 2005) maintains that silence could both conceal and betray a depth of emotion, stoicism was far from apathetic, rather economic circumstances stunted its expression, both love and grief, like life, were understated. Yet Strange's (2002; 2005) assertion of silent stoicism overlooks Irish working class communities. Murdoch (2015, p.36) shows how the mourning behaviour of nineteenth century Irish immigrants in London, were subjected to the wrath and disgust of English social reformers due to their "misplaced emotions" and their "crying, howling and praying" at home based wakes.

In contemporary cultures, emotional responses to perinatal death must also be evaluated in the context of high and low resource settings. The influence of poverty, destitution and deprivation (low resource settings) on women's reproductive lives (which include high levels of fecundity, maternal and infant mortality; maternal morbidity; and recurrent pregnancies and pregnancy losses) in the scholarship is clear (Knight 1977; Scheper-Hughes 1992; Elliot 2014; Hunter & Leap 2014; Earner-Byrne 2017; Withycombe 2018). These authors detail a range of emotional responses showing that generational loss could be cause for relief as much as sadness.[31] Earner-Byrne (2017) found impoverished twentieth century Irish Catholic mothers expressed relief when God took their children, sparing them from further poverty, with references to being burdened by large families, themes reflected by Hunter & Leap (2014). Scheper-Hughes' (1985, p.314; 1992) critique of Brazilian slum life, recorded similar dilemmas in the context of perinatal death, with impoverished mothers suffering the inhumanity of making "choices no woman should have to make" and where women faced such deaths with 'culturally appropriate stoicism'. Scheper-Hughes (1992) questions whether such stoicism masks a depth of sorrow, grief, shock, numbness or trauma, but concludes that the emotion most observed is indifference – mothers shrug away their loss with the view that it is better for the baby rather than the mother to die.

[31] Generational loss meaning miscarriage at any gestation, stillbirth, neonatal and child death

Describing local Brazilian culture as successful in defending women against the "psychological ravages" of grief, Scheper-Hughes (1992, p.431) writes, "emotions are discourse, constructed and produced in language and human interaction, without our cultures we would not know how to feel". The emotional discourse of Brazilian culture, meant mothers were "coached in the art of resignation" with excessive emotions viewed as unhealthy in a low resource society that contends with significant infant mortality, an attitude that lies in fear for both the health of the mother and her household (Scheper-Hughes 1992, p.427). This theme is echoed in recent evolutionary biological studies of grief by Reynolds *et al.* (2020) – but it is equally a clear example of Lofland's (1985, p.173) assertion that grief is "profoundly socially shaped". This minimisation of grief is a rejection of the contemporary western biomedical approach to perinatal bereavement and may be described as a traditional protective approach to high mortality in low resource environments. This example has resonance for an evaluation of psychological theories relating to disenfranchised grief, particularly in low to middle income countries (LMICs). As Reynolds (2004) reminds us, Western psychological theories pertaining to perinatal death exist as degrees of confrontation (seeing or naming the baby, mementoes, funeral, etc) and insistence on confronting loss may deprive parents of the needed protection of denial. The denial or absence of these 'degrees of confrontation' is no different to the minimisation observed by Scheper-Hughes (1992). Further, clinicians have understood higher levels of perceived social support (through funeral and post-funeral activities) as indicative of lower levels of emotional distress, but the data has not always supported this assertion (Hoy 2021).

Though it is noted that cultural beliefs around death vary enormously and impact on grief, recent research in Africa has identified comparable themes to those outlined above: illicitness, stigma, silence, rapid disposal, absence of funerary ritual and hospital burials, among others (Kiguli *et al.*, 2015; Kiguli *et al.*, 2016; Heazell *et al.*, 2016; Ayebare *et al.*, 2021). Authors (Kiguli *et al.* 2015; Kiguli *et al.* 2016; Adebayo *et al.* 2019; Ayebare *et al.* 2021; Popoola *et al.* 2022) note psychological distress in perinatally bereaved parents in sub-Saharan Africa, these births predominantly having taken place in hospitals - this distress is similar to other studies in the West (Heazell *et al.* 2016).

The difficulties in resolution of parental grief are attributed to traditional custom and ritual which disenfranchise parents and suggest there is a requirement to sensitively overcome what they believe to be stigmatising cultural responses (Kiguli *et al.* 2015;

Kiguli *et al.* 2016; Heazell *et al.* 2016; Ayebare *et al.* 2021). This dialogue between the new and the old ways is observed in early twentieth century Anglo-American hospitals (see Chapter 5), and can equally be explained as the difference between the "dominant framework of modernity" which is individualistic, versus the legacy of collectivist culture (Howarth 2007a, p.261). The root of this individualism lies in the adoption of Protestantism in American and English culture from the sixteenth century (Jalland 2006). The consequence of individualism is that it neglects the agency of how people construct grief in order to make sense of it, resulting in biomedical models of grief (Howarth 2007a; O'Sullivan 2021), but it also has an effect on social rituals.

2.8.2 Expressions of Grief

While mortuary rituals highlight the social beliefs of a culture, these may be inconsistent or incompatible with individual psychological needs, within that same culture (Hockey 1996). This is well demonstrated in Scheper-Hughes Brazilian (1985; 1992) study, where 'angel wakes' and funerals do occur for infants (over six months of age) but expressive maternal grieving is considered unhealthy, senseless or even insane. Repressive grieving is noted by Jalland (2006; 2013) as the *de facto* social response to death in Britain and Australia in the early twentieth century. Within Islam, *sabr,* meaning self-control, is central to Muslim grieving and the uncontrolled public expression of grief is rare as the family is considered the only appropriate forum for true emotion (Hébert 1998; Arshad *et al.* 2004). This suggests restrained emotions may form part of the general social lexicon for grief and its existence for perinatal infants reflects a broader societal expectation of repression.

As Stahl (1991) notes within the Jewish-Oriental tradition,[32] there was great sorrow for babies who died at birth, and parents did not observe the Jewish cultural rule of only mourning babies over 30 days old. Rather, parents personally defined their mourning, yet when one mother was grieving a year later her grief seemed strange and even dangerous (Stahl 1991). In Brazil, folk belief suggests that the crying of mothers, traps children in their graves and prevents the child's spirit from returning to the spirit world (Scheper-Hughes 1992). For the Kuranko in West Africa, tears will burn the infant's skin and cause them pain in the afterlife, and prolonged grief for children is seen as futile (Jackson 1977). These examples illustrated that maternal grief was felt, the community was aware of parental distress but also crafted cultural responses that minimise grief expressiveness. Early twentieth century Oriental-Jewish mothers spoke

[32] Stahl (1991) interviewed older women (Oriental Jews) living in Jerusalem who came from ten different countries in North Africa and the Middle East; collectively referred to as the Jewish-Oriental tradition

pragmatically about the deaths of their babies and children – being perceived as normal, natural and expected, for example (Stahl 1991).[33] Similarly, Scheper-Hughes' (1985) observed when babies were perceived to lack the spirit (*luta)* to live, maternal resignation saw these babies die *à míngua*, neglected, alone and unattended. Scheper-Hughes (1992) is clear about a biological basis for emotions and is adamant that women do feel – it is the western construction of maternal motherhood and bonding that she rejects, replacing 'mother love' with 'watchful waiting'. This cultural attitude to motherhood and infant death arises from dire poverty and the complex socioeconomic climate that women exist in, resulting in a cultural construction of the child as 'human, but significantly less human than the grown child or adult' (Scheper-Hughes 1985, p.312). From a sociological perspective, if the ultimate purpose of mortuary rituals is to enable the living to get on with living (Lee & Vaughan 2008) then this cultural attitude to perinatal death and burial described by Scheper-Hughes makes perfect sense.

2.9 Socioreligious Elements of Death & Burial

Within European Catholicism, exclusionary burial practices for unbaptised babies, particularly stillborn infants, are observed. The stillborn, as they could not be baptised are excluded from burial among their communities (Charrier & Clavandier 2019); buried anonymously in unconsecrated ground in graveyards (Faro 2020); without ceremony (Peelen 2009; Bleyen 2010). . In Catholicism, the unbaptised are consigned to *Limbus Infantum* (limbo),[34] a place of darkness without suffering, where the unbaptised are unable to unite with the dead in heaven (Cherryson *et al.* 2012).

2.9.1 Baptism

Baptism is a religious sacrament but as Helmholz (2013) writes, baptism did not infer religious belonging as much as it was the basis for the jurisdiction of church courts who dealt with human conduct;[35] if baptism could not be proven, the jurisdiction of the

[33] Though an individual name can be recorded before burial or may even be given later after burial, *kaddish* (funerary prayers) and *shivah* (official mourning) are not typically observed, at a father's insistence they may be applied (Lamm, 1969; Stahl, 1991; Riemer, 1995).

[34] *Limbus Patrum* (or *Limbus Inferni,* meaning edges of hell (Orme, 2001, p.140) is more commonly known as Purgatory, a place of suffering being where the souls of the dead would wait to be cleansed of sin before entry to heaven – prayers of intercession could alleviate the distress of the dead by the living. By the 12th century the theological thinking was the souls of the unbaptised child also went to purgatory but would instead enter a pain free afterlife called *Limbus Infantum,* in Irish referred to as *Dorchadas gan Phian* (Darkness without Pain) (Dennehy, 2003; 2016)

[35] Baptism had an effect on other aspects of life, it created kinships ties between families and defined legal consequences (e.g. sponsors could not marry their godchildren) (Helmholz 2013).

church did not apply, and legal proceedings could be negated.[36] This gives rise to four different types of baptism (lay, private, solemn, conditional). Baptism originally did not require a priest for validity and any person (man, woman, pagan, etc) could baptise, as long as the correct formula was used (Helmholz 2013) – this form of baptism is called lay baptism. Private baptisms were supposed to be conducted in cases of emergency, usually at birth or if a baby was not expected to survive.[37] Prior to the compilation of parochial registers in the sixteenth century, baptism could not have been presumed to have occurred and the solution offered was that of conditional baptism (Helmholz 2013). Solemn baptism (i.e., official sacramental baptism by clergy in public) was the preferred form of baptism. If there was doubt over the quality of baptism (i.e., if baptism had either not been performed or been incorrectly applied during a lay or private baptism), the way to ensure it was complied with was through repeating solemn baptism, known as conditional baptism. Conditional baptism corrected any perceived flaws in the ritual.[38]

Baptism is often interpreted as cleansing the soul of Original Sin – this was the position of the early Christian theology of St Augustine in the 4th century, the unbaptised were destined to eternal torment, which included the souls of unbaptised infants (Murphy 2011). From the 13th century, theologian St Thomas Aquinas introduced the kinder alternative of limbo, a place of eternal darkness without pain, which never became official doctrine but nonetheless was widely believed (Murphy 2011; Sullivan 2011). Debates about the fate of the unbaptised were a feature of Catholic theology through the ages.[39] Vatican II (1962-1965) insisted on the universal salvation of God meaning that if God willed the salvation of unbaptised souls they could indeed leave limbo and enter heaven (Sullivan 2011).[40] This position may be long reflected in the social rituals of ordinary people. In Brazil, for example, posthumous lay baptism of the infant in its coffin was practised, godparents were appointed and attended an angel wake, with

[36] From the 12th century canon law separated from theology; canon law dealing with the regulation of human conduct and the governance of the church; theology dealt with beliefs (Helmholz 2013).
[37] Private baptisms were those performed at home with a clerical officiate. These were solemnised (performed in public at the church) later if the baby survived – this was the case for both Anglican and Catholic baptisms (Woywod 1917; Tjondrowardojo 2010). Private baptisms for Anglicans reflected wealth, status, and religious sectarianism; non-emergency baptism was a marker of excessive individualism that emerged in the late seventeenth century (Tjondrowardojo 2010). In the historic record private baptism is sometimes used interchangeably to indicate lay baptism.
[38] See Canon 737, Woywod (1917)
[39] See Wall's History of Infant Baptism for the contradictory and nuanced arguments put forth by various Christian traditions (Wall 1848)
[40] Vatican II, the Second Vatican Council, was established to promote unity amongst Catholics. It was held from 1962 – 1965 (Lane 2004).

mothers recording the posthumously given baptismal name on her makeshift family records (Scheper-Hughes 1992).[41]

In the 13th century, midwives were accustomed to baptising infants even if stillborn, and exclusionary burial was not always practised (Orme 2001). By the late nineteenth century, Maltese midwives were instructed by clergy to administer baptism in all cases of miscarriage, foetal and neonatal death such was the concern then for the spiritual fate of the unbaptised (Savona-Ventura 1995). The right of midwives to baptise babies is often referred to in historical scholarship in the context of ecclesiastical licensing of midwives (Savona-Ventura 1995), yet no evidence of ecclesiastical licensing of midwives exists for Ireland (Gorey 2019). Cameron *et al.* (2008) found in their analysis of twentieth century UK midwifery textbooks however, that midwives were instructed in the art of baptism *in extremis*, and this may be a hangover from ecclesiastical licensing. These textbooks originate in the UK, where Anglicanism was the dominant religion through the twentieth century.[42] However, Anglicanism had no belief in limbo, and as midwives continue to bestow baptism at birth suggests that baptism was perceived as a cultural *and* religious practice. These textbooks form the basis of midwifery instruction in Ireland, where Anglicanism was a minority religion, and further illustrates the continued influence of Anglicanism in Ireland.

2.9.2 Death & Burial

As noted by Cherryson *et al.* (2012), the most enduring element of post-medieval mortuary ritual lies in folk belief rather than religion or science – there was no theological basis for ceremonial disposal, sanctified (consecrated) ground, ancestral burial, or keeping wakes yet these all form part of normative mortuary ritual. This echoes a later study, which noted that cross culturally Christianity had little effect on twentieth century death customs, grief and mourning rituals (Rosenblatt *et al.* 1976). In working-class areas of England, performance of traditional mortuary rituals endured into the mid-twentieth century, infused with strong folk and spiritual beliefs and stoic acceptance of the loss of infants and children (Jalland 2013). In Ireland, folk and spiritual beliefs in fairies and magic persisted through the nineteenth century as a consequence of an insufficient clergy and sparse ecclesiastical infrastructure, these folk beliefs being overlaid and intertwined with conventional Catholic ideologies (Barr 2018). This may explain why in Ireland, as Ó Súilleabháin (1967) and Breathnach &

[41] Posthumous naming is also noted in Judaism (Lamm 1969).
[42] Anglicanism retained its dominant and influential position in the UK through the early twentieth century (UK Parliament 2022)

Butler (2013) found, through the nineteenth century there were highly varied mortuary customs and no universal orthodoxy relating to death and burial traditions. Wakes, however, formed the primary, if not universal, component of Irish mortuary rituals through the nineteenth century, across all social groups (Lysaght 2003).[43]

Henderson (2014) maintains that the control and regulation of mortuary ritual and burial practices fell under the remit of the minority ruling class of the Anglican Church until the nineteenth century, thus, the majority Catholic population were prevented in law from having their own burial grounds or performing funeral rites. The growth in public cemeteries through the nineteenth century, however, eroded Anglican power over burial (Cherryson *et al.* 2012). Due to mass poverty, the complex issue of land ownership, the minority Protestant ruling class, the scarcity of both Catholic churches and priests, and the distance to travel to access religious services, the sacraments to this point happened at home (Barry 1959).[44] Kennedy (2001) maintains nineteenth century Irish Catholics took a select approach to religion, ignoring what did not suit and choosing what supported them materially rather than spiritually. This is illustrated in twentieth century letters to the clergy requesting material assistance well into the 1930s, exposing a "national culture of poverty" in Ireland (Earner-Byrne 2017 p.254). Yet the study of Irish death and burial has paid scant attention to the impact of poverty or the power of the Anglican Church in Ireland, rather the focus has remained on the Catholic Church predominantly it would seem due to the practice of segregated burial of the unbaptised infant – the unbaptised infant "deemed unfit" to share consecrated ground with baptised Catholics (Kennedy 2021, p.244).

2.9.3 Infant Burial in Ireland

In 2021, an update on the implementation of the National Bereavement Standards was published (O'Donoghue & Cotter 2021) which merges historic burial practices with contemporary interest. This report has taken a sentimental anachronistic approach to history and blended it loosely with fact, for example:

[43] As Murdoch (2015) notes, at that time English Protestantism characterised the Irish Catholic wake as repulsive, positioning the tendency of working-class families to retain the bodies of their dead, including stillborn children, in the home for extended periods of time as dangerous to public health. English burial reforms in the nineteenth century emphasised the removal of death and mourning from the home placing it into the public sphere, this overlooked the wake as a mechanism for grief and connection.

[44] The performance of sacraments in private homes on a rotational basis was referred to as the 'Stations' – a priest would come to a parish every few months or years, to collect dues and perform sacraments. This reflects the practicalities of having no place of worship and insufficient clergy to administer sacraments. The ratio of clergy to parishioners varied from 1:2150 in Dublin to 1:4546 in the most impoverished parishes of Tuam (Barr 2018).

> A baby who died without baptism was denied burial in consecrated ground and in effect was disregarded by society. This led to a troubling tableau of burial sites outside consecrated ground…. Faced with this harsh backdrop, parents buried their babies under the literal cloak of darkness and secrecy out with consecrated burial grounds or churchyards… Ireland is therefore scattered with the tender rebellions of parents who buried their babies in *cillíní*, consecrated not by formal religious ritual but by the intention, love, and deeply felt and innate value of the life of each baby (p.3).

This is perhaps an accidental distortion of the past due to the limited research in the area. Though this is not the only work to lean into issues of anonymity, darkness, secrecy and shame, there is a responsibility to be accurate, particularly in the context of biomedical reporting which wields significant influence. As with all research, including this study, there is the expectation that any claims must be grounded in evidence and be open to contestation. Some of the scholarship is muddy in this regard and the line between evidence and opinion is less certain. Garattini (2007, p.194) for example, writes that unbaptised infants were sometimes buried in fields (as noted by Ó Súilleabháin (1939)), adding in brackets after "as was done with animals".[45] This is not accidental language. The emotive language and positioning of experience in more recent scholarship is not present in the earlier works by Ó Súilleabháin (1939) who first wrote on the topic, relying on the work of antiquarians and folklorists from the nineteenth century.[46] This shift may be due to a reliance on socioreligious aspects of burial, or following decades of controversy over the Catholic Church in Ireland, shaped a particular emotional framing of language – this is also evident in works from Europe by Peelen (2009) and Bleyen (2010). More importantly, though understandably, it shapes both scholarship and clinical practice using emotion rather than evidence.

The mortuary treatment of the perinatal infant (specifically stillbirths, often noted in the historical record as 'unbaptised') has traditionally differed from adults. The traditional Irish mortuary ritual regarding infants is summarised by O'Connor (2005) but this differs somewhat from the original descriptive version put forward by Ó Súilleabháin (1939) who maintains there are many rules governing the wake and burial of young children. Ó Súilleabháin (1939) confirms that a stillborn baby may be laid out at home for a couple of days with a wake, though equally there may be no wake or funeral. Children

[45] Similar inferences show up in phrases such as, 'dealt with quickly' (Finlay, 2000, p.413); burial taking place 'in secret, in the middle of the night or twilight' (Finlay, 2000, p.413; Dennehy, 2003, p.17); 'no priest allowed to officiate' (O'Connor 2005, p.72) or 'such death was hidden from clergy' (Dennehy 2003, p.16) amongst others.

[46] Ó'Súilleabháin (1939) relies on and is in agreement with three noted antiquarian scholars of the time, Wakeman, Wood-Martin and McNamara who all believed *cillíní* originated as pagan burial sites

under six months were wrapped in a white *barrlín* (cloth) before coffining, no nails were used on their coffins.[47] Coffins were made from little boxes, or in Donegal, willow baskets (when wood was scarce).[48] Children to the age of two, would be buried in the evening, at night or before daybreak. The death and burial of a child was considered a "private event", and thereby neither the '"circumstances or reasons" existed for a public wake or funeral, and by extension it was uncommon to have a priest or a crowd at a funeral (Ó Súilleabháin 1939, p.152). This social practice has been summarised a little differently by O'Connor (2005). The perinatal infant was wrapped in a white cloth, laid in a white box, and brought for burial by its father or nearest male relative to an unmarked, unconsecrated grave, after sunset or before sunrise; no priest "was allowed to officiate", there was no wake or funeral, only a few prayers said (O'Connor 2005, p.71).

As place of birth changed to hospital in the mid-twentieth century so did place of perinatal death, and seemingly the reliance on hospitals to arrange burial – this is clearly noted in Cooper's (1980) British study, but is not so clear in an Irish context. The later twentieth century burial practices for stillborn infants in Northern Ireland are described by Prior (1989, p.173) as follows; "unwanted infants who populate the hospitals" are contracted out to a firm of undertakers who bury these babies in common graves, without religious rituals.[49] Though older babies burials are also devoid of ritual, there is a "distinct privacy" regarding the burial, it is never announced and neither extended family or communities are involved (1989, p.173). This emphasis on privacy is similar to Ó Súilleabháin's (1939) description. McCreight's (2004; 2008) Northern Irish study also found different mortuary treatment of infants, one father believed his child had been incinerated by the hospital, and parents did not realise they could request the remains of their child be returned to them. Incineration in hospital

[47] A *barrlín* is described as a white linen head cloth. This may be similar to a chrisom cloth, a reference to the anointing of infants with chrism at baptism. A child that died before a mother's churching was also known as a chrisom child and was buried in a chrisom cloth (Orme 2001)

[48] In Co Clare and Co Galway, the foot board of the coffin was left off to allow the child's feet to grow. In many places the child is buried face down, especially if the mother almost died during labour or the child disowned by its father (Ó'Súilleabháin 1939)

[49] In general, common, public and fourth class graves are owned by burial boards for which a nominal interment fee is charged. These graves may contain more than one person. As these graves are shared graves and/or belong to the burial board, individual grave markers are not usually permitted (Strange 2005).

incinerators was an alternate pathway for human remains, as noted for the early to mid-twentieth century (O'Morain 2000).[50]

Cemeteries were designed as eighteenth century responses to overcrowded churchyards which posed a hazard to public health, though sanitary reform did not take effect in Britain until the early nineteenth century (Rugg 2021). Pre-dating and parallel to cemetery usage, most unbaptised infants were likely buried in churchyards, particularly during the early Modern period (Cherryson *et al.* 2012). Within churchyards children's graves could be scattered amongst adults or kept in one space, though Anglo-Saxons were in the habit of burying children under church eaves (Orme 2001). Medieval graves were shallow mounds and constantly reused for new burials; children's graves like those of adults, had no permanence in the medieval period (Orme 2001). In one Kerry churchyard, a baby was buried in an unconsecrated part of the graveyard the night she died, despite being baptised, which is attributed to the potential inability to pay formal burial fees (Dennehy 2016). This would indicate that segregated burial was not a consequence of spiritual belonging or exclusion but economics.

Perinatal or unbaptised infants were also buried in a *cillín* (anglicised as killeen, plural *cillíní,* pronounced kill-ee-nee) or Children's Burial Ground, supposedly still in use up to the 1980s (Dennehy 2016; Graham-George 2020). The origin of these burial grounds has proven elusive but the archaeological evidence dates these to the post-medieval period, proliferating from the seventeenth century (Donnelly & Murphy 2008; Dennehy 2016). *Cillíní* are traditionally believed to be reserved for the exclusive burial of the unbaptised infant, this being attributed to their use from the Counter-Reformation (mid-1500s), canon laws regarding baptism and segregated burial (Murphy 2011), and their status as unconsecrated (Hamlin & Foley 1983; Finlay 2000; O'Connor 2005; McKerr *et al.* 2009; Dennehy 2016). Earlier scholars (Westropp 1923; Ó Súilleabháin 1939; Aldridge 1969) believed the origin of these sites to be pagan and so lacked consecration, however, they also leave a remnant of doubt regarding this.

[50] Incineration of foetal remains within hospitals (not just Irish hospitals) was not uncommon when the foetus was under 28 weeks gestation (Charrier & Clavandier 2019; Ruiz 2012; Flohr Sorensen 2011) but it is unclear whether this was also the pathway for foetal remains over this age.

Concentrated on the western fringes of Ireland, approx. 1400 *Cillíní* are recorded on the National Monuments Service and afforded protected archaeological status;[51] sixteen of these sites have been archaeologically excavated (Donnelly & Murphy 2008; Dennehy 2016).[52] *Cillíní* are considered to be marginal and peripheral, reflecting the liminal spiritual status of the unbaptised infant (Finlay 2000; Garattini 2007; Murphy 2011; Dennehy 2016). Despite the popular belief that *cillíní* were used exclusively for unbaptised infants, this is misleading (Dennehy & Lynch 2001).[53] Fortunately, one eyewitness account of an infant *cillín* burial was recorded for the early twentieth century (Flower 1945), which reflects a tradition rooted in "parental responsibility and a familial way of life" (Henderson 2014).

A common misnomer is that *cillín* graves are unmarked, however, some have a grave stone but few had a name or distinguishing mark, and people remain unidentified (Ó Súilleabháin 1939).[54] *Cillín* come with cautionary warnings, bad luck befalls those who interfere with them within the folkloric record (Ó Súilleabháin 1939). This may be due to their association with fairies, a superstition enabling their protection and continued use (Finlay 2000). Despite these superstitions, a late twentieth century mapping study of disused burial grounds found the majority were under tillage and physical evidence of their existence had been destroyed (Donnelly *et al.* 1999). By 1939, *Cillíní* were still being used occasionally for the burial of adults, and it was known that unbaptised children were buried in family graves in churchyards and cemeteries (Ó Súilleabháin 1939), though Cecil (1996) maintains this was not allowed until the 1960s. As with the power of the keen (*caoin*) for conveying emotions of the heart, which had by the late nineteenth century vanished (Wood-Martin 1901, p.310), the knowledge and use of *cillín* was faltering by 1939, passing out of the consciousness of the community (Ó

[51] Cillíní are included in the national record of monuments and thus entitled to statutory protection under the National Monument (Amendment) Act 1994. Within the landscape, *Cillíní* take many forms, these sites are diverse and include prehistoric monuments (ringforts, raths, megalithic tombs), abandoned ecclesiastical sites and natural landmarks (boundaries, lake and seashore, crossroads, etc) (Ó'Súilleabháin 1939; Cherryson *et al.* 2012).

[52] There are variety of names used to describe ringforts, including duns, raths or lisses (if earthen), and cashels if made of stone (Ní Cheallaigh 2012).

[53] *Cillíní* reportedly include babies who are illegitimate, abandoned or victims of infanticide; impoverished families; children up to the age of five, children in receipt of lay baptism (Dennehy 2003); and other excluded dead such as strangers, suicides, famine victims, criminals, shipwreck victims, unchurched women, heretics, and the mentally disabled (Hamlin & Foley 1983; Garattini 2007; Murphy 2011; Dennehy 2016).

[54] In Kildare, in a graveyard for stillborns is a large holy ash tree, for every child buried there, an iron nail or spike is driven into the tree, these are known as *dolaí báis* (dollabushes), which translates as 'tributes to the dead' (Ó'Súilleabháin 1939). White quartz is common at *cillín* sites (Cherryson *et al.* 2012), in Northern Ireland, these are called 'Godstones' (Wood-Martin, 1901). A similar tradition is noted within Judaism, being known as 'visitation stones' (Jewish Cemetery Association of Massachusetts, 2014).

Súilleabháin 1939).[55] Without an interest or local help, these sites will be forgotten or destroyed, and will be lost to Irish culture with time, their community significance fading as those who once knew the dead disappear (Aldridge 1969; Donnelly *et al.* 1999).

2.10 Chapter Summary

This chapter has explored the sociology of mortuary and funerary rituals and emphasised the multiple historic terms used to describe reproductive loss. These alter across time, in part, this explains why systematic search strategies are difficult to conduct as they mean different things to different people at different times. Additionally, this chapter raises the issue of economics, an aspect of mortuary ritual that is not well attended to in the scholarship.

From a sociological perspective, the ultimate purpose of mortuary rituals is to enable the living to get on with living (Lee & Vaughan 2008). As a component of mortuary ritual, there is no agreement in the scholarship as to what constitutes a funeral or what benefits funerals offer. Funeral rites do however represent an important aspect of collective behaviour in human society, and traditionally formed a system which relied on mutual trust to ensure the survival of the community (Shimane 2018). Though Charrier & Clavandier (2019) have outlined changes in midwifery practice and how this has affected French mortuary rituals, no such exploration has occurred for Ireland. The slow pace of change with regard to funeral rituals means they are threads to our cultural heritage (Irion 1991; Hoy 2021) offering us ways back into the past, but the study of death in Ireland is yet to pull these cultural threads.

With regard to perinatal death and bereavement, cultural bias becomes pertinent as this field has relied so heavily on psychological research – which, if Cann & Troyer (2017) are correct, is infused with American cultural values. This raises three important points for consideration. First, the recurrent themes in the psychological scholarship (silence, shame, etc), prior to and since the shift in hospital management of stillbirth in the 1970s, raises a query over the reliability of these theories. If these theories were fundamentally sound, then these psychological behaviours should not continually occur – which leads us to consider that social rather than psychological factors are equally, if not more important in the context of death. Second, changes in hospital protocols, from the 1970s, are dictated by these psychological theories which promote the idea of funeral and enact practices which fundamentally alter social traditions regarding death,

[55] The Irish *caoin* (cry), anglicised as keen or keening, is a distinctive funeral lament

burial, and bereavement. Third, these theories centred on the resolution of grief via a specific form of funeral – though funerary practice is accepted as being culturally embedded and grief as culturally situated.

Overall, the scholarship agrees that grief is historically and culturally situated, yet this does not align with clinical practice which is entrenched in Anglo-American psychological practice and purportedly, agnostic clinical management. The reliance on these theories was plotted above and reflects macro factors which saw lower mortality in higher resource settings from the mid-twentieth century. In low to middle income countries (LMICs), where 98% of stillbirths occur today, Heazell et al (2016) maintain mothers suppress their grief publicly and that parental grief is disenfranchised within these societies, as death is taboo and dead infants are not deemed people. This is an application of an Anglophone centric psychological view of grief developed in late-twentieth century America in a high resource, low mortality culture. It is now being applied to low resource, high mortality regions which more closely resemble 1980s Brazil – or even early twentieth century society. Therefore, this should lead us to contemplate how clinical practice and language influence the discourse of emotions in our own culture, and if they did and do displace the traditional protective psychological defences of minimisation present in Scheper-Hughes (1992) analysis. In particular, this requires further scrutiny, as Giblin & Hug (2006) assert there are no guidelines for what constitutes normal as opposed to deviant mourning, no definitions for proper grieving and normal grief responses are still to be fully realised.

3 Philosophies of Science

3.1 Philosophy: A Love of Wisdom

The direct translation of philosophy simply means a love of wisdom. This seemingly simple definition has in practice been forged over millennia and unites complex strands of thought. These branches of philosophical thought incorporate axiology (the study of ethics and aesthetics), logic, metaphysics (the study of cosmology and ontology) and epistemology (the study of knowledge); in essence, philosophers have refined ways of knowing to create a system of rational inquiry (Payne 2015).

The evolution of metaphysics continues to comprise a vibrant range of philosophical questions and debates. Philosophy, McLeod (2011, p.43) opines, "is a never ending conversation about human existence, it is a training in thinking things through". This chapter then is concerned with the process of "thinking things through". It focuses on the fundamental claims and interconnected activities of research: what knowledge exists (ontology); how we can acquire it (epistemology); what values it has (axiology); how we communicate it (rhetoric); and the processes for studying it (methodology) (Denzin & Lincoln 2011; Creswell 2013; Moon & Blackman 2014).

3.2 Interdisciplinarity: Finding Common Ground

Philosophers have toyed with the theoretical perspectives which form the paradigm (set of beliefs) that guide a researcher's action; each of these perspectives is based upon its own ontological and epistemological assumptions. Ontology (the nature of being) and epistemology (nature of knowledge) are difficult to strictly separate, and they tend to emerge together to inform a research paradigm (Crotty 1998). Blaikie's (2007) approach to ontology is better understood however, as a theoretical perspective on the nature of social research versus a strict philosophical ontological position. This gives rise to three philosophical orientations - metaphysics, ontology, and epistemology – and is the format used here (see below). Realism (materialism) as a metaphysical (or overarching) ontology sits in opposition to Idealism (the ego) with a range of epistemological choices which are often represented as oppositional forces, leaving researchers with what Schwandt (1998, p.245) refers to as a "bewildering array of conflicting considerations".

As researchers, Creswell (2013) further maintains that we always bring certain beliefs and assumptions to our research whether we are aware of it or not. These

philosophical assumptions can be deeply rooted in scholarly training and reinforced in academic disciplines, in turn this can shape how we formulate and delineate research problems (Reagan 2003; Creswell 2013). These preferences for ways of knowing are rooted in the splintering of philosophy thus creating scientific disciplines with competing ontologies and epistemologies, occurring along a continuum from traditional realism to contemporary relativism, and objectivism to interpretivism and alternate theoretical orientations (Denzin & Lincoln 2017; Denzin & Lincoln 2011; Mackenzie & Knipe 2006; Russell 1998).

This means that the blueprint for every research project is dictated by interwoven ontological and epistemological choices (or a theoretical framework) (Schwandt 1998; Denzin & Lincoln 2011; Creswell 2013) which informs the research design and methods, collectively a methodology (Mackenzie & Knipe, 2006; Nash 2015; Pope & Mays 2020).

This section discusses the ways in which each of the three disciplines in this study approach research, their preferences for the creation of knowledge, and how these preferences intersect. After all, interdisciplinary research as a concept would not be feasible without the "foundational structure of *disciplinary* studies" (Misiewicz 2016).

3.2.1 Mind the Gap: Understanding Interdisciplinarity

3.2.1.1 Structural Issues

At first glance, social science sits neatly between history and midwifery. It has a wing in both – seen most clearly in comparative historical sociology or social histories on the one hand, and in psychosocial research or social psychology on the other. Social science thus has a shared heritage with both these disciplines. This is a nuanced distinction that in practice was much more difficult to negotiate.

Disciplinary fields retain their own culture, cognitive and intellectual values (Becher 1994) and for this reason, finding a middle ground between disciplines is often unsuccessful (Bullough 2006). Yet, much is also lost operating within disciplinary silos despite the fact that the academy is an ecosystem which should nurture diversity and interconnectedness (Nissani 1997; Bullough 2006). This conflict is noted by Callard & Fitzgerald (2015) who argue that interdisciplinarity challenges disciplinary conservatism, what Woodworth *et al.* (2022, p.3) refer to as "structural hindrances". For example, sociologists may utilise Grounded Theory as a general inductive

approach versus nurse researchers who define it as a specific methodology as authored by Glaser & Strauss (1965) (Cooper & Endacott 2007).

These structural hindrances extend to doctoral programmes which establish disciplinary norms, and reinforce scholarly standards explicitly and implicitly, having a consequent effect on how clinical knowledge is constructed (Pellmar & Eisenberg 2000; Malterud *et al.* 2017), carrying through to practice, and the creation of evidence based knowledge (Sibley 2019). Such 'hindrances' emerge between disciplinary preferences for ways of knowing, presentation of findings, use of data sources, preferred literature search protocols and scholarly referencing systems (Reagan 2003; Malterud *et al.* 2017), and this study was no exception.

3.2.1.2 What is Interdisciplinarity?

As philosophy splintered into its specialisms in the nineteenth century, the unity of knowledge gave way to specialisation, and it is this unity of knowledge that interdisciplinarity seeks to restore, recognising some complex problems can only be resolved through gathering insights from multiple disciplines (Nissani 1997). Interdisciplinarity is contested in the literature however, and lacks clarity about what it is and how to do it (Woodworth *et al.* 2022; Nissani 1997). Multidisciplinarity is defined as the addition of more than one disciplinary perspective to another; working in parallel silos, integration occurs towards the end of the process (Woodworth *et al.* 2022), this being the preference in interdisciplinary collaborations (Bullough 2006). When multiple disciplines utilise methodologies that "impact, change and transform" each of the disciplines involved, creating synergistic cohesion that extends beyond disciplinary boundaries, this is transdisciplinary research (Cann & Troyer 2017, p.106; Woodworth *et al.* 2022). Though Cann & Troyer (2017) assert interdisciplinary research is a conversation between disciplines, indicating two disciplines, Woodworth *et al.* (2022) see it as a form of interaction that marries disciplinary knowledge into a coherent whole. Nissani (1997) maintains interdisciplinarity can be applied in four ways; to disciplinary knowledge, research, education and theory. In this thesis, interdisciplinary research combines three disciplines to bring together previously unrelated ideas to achieve a "creative breakthrough", using the 'sociological imagination' (Mills 2000; Nissani 1997, p.204).

Mills' ([1959] 2000) sociological imagination (see further below) is a holistic approach to social research, which in the context of interdisciplinarity, acknowledges that some research problems fall outside disciplinary boundaries and between scholarly 'gaps'

(Nissani 1997; Cann & Troyer 2017). Liamputtong (2019a, p.1073) argues for the transformative power of imagination which thrives between these scholarly 'gaps', seeing it as equally vital to quality research as the concept of rigour. Here, Liamputtong (2019a) is also referring to the sociological imagination as being essential for the dynamic world of health and social science research, with innovative and creative approaches deriving insights through new designs, methods, concepts, and ways of doing research. This is consistent with the conceptualisation of critical-historical approaches in social psychology to explain *holistically* how a specific event or psychological attitude emerged from any given set of historical circumstances (Sullivan 2020). The critical-historical approach seeks "deep interdisciplinarity" to integrate "historical data, contemporary and methodologically precise empirical findings, and philosophical analysis" (Sullivan 2020, p.83).

3.2.1.3 Philosophical Aspect of Interdisciplinarity

Whilst disciplinary focus can create depth it sacrifices breadth and consequently limits the value of the research, maintain Cann & Troyer (2017). Interdisciplinary research is a deliberative and time-consuming process of knowledge synthesis, described as "slow research", essential for "deep thought, creativity and problem solving" (Berg & Seeber (2017), as cited by Woodworth *et al.* 2022, p.3). In the context of midwifery, this type of "deep listening" quality is undervalued in research and practice, according to Newnham & Rothman (2022, p.4) who call for

> midwifery and maternity care researchers to hold space for qualitative expertise; for deep, slow, reflective, theoretical thinking; for exploring tacit and experiential knowledge; for tangential asides; for creativity; for meandering down various paths; for seeing what is possible; and for discussion of why these are important to midwifery research, just as we discuss how such things are important to midwifery practice.

Science, concerned with patterns of consistency, congruence, aggregation and generalisation, is not equipped to evaluate otherness or difference; this is the domain of humanities who embrace outliers, purpose, morality, connection and meaning (Bullough 2006; Sarnecky 1990). For example, Cann & Troyer (2017) posit UK death studies which has a sociocultural focus to death research, results in more effective policy-making than their US counterparts who privilege psychological and psychiatric perspectives. The focus on psychological research fails to consider the broader social context of death, which in turn distorts understanding of the experience of loss (Thompson *et al.* 2016). To gain a more holistic understanding of this experience, requires diverse disciplinary perspectives (Sallnow *et al.* 2022) and expanding the

focus of research to include a historical and cultural context of death and grief (Layne 2003; Neimeyer *et al.* 2014; Thompson *et al.* 2016; O'Mahony 2017; Murphy 2019; Šmídová 2019a).

History infuses critical debates on health reform, part of a process of decolonisation of global health, death studies, death practices, and end-of-life care (D'Antonio & Fairman 2010; Sallnow *et al.* 2022). History as a methodology, however, is not afforded the same respect as other methodologies in nursing research, though it has an equal contribution to make to both the profession and clinical practice (Sarnecky 1990). Nursing research is reluctant to use history as a valid source of knowledge, prioritising statistical data and scientism over humanities in professional education – yet nursing practice, like history, is filled with ambiguity and uncertainty (D'Antonio & Fairman 2010; Sarnecky 1990).

Seen as essential to sociocultural context, history has a reputation for being time consuming and complex, which may contribute to its relative underuse in clinical research (D'Antonio & Fairman 2010; Lewenson & McAllister 2021; Marková 2012). Sarnecky (1990), however, maintains that history is predominantly qualitative in nature. Theoretically, similar to other forms of social research, historical research is generally unstructured (Gerson 2017), is rarely a linear process (Lewenson 2010b), does not predict outcomes i.e. has no hypothesis (Lewenson 2010b), and may offer no answers but only more questions – a characteristic common to all qualitative research but especially the historical method (Lewenson & McAllister 2021).

Though integrating social sciences and history research may produce fresh insights and ideas (Hofstader (1959), as cited by Lewenson 2010b), practically, the integration of history and scientific social research is challenging. Whereas social sciences focus on aggregated rather than individual data, using social theory to examine entire societies, historians solve a different type of problem (Tosh 2009; Gerson 2017). History focuses on descriptions and interpretations of a situation or sequence of events (Gerson 2017). This renders traditional sociological methods difficult for historical research as, for example, grounded theorists tend to seek understanding within a specific set of circumstances (Gerson 2017). Examining how variables interact within time and place to effect change, historians create a chronology of reliable and valid facts (D'Antonio & Fairman 2010), or what Gerson (2017, p.261) refers to as "getting the story straight". To do this, historians typically rely on fragments or traces of evidence from the past, rather than a discrete set of systematic observations which can be generated in other forms of qualitative research (Kipping *et al.* 2013). Further, the

perception of time may differ between disciplines and can be refined as either *chronos*, (the expression of time as a measure i.e. chronology), or *kairos* (the qualitative component of time and its subjective meaning or significance) (Smith 1969; Niles *et al.* 2021). These specific contrasts between particulars and generalisation, creation of datasets, the mechanism for collecting and analysing data, the conceptual models of time, the tension between getting a chronological story and evaluating experience in a specific context, are not well addressed in the 'doing' of interdisciplinary research. For all the above reasons, Sarnecky's (1990) assertion that scientific methods are incongruent with history is valid, and thus both positivist and post-positivist tendencies do not work for historically oriented research.

3.2.2 Shades of Grey: Sociology & History

Social Science refers to the scientific study of human behaviour which occurs in a social context with the aim to build explanatory theory about people and their behaviour, based on and tested against real world data. It has been influential in identifying inequalities in health, particularly the experiences of women and their families (Green & Thorogood 2004; Nash 2015a). Sociological studies often utilise the scientific method to observe the relationship between dependent and independent variables. However, other sociological studies use an interpretive framework as an alternative to the scientific method. The tradition of using qualitative methods to study human phenomena is grounded in the social sciences because aspects of human values, culture and relationship were unable to be described using quantitative methods (Denzin & Lincoln 2012).

As in other disciplines, history traditionally tended towards a positivist or neo-positivist framework which took a quantitative stance to show cause and effect relationships (Carr [1961] 1990). The contemporary idealist perspective is more closely aligned to the principles of qualitative research, where the focus is on trying to understand individuals located within a specific time, place, and situation (Morse & Field 1995; Tosh 2009). Like some forms of qualitative research, History does not predict outcomes or use a hypothesis however, researchers do form theories about the relationships under exploration meaning that history is both relativist and interpretive (Carr [1961] 1990; Tosh 2009). Sociological investigation observes a strict criterion for structural analysis of social interdependencies and though it explores historical trends it processes these at a more general level. The primary difference between history and sociology thus, is that sociology does not depend on the same level of historical

'evidence' to evaluate social process (Habermas 1989). This makes sense in many respects as historical investigation is itself an interpretation of events.

An often overlooked component but one that is critical in history, is to avoid the use of 'present mindedness' or anachronism, that is using contemporary perspectives to analyse the past which may lead to inaccurate conclusions (Tosh 2009; Lewenson 2010b). As contemporary history moves to the study of living memory, Tosh (2009, p.53) points out that historians may lack sufficient detachment and are "handicapped" by limited access to confidential records and for this reason historians must do the best they can to create sound knowledge, as people come to rely on recent histories to inform them. This is where history begins to encounter the problems for which sociology is equipped, the "practical guidance" Tosh (2009, p.93) refers to - ethics, informed consent, analytic frameworks, limited access to personal records, sampling strategies, creation of primary data sources and fieldwork protocols.

3.2.3 A Tale as old as Time: Midwifery

The history of midwifery can be traced back to biblical times (Nash 2015a) and arguably is as old as humankind. Prior to the twentieth century, the usual place to deliver a baby was at home. By the 1930s, two leading models of care were in practice, a consultant led hospital model and a community midwifery-based model. The move to hospital-based births as the dominant model of care was cemented in the UK in 1967[56] and can be considered one of the single greatest sociological changes of the twentieth century, despite the fact "there was no robust evidence to support this change" at that time (Nash 2015b, p.23).

As the medical dominance of birth progressed, the value of midwife led care promoting normal birth and women's views were diminished, with a perception that both were subordinate to doctors (Nash 2015b). This results in two opposing birth models as a result, suggests Davis-Floyd (2003); the technocratic model of birth which considers birth inherently dangerous versus the holistic midwifery led model of birth where birth is considered a social event based on normal physiological process. This oversimplifies things according to Pollard (2011) who suggests putting these two models at either end of a continuum of care. This broadly aligns with the objectivist versus subjectivist, realist vs relativist continuum discussed above and can be considered different ways of knowing. The ability to engage and understand research and evidence-based practice now forms a vital part of the midwifery curriculum (Nash 2015a). Given the biomedical

[56] 1967 UK Peel Report: Maternity and Midwifery Advisory Committee

model of birth, by 2000, the progression of nursing and midwifery research focused on the production of evidence-based practice. This led to debate about what constitutes evidence and the merits of doing qualitative versus quantitative research (Streubert 2010).

Bick & Graham (2010) highlight that many interventions in clinical practice are introduced on the *assumption* of benefit rather than a thorough evaluation of impact and outcomes, particularly in relation to maternity practice. The residual impact of such practices is problematic in healthcare and illustrates the flaws in the development of theory and practice. As Sibley (2019) notes, medicine respects evidence with clinician training and professional development informed via medical research, which in turn, informs clinical guidelines and practice protocols, as evidence-based. As medical research progresses, and older evidence becomes obsolete, Sibley (2019) asserts that its importance is "cherished" as historical evidence, and preserved in archives as part of organisational memory and the genealogy of knowledge – a reflection of what Bick & Graham (2010) refer to as the influence of context and culture on research knowledge; shifting evidence from instrumental knowledge (clinical practice) to symbolic knowledge (a tool of persuasion). In contrast to the protection of medical evidence, Sibley (2019) contends that since the 1970s patient experiences are treated as "disposable", with patient experiences gathered but not archived resulting in a loss of patient derived evidence (in the UK). This devalues the patient experience which clashes with the current healthcare trend towards Public & Patient Involvement (PPI) revolving around the central value of 'nothing about us without us'. Overall, this reinforces the point that in health sciences, qualitative research is often seen as playing a supportive role to quantitative and/or evidence-based research (Morse 2012; Creswell 2013; Nash 2015a). In part, this is due to the various approaches and lack of uniformity in language, methods and methodology, which raises queries regarding validity and reliability of these studies (Nash 2015a).

Yet, Goldenberg (2006, p.2630) suggests that while evidence-based approaches can improve practice, "evidence-based should not be understood to be synonymous with 'best practice' in all relevant respects". This rationale is rooted in the assertion that implementation of evidence-based research remains haphazard, as highlighted above (Davis-Floyd 2003; Bick & Graham 2010). The difficulty thus becomes how can anyone trust any research to be wholly accurate? The more perplexing question is what are practitioners to do – follow the evidence or follow best practice? Which leads to the equally perplexing question where does best practice come from?

Healthcare research methods have their roots in sociological inquiry. In the mid-1990s there were few published qualitative studies and few qualitative nurse and midwife researchers. Most of these nurse and midwifery researchers were trained by humanities (sociology, anthropology and psychology) and so qualitative nursing and midwifery research has evolved from this tradition (Morse 2012). Critics of the scientific approach maintain it is reductionist and misses the progress to be made in the objective exploration of the human subjective experience (Streubert 2010; Nash 2015a). This point is made by Goldenberg (2006) who asserts that though clinicians make diagnoses in physical, psychological and social terms, evidence-based practice restricts itself to *physical* evidence. This places physical evidence at the top of an evidence hierarchy which conflicts with a *patient's search for meaning* (Goldenberg 2006).

Where positivist research has a place in answering questions related to effectiveness or outcomes, qualitative research is most effective in answering challenging questions regarding subjectivity (Patton 2001; Nash 2015b). This is a humanist approach to research where the search for truth is only possible through social observation and interaction (McLeod 2011) and the idea that meaning-making in nursing is a mutual process (Reed & Runquist 2007). Qualitative approaches to research recognise that qualitative healthcare can be particularly difficult to investigate with specific complexities regarding intrusiveness, invasiveness and vulnerability (Morse 2012). Further, as Patton (2001, p.159) observes, Randomised Control Trials (RCTs) have been elevated to the 'gold standard' of clinical and evidence-based research, which useful as they may be for testing drug efficacy, are "inappropriate and misleading for the study of the human condition". As identified by Harvey et al (2008), perinatal bereavement interventions whilst generally considered beneficial are compassion-led, rather than grounded in evidence. This reflects Bick & Graham's (2010) earlier point regarding clinical practice that is not necessarily evidence based. Though Harvey et al (2008) concede that future RCTs be sensitively approached, Koopmans et al (2013) in their later Cochrane review, found no complete perinatal bereavement intervention RCT studies.[57] This the authors attribute to the sensitive nature of the topic and small sample sizes. The difficulties in conducting rigorous RCTs for sensitive research such as bereavement are not easily overcome – current care pathways are defined, interventions cannot be withheld ethically, and the emotional state of parents to

[57] A Cochrane Review is a systematic review of research, following a specified methodology, in health care and health policy that is published in the *Cochrane Database of Systematic Reviews https://www.cochranelibrary.com/*

consent to participation in research studies in a heightened state of vulnerability remains questionable. The consequence is that existing compassion-led interventions continue to limp along with conflicting ideas relating to patient outcomes, and the need to devise other empathetic models of research remain pertinent.[58]

Dilemmas arise for midwives as they negotiate a conflict in research and practice as they contend with birth as a biological, medical, emotional, spiritual and psychological event (Hunter 2015). Carper (1978) describes four patterns of knowing for nurses; the empirical (traditional objectivist and positivist technomedical); personal (reflexivity and self-actualisation); moral (reflecting ethical obligations of what is right) and finally aesthetics. Aesthetic knowing is the 'art of nursing', the abstract, subjective, difficult to describe quality of altering practice based on patient need. Aesthetic knowledge is the concept of intuition (Streubert 2010).

Intuition has been "dismissed" by the rational scientific model and evidence-based practice is touted as the way to replace such "primitive" ways of knowing (Misak 2008; Hunter 2015, p.97). It is apparent that a masculine development of scientific theory gives rise to this idea of intuition as 'primitive' ignoring the fact that primitive intuition is what has kept the human species alive for thousands of years. For the scientist looking for evidentiary proof, a study conducted by Bechara et al (1997) explored instinctive responses in gambling and concluded that intuitive decisions, governed by the limbic brain, knew the right answer, often before the rational conscious brain (neo-cortex) did – meaning intuition is an 'early warning system' that activates before the ability to think.

What the above discussion tells us is that there are multiple ways of knowing, that within a medical world, empirical evidence subordinates intuitive knowing. Yet as the above study by Bechara et al (1997) illustrates, this is misguided. The task of midwife researchers is vast. The task is not to make subjective, intuitive knowledge 'more like science' but to have the confidence to reclaim aesthetic knowledge and subjective experience as *equally valid* ways of knowing. This theme is echoed most recently, by Newnham & Rothman (2022, p.175), who suggest quantitative midwifery research risks "reproducing patriarchal, colonizing and medically dominant systems of thought and knowledge creation", thus ignoring humanistic principles and prizing research models that oppose these values. What remains is to generate an integrated model of

[58] Hughes et al (2002) controversial paper on the practice of seeing and holding the dead infant is an example of this conflict.

research that is adaptable and adoptable by practitioners. Whilst empirical evidence is valuable, intuition is equally so. What philosophy has shown is that ways of knowing are evolutionary, that we need both kinds of knowledge to thrive. The task then is to dismantle the pyramid of evidence-based *physical* knowledge and create one that looks a little more like an intertwined yin and yang, incorporating the *intuitive*, *psychological,* and *social* elements of research.

3.3 Theoretical Perspectives for this Study

According to Marshall & Rossman (2014, p.152), producing research is "confusing, messy, intensely frustrating and fundamentally nonlinear" contrasting with the "pristine and logical" structure of journal articles. In keeping with the principles of qualitative research, here this nonlinear, iterative process of 'thinking things through' is explained.

As a social researcher my practice is influenced by the early twentieth century Chicago School of Sociology.[59] Chicago was the cradle of humanistic sociology where knowledge was to be used for the betterment of humankind to "usher in a humane society" but by the late 1930s this qualitative approach was subsumed in favour of quantitative approaches to knowledge (Scimecca 2007, p.24).[60] Dominating sociological scholarship for the early twentieth century, the Chicago School became the *de facto* modern sociology. This is important in the context of interdisciplinarity and health research for several reasons. First, the Chicago School was progressive and purposely interdisciplinary, being staffed with an eclectic mix of scholars and 'renegades' from other disciplines (Plummer 1997). This means that the research philosophies and methods they created were a consequence of this interdisciplinarity.[61] Second, the research methods and philosophies developed in Chicago continue to influence sociology and health researchers through the use of Pragmatism, symbolic interactionism, and grounded theory, as examples. Third, it was the birthplace of social

[59] The Chicago School of Sociology at the University of Chicago, was led by Albion Small (1854–1929) (Plummer 1997) with researchers who empirically studied real world problems using burgeoning Chicago as their research field (Crotty 1998).

[60] Humanistic sociology, as practised in the early twentieth century at Chicago, was a moral and ethical endeavour emphasising freedom of choice on the part of individuals, and social justice as a basic right with an applied intervention focus (Scimecca 2007).

[61] Considered one of the key intellectual contributions of American philosophy borne from the Chicago School, Pragmatism originated around 1870, espousing a naturalistic approach to knowledge. Pragmatism sought understanding through the language of observation of values (Legg & Hookway 2019). Symbolic Interactionism is a sociological micro theory that stems from the work of social psychologist and philosopher George Herbert Mead (1863 – 1931) but refined by his student Herbert Blumer (1900 – 1987) as a theoretical perspective which focuses on the language and symbols that give meaning to human experience (Crotty 1998; Schwandt 1998).

psychology, which has come to make its way into clinical practice, influencing grief theory and hospital bereavement care pathways (see Chapter 5), hence the emphasis on social psychology in this chapter.

The early twentieth century Chicago School was instrumental in the development of sociology and psychology, fused together in the creation of a new discipline called social psychology (Oishi *et al.* 2009). At this time, social psychology as practised by psychologists (psychological social psychology) and social psychology as practised by sociologists (sociological social psychology) were indistinguishable (Oishi *et al.* 2009). Since then, the disciplines have diverged sharply, with psychology aligning to the political, biological, and economic sciences (Oishi *et al.* 2009). In time, psychological social psychology modelled itself on the natural sciences, losing its sociological perspective and today relies primarily on investigating individuals (their thoughts, feelings, actions) and their immediate social context (Oishi *et al.* 2009; Kohn 1989). This means that social psychologists do not examine collective phenomena e.g. religion or socioeconomic factors, and even if included, these are treated as individual variables (Oishi *et al.* 2009).

Sociology by contrast, explores these factors at a higher continuum of social complexity and slightly more removed from the individual (Oishi *et al.* 2009). Macro sociology orients towards the collective, focusing on institutions and large scale social structures and their influence on individual and group psychology (Oishi *et al.* 2009). Micro sociology is oriented towards individuals (sociological social psychology), it explores the interaction between people (Oishi *et al.* 2009; Kohn 1989). The micro sociological approach, which links the individual and environment, reflects an influential theoretical development known as the sociological imagination.

Recognising the divergence between sociology and psychology, in 1959, Mills penned the *Sociological Imagination*, an appeal to sociology to engage with both top-down (macro) and bottom-up (micro) approaches to social research (Mills 2000). Mills argued that individuals existed in, and were shaped by their environments, and that this interdependency meant it was impossible to separate them (Mills 2000). Individual problems could also be societal ones, thereby the sociological imagination endorsed a comprehensive and holistic exploration *and* explanation as critical to understanding. Mills also believed that both span of time, as well as moment in time, were equally necessary to understanding society and how people operated within it (Mills 2000). In essence, both historic and contemporary social context was essential (Mills 2000).

By the 1970s, sociology had dispensed with symbolic interactionism in favour of models that explored narratives of identity and power (Oishi *et al.* 2009). This reflected an interest by social psychologists in the psychology of everyday life, which oriented towards individual feelings (mood, personality, attitudes e.g.) and interpersonal environments (Oishi *et al.* 2009). The problem for Kohn (1989) is that sociological social psychology, has aligned too far with psychological social psychology, equating the environment to the *interpersonal* environment, as if there is no other reality than the interpersonal reality. This constructivist approach ignores the impact of larger social structures on people's lives, and omits the sociological imagination from psychology (Kohn 1989; Oishi *et al.* 2009). This is particularly important in the context of mortuary ritual, which is not just an individual experience but a social response to death.

Psychological social psychologists, restrict their analysis to the 'inner' world or micro process. It is preferable however, for sociologists to start analysis, not with the individual, but with large scale social process, attending to the interconnectedness of the micro and macro experience (Kohn 1989). This enables sociologists to systematically bridge two levels of analysis i.e. the collective or large scale social, and the individual – this is sociology's distinct contribution to social psychology (Kohn 1989).

As previously outlined, the study of death and grief are seen as culturally, historically, and socially situated. Social psychologists can benefit from historical explorations which contextualise and enrich theoretical models (Glăveanu & Yamamoto 2012), though as outlined earlier, social psychologists pay little attention to the macro context of individual experience (Sullivan 2020). Though history is useful for describing health and social issues, and understanding the past is valuable, how this informs contemporary research is more important (Sweeney 2005; Lewenson & McAllister 2021). Historians with an Idealist orientation, are interested in individual perspectives, and this aligns most closely with the values of qualitative research (Lewenson 2010b; Sarnecky 1990). This in turn aligns to sociological inquiry which connects the micro level biographical experience with the macro environment that shapes and contains it (Leavy 2011).

3.3.1 Valuing the Human Experience

To paraphrase McLeod (2011) when it comes to defining theoretical approaches, like many researchers, 'I am complicated and resist easy categorisation', yet the process of research expects this neat categorisation of complex thought. Instead, Punch (2005,

p.7) offers a good starting point which is simply that research is "organised common sense". Birth and death, and the intersection of both represents the genesis of what it means to be human, and so common sense dictates, that Romantic Idealism with its embrace of holism and the way language shapes our meaning of the world is the appropriate foundation for this study.[62]

Science has "two essential parts", argues Punch (2005, p.8) - data and theory; what matters is both parts exist, not the order they occur, nor is it mandated that data must be numeric or measurement oriented. Science aims to build explanatory theory about data, in social sciences this manifests as explanatory theory about people and their behaviour (Punch 2005) – with psychology focusing on individuals, versus sociology which focuses on groups and social context (Oishi *et al.* 2009). Realism, through its underlying association with the scientific method asserts it is possible to arrive at an objective singular truth; in contrast to its opposition Relativism which maintains that nothing can ever be definitively known with no clear claim of truth. A relativist epistemology is thus subjective, and multiple realities can constitute a 'truth'. For qualitative researchers, both extremes are problematic. Realist perspectives ignore the role of the researcher in the creation of research paradigms, reported findings, and the assumption of a knowable and independent reality (Kuhn 1962; Andrews 2012). Relativism concludes nothing can ever be definitively known thus no single reality takes precedence over another, and none can claim to be representative of social phenomena. This is clearly problematic in health research which looks for evidence-based knowledge that is representative of, and meets the needs of, diverse patient populations.

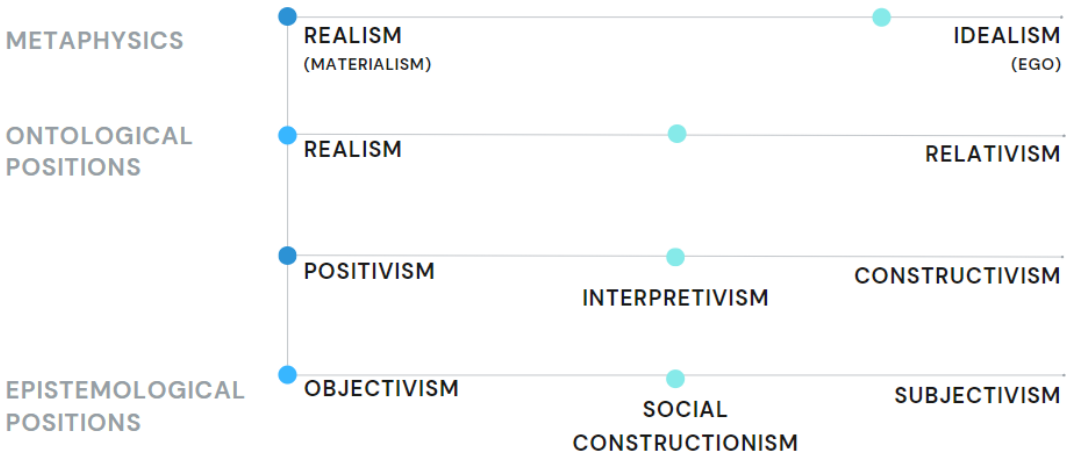
Qualitative research then conforms to the principles of the scientific method but differs in its character, making explicit what is implicit in the scientific method (Henwood & Pidgeon 1992; Bryman 2012; Marshall & Rossman 2014). Firstly, qualitative research is naturalistic, with deep attentiveness and empathic approaches to lived experiences of those under study (Punch 2005). Further, qualitative research uses multiple data sources (often unstructured); considers the researcher as a key instrument in collecting the data; includes multiple perspectives; provides a holistic context to the issue under study; incorporates reflexive practice; often has an emergent design that is gradually

[62] By the late 18th century, Immanuel Kant (1724 – 1804) had attempted to bridge Rationalism and Empiricism. Romanticism (1770 – 1850), with Romantic German Idealism opposing Kantian philosophy which failed to recognise that thought was formed through language (Gorodeisky, 2016). Romanticism emphasised the aesthetic of being human, the study of nature, and the place of the scientist in discovery of knowledge (Gorodeisky, 2016).

refined; employs inductive and deductive approaches to data analysis; and may have intense or prolonged contact with participants during fieldwork (Marshall & Rossman 2014; Creswell & Creswell 2018). Morse (2012, p.399) further observes that qualitative health research, though sharing the same orthodox origins common to the social sciences, is a specialist field of qualitative enquiry due to ethical issues and emotional aspects of conducting health research that span the "intensity of birth and death, pain, suffering and survival".

The fundamental starting point thus is affirming that the social world cannot be objectified and studied in the same way the natural world can be. This leads to the selection for this study of an idealist metaphysics, an interpretivist ontology, and an interactionist epistemology (social constructionism), discussed further below. Whilst these distinctions are being made explicitly, it is easy to be swayed by the call from Schwandt (1998) to dissolve these dichotomies. His esteem for interpretivists incorporating socially constructed meaning and practice underpins his assertion that the future of social research lies in "blurring the lines between the science and art of interpretation, the social scientific and the literary account" (Schwandt 1998, p.249), an opinion reflected by Geertz (1980).

FIGURE 1: THEORETICAL POSITIONS FOR THIS STUDY



3.3.2 Interpretivism

The metaphysical position for this study is one of Idealism, it is the source of the Interpretivist and Constructivist traditions, those concerned with lived experiences, often applied in social research. Interpretivism is a relativist theoretical perspective

rooted in hermeneutics (exploring the hidden meaning of language in texts), which springs from Weber's concept of *verstehen* (understanding) (Crotty 1998; Patton 2001). Due to the unresolved tension between rationalist and romanticist origins embedded in Idealism, Interpretivists wrestle with the duality of subjectivity and objectivity, seeking to prioritise subjective lived experiences but then objectifying them for analysis. This duality represents the inherent challenges encountered within this research – a tug of war between disciplinary conflicts seeking interpretation (history) and evidentiary proof based on meaning (midwifery). Interpretive research as it seeks insight and understanding of specific problems, which Green & Thorogood (2004) maintain is useful for assessing behavioural change opportunities in public health and health promotion, is thus an appropriate perspective for this study.

3.3.3 Social Constructionism

The terms constructivism, social constructivist, constructionism, and social constructionism tend to be used interchangeably (Crotty 1998, pp.42–63; Flick 2009, p.223; Andrews 2012; Bryman 2015, p.710). For the purposes of this research study, the term Social Constructionism (Social Constructionist) refers to the epistemological work originating within the humanist sociological (Berger and Luckmann 1966), and psychological works of Gergen (1985) with its social rather than individual focus, emphasising the role of culture in the creation of meaning (Crotty 1998). The remaining terms will be subsumed under the term Constructivism (Constructivist), which refers to cognitive process arising from the field of psychology (Crotty 1998).[63]

As a consequence of World War II, social psychology as a field, emerged from UK and US government attempts to 'weaponise' psychology for propaganda purposes (Burr 2019). Government investment resulted in laboratory research and theorising devoid of real world context, tipped the balance of power in favour of the researcher, and further oppressed and marginalised the already oppressed and marginalised, maintains Burr (2019). Social Constructionism from the 1970s, became the critical voice of mainstream psychology which was a perceived response to recalibrate these imbalances (Burr 2019).

[63] Psychology as a discipline, devolved from philosophy, in the late nineteenth century under the scholarship of Wilhelm Wundt (1832 – 1920) and his focus on the individual and intrapsychic (Kim 2016). Wundt's ideas regarding the importance of sociocultural influences in understanding human behaviour embedded itself into American sociology via his former student, George Mead (Burr 2019) and what would later be termed symbolic interactionism.

Where classic Constructivist psychology focuses on cognitive process and positivist frameworks, Social Constructionism emphasises the collective (or co-constructed) generation of meaning, shaped by social process and the conventions of language (Patton 2001; Young & Collin 2004).[64] This distinction becomes important in health research which favours patient experience and meaning i.e. psychosocial or biopsychosocial research using constructivist ontologies and epistemologies (Burns *et al.* 2022).

The emphasis within Social Constructionism on language, and interaction as meaning, has tangible implications, particularly in health research, where language has a constructive and performative power (Burr 2019) – for example, disease classifications as objective criteria within Western biomedical health systems differ from other indigenous medical belief systems (O'Sullivan 2021). Thus the concepts we use in the shared creation of meaning are culturally, historically and socially situated (Berger and Luckmann 1966; Gergen 1973; Gergen 1985; Patton 2001; Burr 2019). Culture 'shapes the way we see and feel things' and for which we rely to 'direct our behaviours and organise our experiences', in doing so, culture becomes the source of human thought (Crotty 1998, p.58). In short, Social Constructionism, is a macro theoretical perspective concerned with understanding the world of lived experience, arguing that we are born into a world in which meaning has already been made – we are born into culture (Crotty 1998).

Sociology is not fully aligned with either the natural sciences (social psychology) or the humanities (history), suspended between explanation (*erklären*) which looks for causal laws, and exploration, which seeks understanding (*verstehen*) (Oishi *et al.* 2009). The benefit of social constructionism, from a sociological perspective, is it operates in this epistemological duality, linking the micro and the macro, and elucidating connections between social structure and people – it provides context – by embracing the sociological imagination. This is what social psychology must reclaim (Torregrosa 2004; Kohn 1989; Oishi *et al.* 2009; Gergen 1973) and is the basis for the theoretical selection of Social Constructionism, and its application, to this study. To study Disenfranchised Grief, grief that is not *socially* recognised, requires exploring the social as well as the individual world, and how this social world has changed over time.

[64] This is comparable to the use of Grounded Theory familiar to many health researchers, if the emphasis on language is excluded (Andrews 2012).

3.4 Research Design

3.4.1 The Research Problem

This research started with one basic question - 'when a baby died a long time ago, what happened next?' I was curious as to how we have ended up with a culture where, after the death of a baby you are expected to, as Jalland (2013) says, 'do your grieving like your praying' that is, silently. A preliminary review of the literature relating to perinatal death established there was a paucity of research examining the cultural context and existence of perinatal mortuary ritual, and its relevance to grief theory (see Chapters 2 and 5).

An exploratory qualitative research approach was thus appropriate for the topic. Exploratory studies are useful for furthering understanding, particularly when little has been written about the subject (Stebbins 2001). Rather than offering definitive conclusions, exploratory studies usually raise more issues which require further detailed responses (Green & Thorogood 2004). In this study, an interdisciplinary approach offered a more holistic view of a complex topic which tends to be written about in research silos. The overall aim of the study was to understand more about funeral as an intervention and whether funerals, as a part of mortuary ritual, had any effect on disenfranchised grief or continuing bonds, two leading grief theories.

Given the complexities regarding this topic, the kind of research design queries which surfaced were:

- What type of research design is compatible with both point in time and change over time evaluation?
- Can an established methodology be adapted to include seemingly oppositional demands?
- How can data be collected, particularly from the historic past? How will this data be treated? What problems might historical data collection pose?
- Can historical records in qualitative research be considered primary rather than secondary sources?
- Should the entire dataset be analysed and presented singularly – or organised chronologically by source and/or theme?
- Should analysis prioritise living people – or historical/archival records? Should they be given equal weight?
- How should findings be presented?

Qualitative approaches are regularly used in health research, providing both distinct and complementary knowledge to quantitative methods, by focusing on experiences of patients and healthcare professionals (Braun & Clarke 2014). *Experiencing* refers to the individual or inner world, the cognitive processing or sense making of a phenomenon (Percy *et al.* 2015). *Experiences*, however, have an external focus and seek to know what happened or what was experienced (Percy *et al.* 2015).

3.4.2 Generic Qualitative Research

Methodologies are informed by theoretical perspectives, research designs and research methods (Pope & Mays, 2020). There is, however, an absence of textbooks that deal with the methodological diversity and practicalities of researching death studies (Borgstrom & Ellis 2017). Established or branded methodologies (e.g. grounded theory) offer a prescriptive way of doing research, with specified procedures and philosophical orientations; this acts as a shorthand to the scholarly community as to expectation and rigour (Elliott & Timulak 2021; Caelli *et al.* 2003). Scholars can deviate from these branded approaches, however, and may force their research to fit into an established methodology (Kahlke 2014; Elliott & Timulak 2021). Scholars may blindly follow the steps or methodological rules, without understanding the ontological or epistemological framework, ignoring the research purpose (Braun & Clarke 2021; Kahlke 2014). Particularly in qualitative health research, methodological process can be reified and privileged at the expense of theory, subjectivity, reflexivity, interpretation, validity and generalisability; such reification is known as 'methodolatry' (Braun & Clarke 2021; Kahlke 2014; Chamberlain 2000). This reification is a legacy of positivism which has spilled over to qualitative health research (Chamberlain 2000). Methodolatry should be avoided as it can hinder thoroughness with regard to the process of thinking things through; instead the research questions should inform the methodological approach and research methods (Kahlke 2014; Chamberlain 2000). This was one of the most difficult things to define in this research study, due to the competing ideas about what constituted knowledge and the different philosophies that underpin it.

Within branded methodologies, the degree to which a researcher may deviate from the guidelines is subject to debate; some studies, as outlined earlier fall into 'scholarly gaps' or do not conform neatly within a single established methodology (Liamputtong 2019a; Nissani 1997; Bullough 2006; Kahlke 2014); and others simply aim to explore specific perspectives with no attempt or requirement to examine cultural rules or build theory (Cooper & Endacott 2007). These types of projects can be grouped broadly under the umbrella of generic qualitative research, and walk a midline between realist

and relativist perspectives (Kahlke 2014; Elliott & Timulak 2021), which is consistent with social constructionism. This categorisation includes branded methodologies, such as grounded theory, phenomenology, and interpretive phenomenological analysis (IPA) (Elliott & Timulak 2021). Generic qualitative research has a core set of similar strategies and procedures, collectively referred to as descriptive-interpretive methods, which share a common goal of describing, summarising, and classifying collected data, before interpreting it (Elliott & Timulak 2021). Generic qualitative methods are known by a variety of names, including basic qualitative or interpretive methods (Kahlke 2014), delineated further into interpretive description and descriptive qualitative approaches (Caelli *et al.* 2003), or Qualitative Descriptive (Sandelowski 2000), Interpretive-Descriptive (Thorne *et al.* 2004), or the Descriptive-Interpretive method also known as Generic Descriptive-Interpretive Qualitative Research (GDI-QR), as defined by Elliott & Timulak (2021). Qualitative Descriptive studies aim to provide a comprehensive summary of events in everyday terms, answering what, where, when and why questions (Sandelowski 2000; Holly 2021), though Sarnecky (1990) categorises 'why' questions under interpretation. Interpretive approaches aim to describe and understand something, the emphasis dictating the selected methodology (Cooper & Endacott 2007). This holds true for historical research, which is also a descriptive and interpretive process, historical research that describes data as quotations or facts, without interpretation adds little value to understanding (Lusk 1997; Sarnecky 1990).

The Interpretive-Descriptive approach as defined by Thorne *et al.* (1997) aimed to specifically meet the needs of nurse researchers, borrowing the best from branded methodologies to generate "grounded knowledge", with an applied clinical practice purpose, and explanatory power (Thorne *et al.* 2004, p.1). This form of Interpretive-Description is a subjective approach to research, and thus is broadly underpinned by a pragmatist philosophy and constructivist epistemology (Thorne *et al.* 2004), this reflects the inner world dimensions of qualitative research (i.e. social psychology approach) and so is not suited to this research problem.

Qualitative health and social science research offers complementary knowledge to quantitative designs, by focusing on patient and professional experiences, in an attempt to describe human experience or action in a coherent manner (Braun & Clarke 2014; Elliott & Timulak 2021; Cooper & Endacott 2007). This is undertaken to either test theory (deductive research) or develop it (inductive research) (Elliott & Timulak 2021; Cooper & Endacott 2007). As this study examines grief that is not socially

recognised, it maintains an external focus. A generic qualitative research design was selected, best summarised by Percy et al. (2015, p.78) as appropriate if the outward focus is on 'content of opinions; actual world experiences and happenings; and thoughtful description and reflection of historical events in people's pasts'. This is more consistent with Sarnecky's (1990) conception of historical research as being both descriptive (answering who, what, when, where, and how questions) and interpretive (answering why).

GDI-QR represents the core aspects of qualitative research (Elliott & Timulak 2021), when research does not conform to a specified methodology, the "difficult but productive work" of building a congruent research framework starts by using these building blocks (Kahlke 2014, p.48). Though branded methodologies have an effusive methodological literature to guide them, which is not the case for GDI-QR, this forces researchers using generic approaches to think deeply and read broadly so they can blend or manipulate other methodologies; this thinking through process is seen as exceptionally valuable by Kahlke (2014). Branded or specialist qualitative approaches are less relevant for practical clinical researchers, however; being explicit about the steps performed is more relevant (Cooper & Endacott 2007). Consequently, in this study these steps and the ways in which philosophy is understood have been given more attention than may be found in other doctoral theses.

3.5 Chapter Discussion

Perinatal death is socially as well as individually experienced, this is influenced by historical and cultural factors. As outlined above, combining history with the demands of positivistic scientific frameworks is inherently problematic, as they exist along two different continuums – meaning qualitative research designs must be cognisant of this. Research designs that focus only on individual experience, i.e., the micro perspective, neglecting the macro social world, will continue to generate unbalanced critiques of the grief experience. Similarly, studies that continue to focus only on macro factors can be ideologically rather than evidence driven. The starting point for the design is dictated by the research question – in this study the research aims have an external focus, as well as a consideration of change over time. This outward focus on "content of opinions; actual world experiences and happenings; and thoughtful description and reflection of historical events in people's pasts" (Percy *et al.* 2015, p.78) is consistent with Sarnecky's (1990) conception of historical research as being both descriptive (answering who, what, when, where, and how questions) and interpretive (answering

why). Regardless of whether a critical-historical, or sociological imagination is preferred, this blending of interpretive and descriptive is reflected in both approaches. The sociological imagination, however, is better distinguished in social and health research as an “eclectic problem solving” technique (Olzak 1981, p.216), suited to the study of mortuary ritual, as it recognises the need for an external as well as internal focus, which social psychologists typically ignore, as discussed earlier

Frameworks for thinking about the social world are comprised of theoretical perspectives and research designs oriented towards a specific aim, with research methods referring to techniques used to gather relevant data (Pope & Mays, 2020). This chapter details the interwoven ontological and epistemological choices made (Schwandt 1998; Denzin & Lincoln 2011) which influence the subsequent research design and methods (Mackenzie & Knipe 2006; Nash 2015a). Humanism means the metaphysical starting position of Idealism, followed by an ontology of Interpretivism which seeks understanding. Epistemologically, Social Constructionism is the study of how people intersect with the social world – the degree of focus on the internal versus external world is subject to disciplinary preference.

The chapter discussed the disciplinary approaches to research and evidence, and the benefit and difficulties inherent in using an interdisciplinary perspective. Interdisciplinarity can be intellectually, methodologically and emotionally challenging as it forces researchers to consider unfamiliar matters (Callard & Fitzgerald 2015). Bullough (2006) maintains interdisciplinarity promises new insights, metaphors and models for meaning-making, and as such, stands as a research method in its own right, due to its form of knowledge generation, and its way of engaging with a research problem. This is comparable to Newnham & Rothman’s (2022, p.2) call for midwifery researchers to take “an educated, thoughtful, analytic” approach to qualitative research.

Due to the interdisciplinary nature of the research; complexity of the topic; span of time; difficult to find historical data; competing disciplinary mechanisms for doing research; and the distinction between ‘point in time’ and ‘change over time’, this made a research design challenging – adapting other established methodologies made little sense. A generic qualitative research design offered flexibility, the selection of which was in part driven by changes in the whole project as a consequence of the pandemic (see next chapter). Being explicit is essential in undertaking qualitative projects, and congruence must be achieved between theoretical perspectives and the research methods used to

collect and analyse data (Bradshaw *et al.* 2017; Gerson 2017; Elliott & Timulak 2021; Crotty 1998), these will be discussed in the next chapter.

4 Research Methods

4.1 Introduction

The previous chapter detailed the theoretical perspective, research design and role of interdisciplinarity in the generation of knowledge. This chapter incorporates the process for data collection, analytic techniques, reflexivity, ethics, and validity, completing the theoretical or methodological framework.

4.2 Checkmate: Adaptive Planning in a Pandemic

Like many people plunged into a world of uncertainty wrought by the pandemic, the disruption brought this project to a standstill. In Ireland, public health protocols curtailed everyday life and culminated in months long lockdown cycles, the closure of archives, prohibitions on local and national travel, and eliminated face-to-face interviews. No matter what new choices were made in the wake of these restrictions – whether to delay, conduct phone interviews, or switch focus – all options would have a domino effect.

The original focus of this research study was to explore the long-term implications of perinatal death in the context of parental grief. The initial research design for this study evolved from Grounded Theory to an Oral History methodology (see Fig 3 below for evolution of study). This narrative methodology combines historical analysis with contemporary interviews, interviewing being used as a foundational method in health and social sciences research (Nathan *et al.* 2018). Due to fluctuating Covid19 public health restrictions from 2020 onwards, face-to-face interviewing was prohibited. This was imposed at a juncture in this project which had been allocated to interviewing. Remote data collection and virtual methods were seen as novel approaches in health research (Braun *et al.* 2017; Liamputtong 2019a) in 2020, but the practical guidance of doing social research in a global pandemic had yet to be addressed in the scholarship (Roberts *et al.* 2021). At this point, it felt like I was 'on my own' navigating new strategies, designs, and methodological approaches not designed for a world dealing with mass death and disease. As such, I drew on my own real-world professional experiences and relied on a broader mix of scholarship to develop a solution.

4.2.1 Deciding against Interviews

From Oral History training completed,[65] I was aware interviewing older people may present some peculiarities, for example, impaired memory, dementia, emotional distress, and relived trauma. These considerations, along with guidance from colleagues used to working with older people, cautioned against phone and video interviews due to; the length of time older people may be comfortable holding the phone for, use of hearing aids, speech difficulties, and the potential presence of others in the home which could inhibit or pressure participants. The 'digital divide' was also a factor - broadband reliability, technical expertise, the reliance on the presence of another to ensure connectivity which in turn may hinder sharing, the need to emotionally connect and the ability to do so via phone or video screen. This inequity was identified during the pandemic by Braun *et al.* (2020) particularly in relation to sensitive research. The idea of hanging up on someone after they shared their story, particularly during a pandemic when people were already so emotionally challenged, bothered me. How would I know as I bid goodbye to the person that they were ok, how could I check-in with them post interview other than phone back again to check on them? All these solidified my view that phone or video interviews were not the right approach during an ongoing crisis, for this topic.

Being unable to interview in-person meant the whole project had to be reconfigured. In effect, this meant a new research focus, new ethics application, redrafting chapters, designing new data collection methods, and redefining methodology - after all, if I was no longer interviewing, was I still doing Oral History?

4.2.2 A Route Forward

Redirecting the research away from interviews as the primary data collection method, was predicated on public health policies, and the feasibility of completing the project. The pragmatic option was to evaluate the data already collected to see what could be accomplished with it, even if this required changing the research question. In researching the background to this topic, I had mined 500 records from the National Folklore Collection (NFC), an oral history archive of Ireland dating to the late 1930s, to glean insights into perinatal death in the past. This data was originally to form the background historical analysis for the study. I reviewed this data and applied

[65] Oral History Network Ireland workshops in the Life Cycle Approach, Interview Skills, Ethics & Oral History; Oral History Center, University of California, Berkeley Summer Institute Advanced Programme in Methodology, Theory, and Practice of Oral History

documentary analysis to it, studying how this data had been acquired and the format and usefulness of it. This prompted further extraction of records from the NFC, generating approx. 1,200 total records for analysis.

The archive offered a bridge between present and past, and more value than initially anticipated. This altered the research and brought the historical data to the foreground. The original research aim was to explore long-term parental grief. This was not a topic that could easily translate from in-person interviewing to other data collection methods, and alternative methods were unlikely to yield the same type of rich data. On review of the NFC records, the research aims and questions were revised to explore the role of social rituals in perinatal death, this remained close to the original topic though the focus was different. These questions asked

- Is there evidence of social rituals for perinatal death in the past?
- What significance did/does social ritual play in family experiences of perinatal loss?
- What effect might hospital birth have had on these social rituals?
- How do families remember their infants, especially in the absence of social rituals?
- Does the absence or present of social ritual influence grief theories, specifically Disenfranchised Grief, and Continuing Bonds?

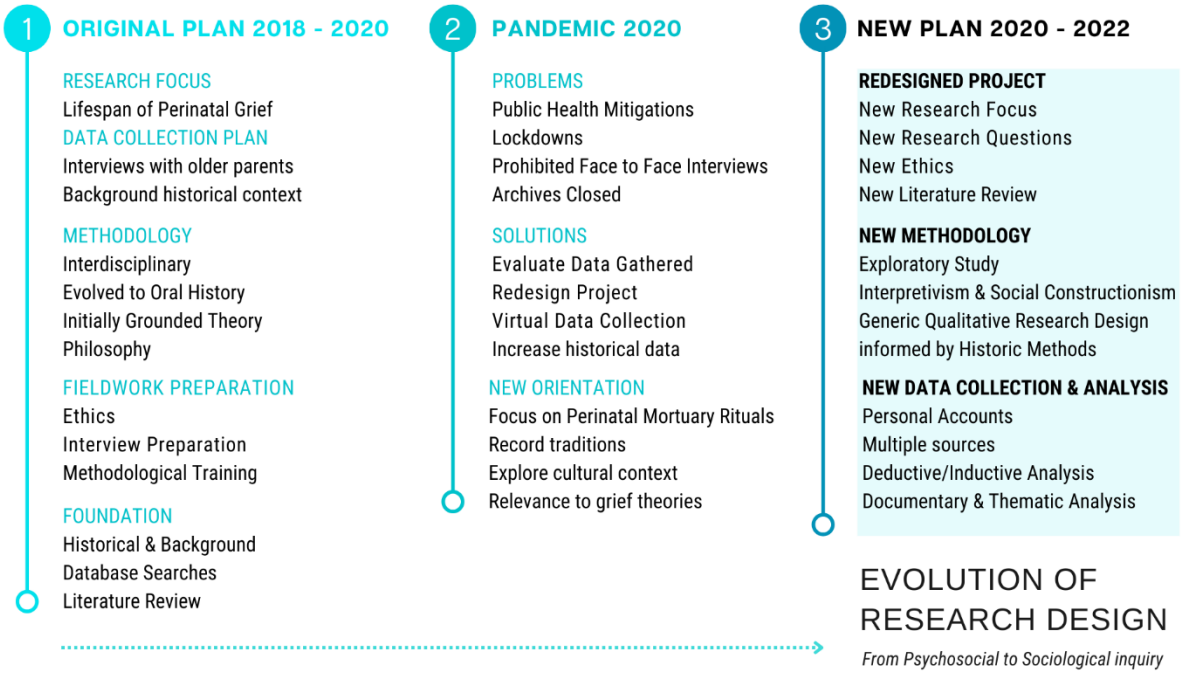
Whilst not being able to complete the original study as planned, the basis of the folklore archive came to be methodologically interesting in four distinct ways. Firstly, the NFC as an archive comprises predominantly 'written down' oral histories. The NFC employed an iterative process of question-asking (focused on specific topics), data collection, and transcription via a network of volunteer collectors. Data collection was guided by a handbook of questions, which was edited based on this cumulative iterative process. The archive is in effect a mega repository of qualitative surveys. I decided to apply the methods from the NFC and follow a similar format for contemporary data collection. Secondly, like the NFC, my study would now use convenience sampling – those who had knowledge could share it. Thirdly, using social media to promote the study and relying on the goodwill of strangers to complete it, is akin to the novel crowdsourced data gathering first introduced by the NFC over 80 years ago. Finally, the data collected would be similarly concise, so the length and 'texture' of the data is comparable. This makes for a more streamlined approach to data analysis.

The consequence of the ban on face to face interviewing, meant only digital methods and archives were possible to use. Though the pandemic created innovative opportunities for the use of remote or virtual research methods (Keen *et al.* 2022), these are not always best suited to social research. Due to the sensitivity of the topic, and the older age of some participants, interviewing using virtual methods was not considered appropriate.

With the current trend in birth and death scholarship and practice to 'rehumanise' both birth and death (O'Mahony 2017; Newnham & Kirkham 2019; Page & Kitzinger 2019) there is an increasing need to focus on the voices of ordinary people and how they experience these events. Within healthcare, this can be considered person-centred research, particularly important in the current trend for Personal and Public Involvement (PPI), which prizes the experiential contribution of service users to improve health care delivery (Maguire & Britten 2020). For social historians, this is the history of everyday life, the "sociological abstractions" of social relationships or "history from below" (Tosh 2009, pp.70, 72). Though there were many changes to the study, one component I was keen to retain was a focus on the 'absent' voices of people most affected by perinatal loss. Though the NFC, from a historic perspective, provided insights into the prevailing social attitudes and mortuary rituals of the late nineteenth and early twentieth century, it did not reflect direct parental experience, in general. The elusive family experiences of perinatal loss were found in an eclectic mix of primary and secondary data.

Using the NFC provides insight into perinatal death at home, in the era prior to hospitalised birth. Contemporary accounts were collected from living participants via a similar process. The potential participant pool was extended from affected parents to also include the adult children of affected parents. This made sense as the study pivoted away from psychological (inner or micro) towards sociological (outer or macro) perspectives. This arrangement gives us both lived and living experiences of the phenomenon under review and constitutes the historical narratives, biographical and autobiographical materials that Scimecca (2007, p.102) identifies as necessary for qualitative research. Using a comparable approach, Kuijt *et al.* (2021) drew on a broad range of multidisciplinary sources, integrated with oral histories, to build their social construction of rural mourning practices in nineteenth and twentieth century Ireland. Similarly, Donnelly (1999) successfully blended oral history interviews with data gleaned from the NFC for her palliative care study seeking knowledge on traditions of care for the dying by informal caregivers.

FIGURE 2: EVOLUTION OF THE RESEARCH DESIGN DUE TO PANDEMIC



4.3 Historically Informed Qualitative Methods

4.3.1 Hunting Absent Histories

Perinatal death has increasingly become a focal point in biomedical discourse, particularly since 2011, as noted in the literature review. However, perinatal research is shrouded somewhat in other disciplinary scholarship, entering the record not as a direct source of enquiry but in relation to another topic, or "sideways", as Earner-Byrne (2017, p.7) puts it when describing poverty scholarship in the context of women's histories, for example. There is no social history of stillbirth or perinatal death and only sparse records of maternal birth stories or care pathways within hospitals over the twentieth century. The scholarship tends towards Western ideals, overlooking the contribution of culturally located perspectives (Scheper-Hughes 1992), in general. The original research question aimed to understand the lifecycle of perinatal grief which meant understanding the context of experiences. The problem was no such context existed. The reoriented research question focuses on this context by studying mortuary rituals. The scholarship for Irish death rituals and burial practices is scant for the nineteenth, twentieth and twenty-first centuries (Albano 2011); what exists for infant and child deaths is limited in its focus. Where scholarship on infant death has tended to focus is on the outliers (infanticide, abortion, residential institutions) but the broader study of infant death, and specifically, perinatal death is inadequate. Cecil (1996)

further notes an absence of the everyday experiences of pregnancy loss in the historical record, yet it is the everyday accounts that Tosh (2009) maintains historians cherish as they leave space for interpretation. By interrogating documentary sources for incidental remarks, turn of phrase, or use of language, and combining these with retrospective oral evidence it is possible to build a rich exploration of issues ignored in official records (Cronin 2007).

Sometimes 'old' topics just need new ways of thinking about them (Kahlke 2014, p.49; Liamputtong 2019a). In this study, a historic lens is applied to social research in the context of studying experiences of mortuary ritual in the past and their relevance to grief theory. Montgomery *et al.* (2020), for example, connected staff perspectives to patient experiences, in a process they refer to as 'rewilding' (an ecological restoration of species to their original habitat). Montgomery *et al.* (2020, p.13) integrated the "tacit, intuitive, informal and embodied information" of frontline staff to fill in missing facets of patient experience, terming this informal information 'wild data' as it "escapes capture" and is "lively, untamed and powerful". Wild data is a useful analogy for researching sparse or problematic "tendencious, fragmentary, silent where it ought to be explicit" historic data (Collingwood 1928, p.214). In the absence of neat archives of parent's birth experiences, what is left is a disparate array of official records, reports, and fleeting references which comprise the structured data of the past and present, disconnected from personal experience. Whilst these documents may be considered secondary data that offer "cultural fragments" (Braun & Clarke 2013, p.153), Beiner (2018, p.13) uses the term "vernacular historiography" as an approximate equivalent, placing the muffled voices within folklore and oral history on a comparable footing to traditional historical documentary sources. This combination of oral history, folklore, and documentation, becomes the data to rewild the scholarship and build a mosaic of meaning regarding baby loss. As Knott (2019, p.7) remarks in her work on mothering and reproduction it is wise to put "grand narratives aside, and pay attention to the fragments and the anecdotes". So, channelling Silverman's (2013, p.141) research maxim to "make a lot out of a little", this is what I did.

4.4 Operationalising Research

Historical research is useful for analysing processes or the meaning of events for people, individually or collectively (Polkinghorne 1988; Flick 2009; Madsen 2018). This includes defining the appropriate people, boundaries of time and determining which historical sources and documents should be used to supplement interviews (Flick 2009;

Madsen 2018). Within social research, the process of moving from the theoretical to the practical is referred to as operationalisation, in which concepts and frameworks are made explicit (Merriam 2015).

This research area is rife with conceptual challenges. Concepts provide a language for professionals to arrive at a shared understanding of a phenomenon - if you do not have a language you cannot talk and if you cannot talk, you cannot do (Zeanah 1989; Blumer 1992; Corbin & Strauss 2008; Fenstermacher & Hupcey 2013). Language then sets the basis for "all scientific and moral endeavours" as it holds value judgements and collective patterns in which meaning is conferred (Scimecca 2007, p.26).

Where the biggest difficulty lay in this project was defining the conceptual ambiguities that seem to be overlooked in scholarship. For example, how do we define birth trauma, long-term, or death - or come to think of it, birth? These are fluid concepts, frequently undefined in the scholarship yet taken as 'true'. In reality, many of these are linguistic variables subject to 'fuzzy logic', to borrow a phrase from the field of mathematics (Cintula *et al.* 2017).[66] Further, the meaning of variables change over time, so historical researchers need to determine the correct meaning of words in the context of the time under investigation (Lusk 1997). When attempting to define the perinatal infant, this is perhaps the most difficult task of all. The primary task in operationalising this study then became one of defining core conceptual ambiguities.

4.4.1 Definitions & Concepts

4.4.1.1 Concept 1: Perinatal Infant

As discussed in Chapter 2 and 4, generation terms are used interchangeably to describe different reproductive experiences, including the everyday term 'unbaptised'. This fluidity of 'generation' terms for the same event, complicates the historical and social context, particularly, as when examining change over time, historical research needs to determine the correct meaning of words in use at any given time (Lusk 1997). The problem is that definitional ambiguities persist both within and across time periods (see Table 2 for some of the contemporary definitions in use in Ireland today). 28 weeks gestation was the medicolegal barometer for the treatment of remains through the twentieth century, until the introduction of the stillbirth register in 1995 which lowered the legal age of viability to 24 weeks in Ireland (Taylor 1994).

[66] Fuzzy logic may best be explained by asking when does an apple become an apple core - we may know it when we see but how do we determine the point at which it changes?

TABLE 2: CALCULATING MORTALITY RATES 2020

Definition	Formula
Stillbirth Rate	# Stillbirths ÷ Total Live births + Stillbirths × 1000
Late Foetal Mortality Rate	# Late Foetal Deaths ÷ Total Live births + Late Foetal Deaths × 1000
Early Neonatal Mortality Rate	# Early Neonatal Deaths ÷ Total Live births × 1000
Perinatal Mortality Rate	# Perinatal Deaths ÷ Total Live births + Stillbirths × 1000
Late Neonatal Mortality Rate	# Late Neonatal Deaths ÷ Total Live births × 1000
Post Neonatal Mortality Rate	# Post Neonatal Deaths ÷ Total Live births × 1000
Infant Mortality Rate	# Infant Deaths ÷ Total Live births × 1000
Maternal Mortality Rate	# Maternal Deaths ÷ Total Live births + stillbirths × 100000

(*Standard Report on Methods and Quality for Stillbirths Registration 2007 Onwards* 2020)

In 1948, the term Perinatal Mortality was coined to cover the overlapping medico-statistical categorisations of stillbirth and early neonatal death based on causes of death (Peller 1948), as described in Chapter 2.[67] Though ultrasound was used for obstetrical scans from 1959, its' widespread use for gestational dating only became commonplace in the 1970s (Campbell 2013) meaning most parents prior to the 1980s are left with estimates of gestational age.[68] Further, in contemporary studies, the term perinatal has been extended outside the original definition put forth by Peller (1948) thus rendering the term 'around birth' subject to further ambiguity. Thereby in this study these strict medicolegal definitions were not applied to the study criteria and were simplified to include all baby and pregnancy loss for data collection purposes.

[67] The World Health Organization (WHO) (2021) introduced a category in 2016, ICD-PM (the tenth International Statistical Classification of Diseases and Related Health Problems i.e. ICD-10), to capture specific causes of death, linked to maternal outcomes, to streamline international data collection and comparison. For international comparison, 28 weeks gestation is used as the defining feature for stillbirth (Blencowe *et al.* 2016) as there are difficulties in applying parameters of weight versus gestational age according to ICD-10 classification, see Lawn et al., (2016) for discussion

[68] Prior to the use of ultrasound, or in its absence, foetal maceration is used as a proxy for intrapartum death; skin maceration occurs between six and twelve hours following death allowing clinicians to determine when it has occurred (Lawn *et al.* 2016). Within hospital records for the 19th and 20th century stillbirths or dead births are denoted as fresh, macerated, or putrid to indicate time elapsed since intrauterine death (Fitzgibbon *et al.* 1927)

4.4.1.2 Concept 2: Grief, Mourning and Bereavement

Fenstermacher & Hupcey (2013), Zeanah (1989) and Stroebe & Schut (1998) all highlight the interchangeable use of grief, mourning and bereavement, in the literature. For this study, mourning is considered a social framework, that is the overt social rituals and customs associated with bereavement, defined by a society or culture; bereavement is considered the 'loss event' i.e. a death that is the trigger for mourning; and grief is considered an emotional response to bereavement, incorporating the psychological and physical which can be associated with health outcomes. This aligns to the definitions used by sociologist Howarth (2007a) and grief theorists Stroebe & Schut (1998). Grief can further be characterised as an individualised 'syndrome' comprising any number of emotions which can differ across cultures (Lofland 1985).

4.4.2 Historical Framework

4.4.2.1 Legal Jurisdiction

Ireland was divided into two states in 1921 under the Government of Ireland Act 1920; six counties in Northern Ireland remained under British rule, the remaining 26 counties became the Irish Free State (Saorstat Eireann) following civil war (1922-1923), and declaration of a republic in 1949 (Republic of Ireland Act) (Daly 2007). Until partition, the island shared a culture, language, folkloric belief, and British administration. As this thesis considers the twentieth century, an all-island approach was taken to data collection, which included participants from anywhere on the island.

Population statistics for Ireland were collected by a variety of agencies (e.g, Annual Reports of the Registrar General (ARRG), General Registrar Office (GRO), Census and Saorstat, some of which have changed recording and reporting responsibilities, as well as names, over time – these are all collectively archived, managed, and now reported by the Central Statistics Office (CSO).

4.4.2.2 Time

The twentieth century forms the parameter of the study as it is bookended by two pieces of relevant legislation. First, the increasing regulation of births and deaths, which defined the legal age of viability at 28 weeks gestation, under the Notification of Births Act 1907. Under this legislation births or perinatal deaths less than 28 weeks gestation were not notifiable to the registrar. Secondly, the introduction of the Stillbirth Registration Act 1994, completes the twentieth century, this enabled formal civil registration of a stillbirth from 24 weeks gestation and/or 500g in weight. Binding the

study using years 1900 – 2000, assumes a fixed span of time. This time frame is used to bind the birth event for families but recognises the ongoing, dynamic living experience of those affected which technically expands the span of time to the present day.

4.4.2.3 Institutional Maternity Care

Birth was increasingly regulated through the late nineteenth and early twentieth century (Loudon 1992), with the profession of midwifery regulated in Ireland under the Midwives Ireland Act, 1917 (Barrington 1987). As the century progressed, birth increasingly moved to hospital away from home, the interwar period observing global trends towards hospitalised birth (Loudon 1992). This pattern was replicated in Ireland where hospital births accelerated from the 1930s so that by 1955, two-thirds of birth took place in hospital (Earner-Byrne 2007). Within this study this gives rise to three distinct time periods; pre-1940 when homebirths are dominant, a transitional phase when birth migrates to maternity units between the 1930s and 1950s, and post-1950s when hospitals are dominant places for birth and death.

Historically, place of birth was not homogenous and included hospitals and other maternity institutions (Loudon 1992). This gives a list of non-domiciliary birth facilities which include: specialist maternity hospitals from the eighteenth century; general hospitals with obstetric wards and specialists; small or cottage hospitals with mixed maternity and surgical cases or designated maternity beds; nursing homes; rural hospitals with general practitioners (Loudon 1992); and old workhouses with lying-in beds or wards, later morphing into maternity hospitals (e.g. the South Dublin Union developed into a municipal hospital, St Kevin's, evolving into St James' Hospital (Coakley 2022)). In 1934, the Maternity Homes Act was introduced to regularise control of maternity services (Barrington 1987). The Irish maternity system was fuelled by a reliance on Dublin maternity hospitals, originally established for the treatment of the poor, which were the backbone of specialist maternity care through the nineteenth and twentieth centuries (Barrington 1987; Earner-Byrne 2007). This was supplemented with a network of institutional medical care delivered via the workhouse dispensary system under the Medical Charities Act, 1851. Though 'institutional' in social histories may refer to residential institutions, within this thesis, the term is used to refer to the delivery of maternity care outside the home within a formal bureaucratic structure i.e. when birth occurred in a hospital, private nursing home, workhouse lying-in ward or other institutional building, as detailed by Loudon (1992). If residential institutions are referenced this will be made explicit.

4.4.2.4 Midwife

The terms nurse and nursing sometimes appear in the historic record when referring to maternity care and midwives, and the distinction between nursing and midwifery is not always made clear. The Central Midwives Board (CMB) was established in 1918 (following the Midwives Act Ireland, 1917) (Ó hÓgartaigh, 2012).[69] Midwifery was a prerequisite for public health District Nurses and in 1950, the CMB was subsumed into a single regulatory authority (*An Bord Altranais*) (Ó hÓgartaigh, 2012).[70] The Nurses and Midwives Act 2011, authorised the renaming of the regulatory authority to the Nursing and Midwifery Board of Ireland (NMBI), and Midwifery was recognised as a separate profession (NMBI, 2023).

Whilst professional midwives in Ireland today may not be qualified nurses, this is not the case everywhere. For example, in Sweden all midwives first qualify as a nurse before undertaking subsequent midwifery education (Silverton, 2018). Due to the way in which both the professions of midwifery and nursing developed, in Ireland and internationally, the terms thus are sometimes used interchangeably in the scholarship and historic records, in this thesis, the terms are used as presented. Further, it should be recognised that though the *scope* of practice differs for both Irish midwives and nurses, both nursing and midwifery are guided by similar *codes* of practice (*Scope of Practice: Standards & Guidance*, NMBI, 2023).

> Midwifery care combines art and science. Midwifery care is holistic in nature - grounded in an understanding of the social, emotional, cultural, spiritual, psychological, and physical experiences of women, and is based upon the best available research and experiential evidence.
>
> Nursing care combines art and science. Nursing care is holistic in nature, grounded in an understanding of the social, emotional, cultural, spiritual, psychological, and physical experiences of patients, and is based upon the best available research and experiential evidence.

[69] Midwifery was regulated under the Midwives Act, 1902 (England and Wales), but not in Ireland until 1918. In the interim, Irish midwives who trained in the Rotunda Hospital, Dublin, could have their names placed on the English midwifery register (Ó hÓgartaigh, 2012).
[70] The Nurses Act, 1950 established *An Bord Altranais* (the Nursing Board) to take over the Central Midwives Board (est 1918) and the General Nursing Council (est 1919), with additional regulatory functions expanded under the Nurses Act, 1985 (NMBI, 2023).

4.4.2.5 Place of Burial

Disposal is an encompassing term which includes burial, cremation (only available in Ireland since 1967, and for infant cremation only since 2014 (RTÉ 1982; *Irish Times* 2014)), incineration (usually referring to the use of hospital incinerators) or resomation (water cremation, an eco-friendly alternative to cremation which is not yet available in Ireland). In an Irish context, disposal of remains, most usually refers to burial of the body, which may occur with or without accompanying social rituals.

Burials occurred in formal cemeteries, churchyards and folk burial grounds (*cillíní*) (Henderson 2014). This research does not focus on burials at residential institutions. The primary reason why is because no normative or typical framework for death, burial, and bereavement in the nineteenth and twentieth century has been written, as yet. From the limited scholarship on burial, there have been many assumptions which are decontextualised, thereby, in this research, the institution of interest is the maternity hospital.

Glasnevin Cemetery, Dublin features in this thesis as it has special significance with regard to infant burials. Originally opening with a two acre site at Goldenbridge in 1828, the cemetery was further extended and remains as a private trust (Glasnevin Cemetery 2022). Glasnevin is the primary burial ground for Dublin born infants, with several areas colloquially known as the 'Angel Plot' or more formally the Holy Angels plot (Garattini 2007) specified for the burial of perinatal infants.

4.4.2.6 Historic Terms

Using historic data and terms can be challenging, for example, Poor Ground burial is often seen as shameful in the past, and in the present. Where historic terms are used within this research, they are used in the context of the social discourse of their time. These are not terms with which any judgement is exercised by the researcher.

4.5 Data Collection

Data collection is an iterative process which must be specific about the form, strength, and weaknesses of each type of data (Creswell & Poth 2017). In general, qualitative research must be explicit in the systematic and logical methods of planning, collecting, and analysing data (Pope & Mays 2020, p.7), thereby defining the strategically relevant data was the first challenge.

As the focus in this study was to explore mortuary rituals and their relevance to grief theory, this necessitated an exploration of historic and contemporary data sources, gathered in an iterative process. The empirical data for this thesis relies on three different sources of data to capture past and present experiences of perinatal death: the National Folklore Collection, personal accounts, and documentary sources, discussed further below.

4.5.1 Primary and Secondary Data Sources

This study uses both primary and secondary data. For health and social scientists, primary datasets are typically ones produced by the researcher with a specific problem in mind which is detailed extensively in a methodology chapter. In health and social research, when the researcher has no role in the production of the data, these comprise secondary data sources (Braun & Clarke 2013).

Atkinson & Coffey (2010) remind researchers however, to avoid the binary of interviews as primary and documents as secondary data, maintaining each source should be evaluated on its own merits. This distinction is frequently attended to by historians who always deal with data created by someone else, however, these can be defined as primary, if the sources are direct creations of their time (Tosh 2009, p.91).

Primary sources are those that offer eyewitness, or first-hand accounts of a phenomenon (Sarnecky 1990; Lewenson 2010b; Marshall & Rossman 2016). In social research, particularly for exploratory studies, interviewing is preferred as a primary source (Nathan *et al.* 2018). In historic research, interviews (oral histories) provide an important primary source for nursing history, as it illustrates aspects of social life often not captured in archives (Lewenson 2010b; Marshall & Rossman 2016). Additionally, documents related to the phenomenon or event under review, including statistical data, annual reports, diary entries or newspaper articles written at the time constitute primary sources (Marshall & Rossman 2016; Lewenson & McAllister 2021; Dunne *et al.* 2016), or as in this study, the National Folklore Collection archive.

The providence of primary sources is of concern to both historians and social researchers, this refers to the genuineness and authenticity of data (Lewenson 2010b). How this is established differs somewhat between history and social research. In social research, subjective experience is valued and the authenticity of data is detailed through the planning and execution of fieldwork (Nathan *et al.* 2018). In historical research, primary and secondary sources establish social facts. Whether something can be considered fact is through corroboration of a primary source, thus multiple

sources are important in the context of verification (Sarnecky 1990; Marshall & Rossman 2016), as such, various sources of data were used in this study. For historians, documentary analysis provides the framework for establishing the accuracy of the data used (Marshall & Rossman 2016). Documents are not inert, neutral expressions of structured data but reflect particular formats or values (Lincoln & Guba 1985; Flick 2009; Atkinson & Coffey 2010; Gorsky & Mold 2020). For this reason, historians treat documents as a rich source of social research data and so their production and social organisation necessitates attention (Punch 2005, p.184). The cultural fragments contained within documents allow social researchers to explore sociocultural practices and meanings, and people's experiences and understanding, with regard to specified topics, and how these are resisted or incorporated (Braun & Clarke 2013)

The first step in using historical documents is to assemble a 'corpus of data' or what is commonly referred to as a data set (Flick 2009). This is subject to the same basic process used in other forms of qualitative research, including sampling, which can be representative or purposive (Flick 2009). Historical analysis in this study has relied on 'everyday' data sources, including the publicly accessible oral histories of the National Folklore Collection deposited at *Dúchas* (University College Dublin). These were used to inform the Topic Guide for collection of personal accounts from parents and adult children of parents who experienced perinatal loss.

Other primary sources included

- Parliamentary and state records
- Civil records
- Ordnance survey maps
- Oral histories from other archives
- Contemporary accounts in biographical records
- Cemetery records
- Newspaper accounts

References to perinatal deaths are rarely the direct focus of these sources, they provide only fragments but, like jigsaw pieces they help to fill in gaps in the historic record. Where used, these are referenced directly in-text. Secondary data was also used for historical analysis. These comprised oral histories collected and recounted by other authors, and historical analysis produced by other scholars, both directly referenced in-text.

4.5.2 National Folklore Collection

The primary data source sampled was the National Folklore Collection (NFC), chosen as it provides a rich source of sociological data on (mainly rural) Irish life from the late nineteenth and early twentieth century. This is a particularly important archive as it straddles the era in which birth moved from home to hospital.

The NFC comprises oral histories collected in rural Ireland between 1937-1945, predominantly as a response to a national interest in capturing the 'authentic' Ireland of the post-Famine generation. It reflects disproportionate data collection from the western and most remote parts of rural Ireland where it was then believed authenticity reigned (Jackson 1946). Whilst scholars of the time believed that Irish religious legends contained in the archive, are remnants of medical legend dating to the fifteenth and sixteenth centuries (O'Connor 2005, p.191), the collection as a body of work, reflects not just mythical life and Irish legend but insights into the social customs, practices, rituals, psychology, and sociology of Irish life in the nineteenth and early twentieth century.

Comprising approx. two million records, the collection was unique at the time for its crowd-sourced approach to data collection when state financial resources were minimal (Dúchas 2021). As a result, several types of folklore were collected in different ways at different times, with extensive records held in the Main Manuscript collection which produced 2,400 bound volumes (Dúchas 2021). The collection has been largely digitised and transcribed, though not always translated from Irish into English.

Folklore can be of three primary genres: tales, legends, and true experience (Degh 1972) and this study relies on the latter category, of true experience or everyday life. The primary data for this study comes from the NFC Schools Collection comprising 1,128 bound volumes collected from 5,000 primary schools in the Irish Free State from 1937 to 1939. These stories were gathered by schoolchildren from their older relatives and neighbours. The dataset also includes a small number of records drawn from the Main Manuscript collection, and photographs from the Photographic Collection.

The NFC is, in general, a highly gendered archive with collectors being primarily men (O'Connor 2005). As such, women's histories, particularly childbirth and loss were not exclusively sought or represented in the original collections. In the 1970s and early 1980s, additional birth questionnaires were circulated however these are not publicly

available and remain with the individual NFC researcher.[71] A small number of Birth related surveys were found in the Main Manuscript collection (for south Mayo) but as this is not digitised, and due to archive closures, it was not possible to keep searching beyond this small sample.

The NFC is best approached as a written versus an oral collection, suggests Ó'Ciosáin (2004), as it does not fit the parameter of oral histories – interviews cannot be repeated, and collection cannot be verified. These qualities render the NFC comparable to qualitative surveys, reflecting a similar dynamic data collection process and methodological principles. The NFC data collection relied on a giant topic guide, published as the *Handbook of Irish Folklore* in 1942 (Ó'Súilleabháin *et al.* [1942] 2014); a book of questions to guide collectors, populated from submissions. As stories were returned and analysed, new items prompted the next wave of collectors to ask similar questions – this iterative process of theoretical sampling is familiar to many researchers working in methodologies such as Grounded Theory (Glaser & Strauss, [1967] 2010).

When analysing the returns in the NFC what is noticeable is their structure. Whilst some entries are discursive or might be considered a story (bearing in mind that good storytelling at this time was culturally respected) many of the returns follow a structured yes/no format. This is not immediately evident as the entries only contain the answers, and not the questions asked or answered. It only becomes apparent by comparing the texture of the entries against the Handbook. When this is done, the structure of the entries conforms less to a 'narrative' and more to the timbre of qualitative survey responses and a qualitative yes/no format. It is here in the Handbook, that the 'sideways' study of perinatal death occurs. It exists in the NFC because of this single question in relation to graveyards: "were suicides, strangers and unbaptised children or any others buried in this [unpropitious] part" (Ó'Súilleabháin *et al.* [1942] 2014, p.236). An adapted version of this question was advised in the Department of Education handbook for the Schools Collection: "Where were unbaptised children buried? What were such graveyards called? Are they still in use?" (*Irish Folklore Commission* 1937, p.35). Without this question, it is debatable that perinatal death would exist in the

[71] The NFC circulated questionnaires to collectors around the country, relating to the specific scholarly interests of its researchers. A questionnaire concerning unbaptised children was circulated in 1979, later forming a component of O'Connor's (1991; 2017) work. A childbirth questionnaire, which included questions on miscarriage, abortion, birth, death and pregnancy, was distributed between 1982 and 1983 (O'Connor, 2017). These questionnaires are yet to be digitised, and are retained by the original NFC researcher, only twelve entries from Balllinrobe, Mayo were available in the archive for copy.

archive at all, and so these fragments, this 'wild data' which embodies laden cultural meaning has been captured.

4.5.2.1 Purposive Sampling

Purposive sampling is a deliberate strategy to use particular data sources with a specific focus or purpose in mind (Punch 2005). Choices must be made about what to include, as not everything can be studied, and this is why sampling becomes strategically important. As Earner-Byrne (2017, p.6) reminds us, the ethics of selection means deselecting others by extension. This is true for the documentary sources selected for investigation but also the illustrative examples chosen for discussion. In this study, quotes rely on the concept of 'information power' (see section on sampling below), i.e., richness of data, and quotes from different parts of the country.

Searching the NFC database is not similar to searching contemporary research databases such as EMBASE or CINAHL. There are no Boolean operators, MeSH terms or simile functions.[72] Mining this database is an exercise in resilience. Part of the reason for this is the bilingual nature of the archive but also that Irish people speak Hiberno-English, a unique form of English which maintains the cadence and descriptiveness of Irish (Joyce 1910; Filppula 1993; Magan 2020). This makes searching somewhat serendipitous rather than definitive. Nonetheless, using an iterative process of searching and analysing, over 1,000 relevant records were identified for use.

This was not an exhaustive sampling of the database for two primary reasons. First, all the material in the archive is not fully digitised, translated, or transcribed. Second, what might be termed 'in vivo' codes (naturally occurring codes in collected data) provide new database search terms but the benefit of new data to the overall sample, given the time required, was debatable particularly given the geographic focus of the archive.

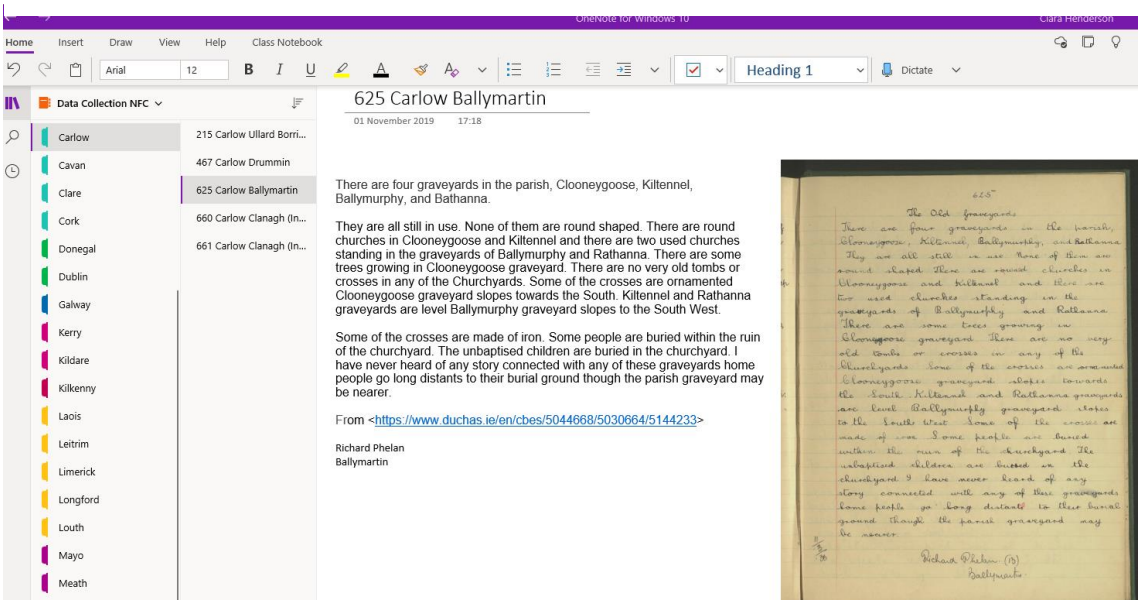
4.5.2.2 Data Management

The data was manually downloaded and organised for analysis and, if necessary, transcribed and/or bilingual entries translated. Entries that were fully Irish were not included as these were beyond the translation skills of the researcher, however, specific phrases and excerpts were verified with a native Irish speaker.

[72] To aid database searches in the biomedical and health data repositories, a hierarchical indexation system was developed, referred to as MeSH (Medical Subject Headings), see https://www.nlm.nih.gov/mesh/meshhome.html

There are few analytic tools for doing historical research and though initially MAXQDA, a qualitative software application, was used, it was unwieldy to use with a large volume of text based images. In practice, the most useful tool for organising and managing the NFC data was Microsoft OneNote. Entries were organised in OneNote by county, page number and townland (see Fig 3). This made it easier to find and eliminate duplicates which resulted from different database searches. The in-text citation follows a similar structure i.e., NFC, Townland, Page Number, Year.

FIGURE 3: ORGANISING DATA IN ONENOTE



4.5.3 Personal Accounts

The NFC and other primary historical sources provide personal or eyewitness accounts. Interviews provide another source of eyewitness testimony; these can be oral histories (i.e., lived experience of a participant, or historic moment, is captured); in-depth interviews (built around a single leading question with no pre-determined end), or the most common method, semi-structured interviews (Nathan *et al.* 2018). Semi-structured interviews balance specified researcher questions (using a topic guide), with a flexibility dictated by the participant (Nathan *et al.* 2018). When the questions to be asked in an interview are written down and self-administered, this constitutes a purely qualitative survey (Braun & Clarke 2013). As interviewing was not possible, a qualitative survey design was used instead.

Qualitative surveys are under used in qualitative research due to a limited methodological literature and an over reliance on interviews as the optimum form of

data (Terry & Braun 2017; Braun *et al.* 2020). Though criticised as lightweight (Moser & Korstjens 2018), Braun *et al.* (2020) maintain that qualitative surveys are equally rich and complex resources, providing focused, useful data. The downside of using qualitative survey is the resulting data can be thin and lack the necessary richness for analysis (Elliott & Timulak 2021).

This parallel phase of data collection sought qualitative data from bereaved parents or their adult children using four modes of data collection (audio recording, postal entries, free text digital upload, or digital qualitative survey). Though the form of data collection differed, in principle all modes were based on the idea of participant generated textual data (Braun & Clarke 2013, p.217), in this instance, qualitative survey. Qualitative surveys, argue Braun *et al.* (2020) are appropriate when they: best fit the participant's needs; cover sensitive topics; engage dispersed populations; when the focus is specific; or a broad range of views are sought.

The aim in providing different modes of participation was to allow participants engage in the way that felt most comfortable to them. The four options for completion of the study were provided to allow for the maximum variation of perceived need in the potential population. For example, an audio recording option was added to improve accessibility for those who may not have the physical dexterity to use mobile devices, and hard copy letters were offered for those who may lack digital access or technical expertise.

4.5.3.1 Sampling Strategy

Sampling is equally important in qualitative research as in quantitative approaches (Punch 2005; Rapley 2014). In qualitative research, sampling is deliberate (Moser & Korstjens 2018). Convenience sampling was employed for the qualitative survey – those who had experience and felt compelled to share it could participate. This was a pragmatic decision based on the reality of life under lockdown and the ability to recruit participants. Given the dual aspects of filling in the historical record with previously silenced perspectives, ensuring diverse and appropriate voices is key and this was achieved (Leavy 2011; Braun *et al.* 2020).

4.5.3.2 Inclusion Criteria

Inclusion criteria are broad as there is no way to control who takes part in a digital survey and participants can self-select.

- Inclusion criteria:

    - Parents or the Adult Children of Parents who experienced a perinatal death (death around the time of birth)
    - This baby died over 20 years ago (prior to 2001)
    - They were living in Ireland at the time of the baby's birth/death
- Exclusion criteria:
    - Parents who have experienced a perinatal death since 2001

4.5.3.3 Sample Size & Data Saturation

Though recommendations for sample size based on data type or methodology vary, there is no magic formula and researchers are often informed by perceived norms regarding sample size (Braun & Clarke 2013; Bryman 2015; Malterud *et al.* 2016; Vasileiou *et al.* 2018). Sample size is linked to data saturation (saturation) borne from the methodology of Grounded Theory, as a component of the iterative data gathering and analytic process called the constant comparison method (Green & Thorogood 2004; Malterud *et al.* 2016). Saturation, based on this specific research method, does not represent all theoretical perspectives (Braun & Clarke 2013). The concept of saturation, usually referring to information redundancy (Saunders *et al.* 2018; Braun & Clarke 2019) meaning a data sample offers no new data, themes or codes, has diffused into other qualitative methodologies, however, these claims relating to saturation are made without offering how this was defined, assessed or achieved (Malterud *et al.* 2016; Vasileiou *et al.* 2018). This is relevant as sample size and saturation are linked to internal validity, meaning the credibility of the findings (Vasileiou *et al.* 2018).

The original sampling plan was to aim for 50 participants from a mix of urban and rural areas, evenly drawn from different decades to provide a baseline of experience. This sampling aim was not realised. The concept of 'information power' (Malterud *et al.* 2016) and 'data adequacy' (Vasileiou *et al.* 2018) are offered as alternatives to issues of saturation. Both terms essentially meaning that the sample is of sufficient size, quality, and variability to answer the research questions. Information power simply means that the more information a sample holds, the more useful it is, and the fewer participants are required. Further, the authors argue it is this characteristic that is more important than the number of participants (Malterud *et al.* 2016) and sample size should not necessarily be considered a study limitation (Vasileiou *et al.* 2018).

In their systematic analysis of data adequacy, Vasileiou et al (2018) offer various justifications by authors for sample size, including 'practical considerations' and

theoretical sufficiency. Theoretical sufficiency maintains qualitative data collection is rarely exhaustive and that rather researchers should rely on a 'sufficient theoretical account'. As exploratory studies aim to offer new insights that either challenge current views or contribute to scholarship in specific areas of focus, they are not exhaustive interrogations of data argue Malterud *et al.* (2016). In practice, qualitative research relies on data quality rather than data quantity (which is tied to the positivist remnants of statistical generalisation) (Liamputtong 2019b). Though the original sampling target was not achieved from living contributors, what was gathered had enough information power and adequacy to answer the research questions.

4.5.3.4 Recruitment Strategy

Participants were sought from the general population (long term bereaved parents / adult children of bereaved parents). Data collection and participant recruitment were advertised via social media platforms, directing participants to the dedicated research study website. The study was shared widely across Twitter, Facebook, and LinkedIn. The study was organically and frequently shared by bereaved parent support groups, on their social media accounts, negating the plan to approach them for direct recruitment assistance. Additionally, the study was featured in the national media making the front-page banner of a national daily newspaper *(Irish Independent* 2021).

Queries were received from parents in Australia, America, Canada, and the UK regarding study participation, illustrating the reach of media and social media. Despite extensive sharing on media platforms, there was a low level of uptake. In part, this I believe can be attributed to the isolation and distress of extended lockdowns during Covid19. There were low levels of roll-off (non-completion) though completion quality was variable. In total 24 respondents replied (parents (n=16) and adults whose parents had a perinatal death i.e., adult children or surviving children (n=8). Data collection commenced in December 2020 and remained open until April 2022. After data collection had closed, further participant queries were received. These respondents were replied to and thanked for their interest, with an explanation that the study was closed.

Two adult children made contact about their parents participating in the study, noting accessibility issues due to impaired vision and dexterity and requested an interview. As this was not possible, an audio recording was suggested and agreed upon. Following an amendment to ethical approval, and software upgrade to allow anonymous audio contributions, the study was adapted to accept these audio

recordings – unfortunately, they did not materialise. The issue of accessibility regarding technology also featured with three of the older participants. One by-passed the upload facility on the website preferring to email the study email account directly, two copied the study email address from the national newspaper article. Following confirmation of consent for their anonymised data to be included, as per the participant information leaflet and ethics approval, their emails were deleted. These anonymised entries were uploaded to Qualtrics (digital survey software) as per the original intended collection mechanism. Despite the entire data collection process being designed to assure total anonymity, almost all participants provided identifiable data – towns, dates of births, names, hospitals and friends and family members. All identifying information was anonymised.

4.5.3.5 Adapting Fieldwork

With Oral History, the purpose is to centrally locate the 'lived experience' of people and the intention was to retain a humanistic focus, even with a change in methodology. I needed to consider how to adapt listening skills to textual data collection. How could I build rapport and engender trust when I would have no direct contact with participants? In conjunction with this, the sensitivity of the topic, the potential vulnerability of participants and with the existential dread posed by Covid19, I struggled to consider how this might work in practice.

Whilst influenced by the work of Braun & Clarke (2006), Terry & Braun (2017), and Braun *et al.* (2020), I drew heavily on my own professional background in strategic communications. My starting point was thus to consider how did I want the participants 'to feel'. This informed the choice of language in the Participant Information Leaflet (PIL), Consent form, the research website text and the final survey questions format and flow. It infused the creative elements of the project, including the website layout, research graphics, choice of colours, images and even the titling of the project.

Information for all participation options was provided on a dedicated research study website. The website was designed to direct potential participants through the study, providing webpages and PDF versions of the Topic Guide (also used in interviews), Support Services and Participation Information Leaflets. A key aspect of the design adjustment was to let people know that the preference had been to meet and speak with them, but this was no longer possible. The change in methodology was communicated to potential participants on the website and the Topic Guide use was explained as follows:

This study was designed as a traditional oral history project. In an oral history project, interviewers ask participants questions in the form of a conversation. Due to Covid-19 public health restrictions on face-to-face interviewing, we are unable to conduct the study in this way. Instead, we are adapting this oral history process so that you can, in effect, 'interview yourself'.

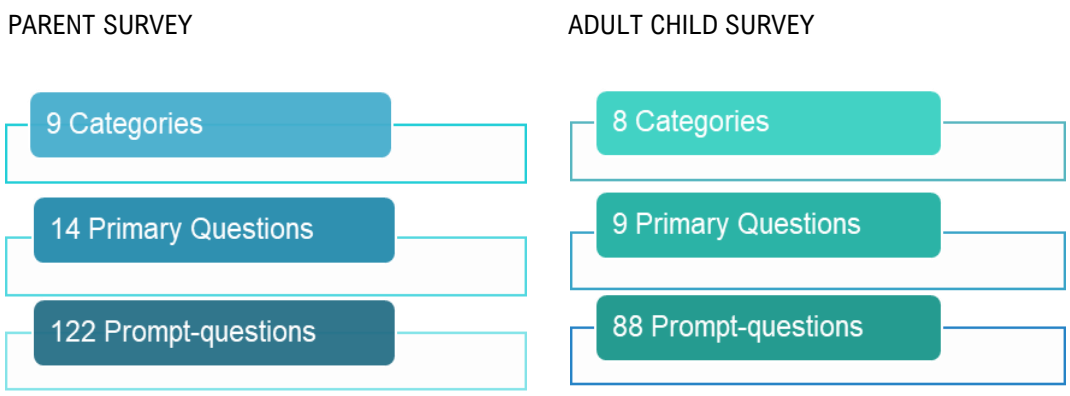
4.5.3.6 Qualitative Survey Design

The starting point was not to adapt quantification surveys but to adapt an interview process in such a way that felt 'natural'. The kinds of questions that might be asked in an interview were then grouped into a structure that would mimic a conversation flow – what question might follow the preceding one if conversing. Participants could choose their mode of completion, opting to follow the Topic Guide or complete the study without consulting it.

Qualitative surveys mix openness with standardisation, comprising a fixed set of questions posed to all participants in the same order (Terry & Braun 2017). Survey questions were informed, in part, by historical analysis and a review of scholarship. As Braun *et al.* (2020) note, wording is critical in survey research – questions must be clear and unambiguous as the survey is self-administered and there is no way for respondents to clarify.

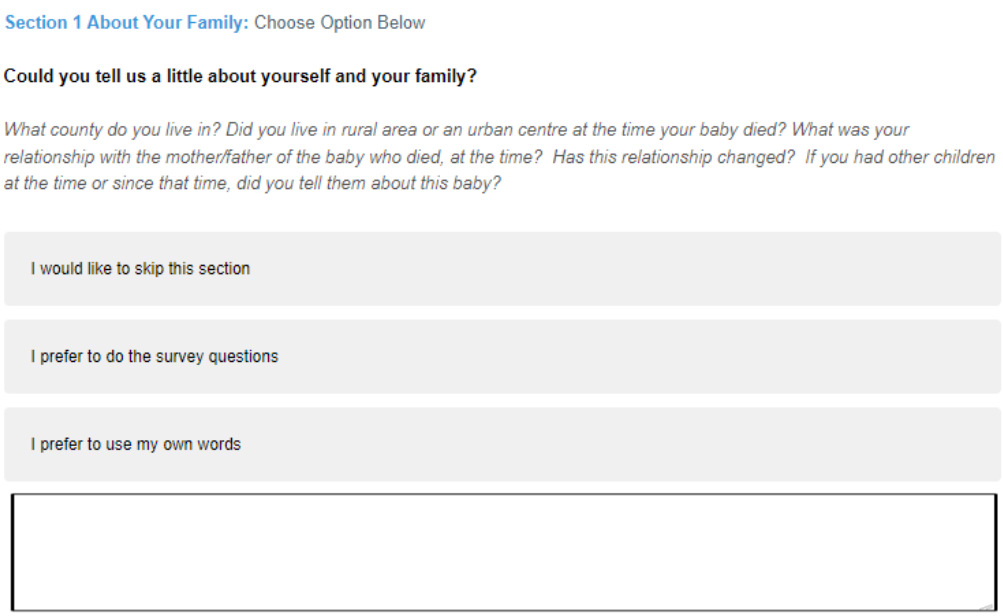
The Topic Guide was formulated first (see Appendices), this was the basis of the qualitative survey, comprising the questions that may have been asked if interviewing. To mimic this natural conversation flow, the Topic Guide was organised into categories, with a set of primary questions, followed by prompt questions (designed to encourage more detail). Parents were provided with a Topic Guide comprised of nine categories; fourteen primary questions; and a maximum of 122 prompt questions, contingent on their route through the survey (see Fig 4). Adult Children were provided with a Topic

FIGURE 4: SURVEY STRUCTURE



Guide comprised of eight categories, nine primary questions, and 88 prompt questions, depending on their decision path. The Topic Guide was displayed differently depending on the format chosen. On the website, the Topic Guide was available as a PDF as well as in an expandable text format. In Qualtrics, a digital software programme designed for survey data, the information layout was different though the survey stuck to the same question structure. Participants could choose whether to skip a category, complete a category in aggregate, or choose the question by question survey (see Fig 5 Survey Flow below).

FIGURE 5: QUALTRICS SURVEY FLOW



Each category opened with an 'own words' option, a medium size text box allowed participants to complete the category accordingly. If the survey option was chosen, the primary and prompt-questions were then structured in a check box format but each question still offered space for participants to use their own words. The skip option enabled participants to move through the survey, in a manner that suited them, either by zoning in or avoiding questions, as required. The final number of questions displayed depended on the route participants made through the survey. Though the total number of questions is long, this was to enable participant control.

The survey finished with two questions asking participants why they took part and if there was something missed, which Braun *et al.* (2020) maintain generates useful data, this proved to be the case. The final component was the end of survey message of thanks. This was followed up with repeated social media posts thanking people for

taking part. Survey flow was designed to feel seamless as participants move from section to section. The survey was piloted with five different colleagues to make sure there were no glitches and the survey flow worked.

The rationale for mixing what might be considered a quantitative structure in with the qualitative one, was again a pragmatic decision based on experience. Most people have access to the internet via their mobile phones and thereby, the check box format was more likely to be used as people do not typically type lengthy blocks of text on phones. As no IP tracking was in place it is not possible to confirm the platforms used but the difference in responses indicates completion is likely to have been via phone for shorter responses.

4.5.4 Ethics

Ethics was sought and approved by Trinity College Dublin, School of Nursing & Midwifery Research Ethics Committee. As the study was entirely anonymous, explicit consent was not required for participation (unless submitting audio files, of which, none were received).

4.5.4.1 Protecting Participants

Dealing with difficult and sensitive topics is always a time to be cautious, though as Liamputtong (2019c) notes the terms sensitivity and vulnerability, closely aligned, are applied to social research without qualifying what that means. Aware that for many older participants they may have never spoken of their experience, a decision was made to allow anonymous participation in this study. Whilst there is no way to 'verify' the originators of these submissions, this method did offer some benefits.

As the qualitative survey was self-administered, it meant participants could control the "pace, time and location of their involvement" (Terry & Braun 2017, p.19). Anonymous data collection offered participants increased autonomy as they had time to reflect on the information they wished to provide and could complete the study according to their pace or abandon it if they wished. This method may reduce the emotional vulnerability of participants as it removed the pressure to answer any questions, which may not have been the case in an interview situation. In this way, the power of the researcher in the research process was neutralised, which along with the decision to provide no follow-up reminders and no compulsory questions increased the agency of the participants in the research process.

Participants were provided with a list of support services and encouraged to use them if they felt it necessary. Acknowledgements thanking participants for their contribution were displayed on submission of their data, along with frequent social media posts of thanks.

4.5.4.2 Privacy, Confidentiality & Anonymity

The decision to do allow anonymous participation was predicated on the basis that anonymity offered a higher degree of freedom of expression to participants, as there is no way to link any individual back to their story. Where identifiable information was inadvertently collected it was anonymised or pseudo-anonymised as necessary to enhance confidentiality and anonymity. No IP tracking was in use, rendering the online data collection entirely anonymous.

Whilst participants themselves have been allocated a pseudonym (based on popular names from the time periods they refer to), referring to babies by the names given – along with their year of death and geography would compromise anonymity. Allocating a pseudonym to the babies, felt as if it was a disrespect or denial of their existence – the very thing under investigation. Instead, the babies given names are retained, but reduced to their initial only. Only regional geographic location is provided to protect identifiable features.

4.5.4.3 Data Protection

General Data Protection Regulation (GDPR) certification was completed. This training pertains to legislative responsibilities of researchers and the collection, storage, usage, and assessment of personal and sensitive data from research participants. As part of this process, a Risk Assessment was carried out on the personal and sensitive data collected, which identified a low risk of identification of subject participants. Electronic copies of all data were saved to a secure server, for deletion after five years. Survey data was collected using Qualtrics and analysed using a combination of Microsoft Excel and MAXQDA, a qualitative analysis software programme.

4.5.5 Data Management

Initially, all the data was uploaded for analysis to MAXQDA, a powerful data analysis software programme. As described above, the historic data was awkward to work with as much of it was image based. Further, all the data was quite fragmented and the overall coherence was obscured using MAXQDA. Instead, I reverted to a simpler way to organise the data according to its type. For the NFC data, the collection and

organisation of the data was straightforward. This was organised, as outlined above, in OneNote. Other historic data was organised in a similar way by source e.g., laws, newspapers etc were organised by year and topic. This made it easier to apply filters for specified keywords or codes. Anonymised participant data was exported from Qualtrics into a password protected Microsoft Excel spreadsheet and a similar process applied to the data.

4.6 Data Analysis

Data analysis can be considered both an art and a science, in which the researcher organises, makes sense of, interprets and theorises the data gathered (Schwandt 2007). For some researchers, analysis is a science, disciplined, systematic, and detailed methodically; others draw a distinction between interpretation and analysis that, like art, is not definable (Schwandt 2007). Regardless of which approach is maintained, the process and method of analysis requires consideration (Schwandt 2007; Creswell 2013; Gorsky & Mold 2020; Pope *et al.* 2020). The form of analysis used depends, in part, on the purpose of the study, the results required, and the kind of knowledge already available (Gerson 2017). This thesis falls under the domain of generic qualitative research and borrows from qualitative methods that subscribe to an interpretive and descriptive approach.

Data analysis is only as good the source material collected; it can be a creative and non-linear process which brings order, structure and interpretation to non-numeric, unstructured, and messy data (Marshall & Rossman 2016; Moser & Korstjens 2018). In exploratory studies, which aim to generate hypotheses for further study, data collection and analysis is iterative, this means researchers read the data looking for trends, ideas and keywords that may help structure analysis (Guest *et al.* 2012; Pope & Mays 2006). Qualitative analysis starts with winnowing the data and organising it into easily identifiable and retrievable units (Braun *et al.* 2017; Creswell & Poth 2017). Then follows an initial reading and immersion in the data, with the aim of uncovering common themes or patterns (Polkinghorne 1988).

Though qualitative surveys can be analysed in various ways, it is important to remember that it is qualitative rather than quantitative data (Braun *et al.* 2020; Terry & Braun 2017). This means data should be presented as thematically organised patterns across the dataset, illustrated through the use of participant quotes (Braun *et al.* 2020; Terry & Braun 2017), whilst avoiding numeric reporting patterns (Braun & Clarke 2013). Qualitative survey data, as the questions are written down, has a semi-structured

quality to the process of data collection, this however, should not be confused with coding and analysis (Braun & Clarke 2013).

Research can be unpredictable and in practice, as was the case here, researchers need to work with the data that they have. In this case, the proposed qualitative survey sample was not realised, and was concentrated on the 1990s rather than evenly distributed across a span of time as anticipated. Data relevant to specific experiences was often distributed across the replies, rather than directly answered, a common issue in qualitative surveys (Terry & Braun 2017). Additionally, some of the data responses yielded 'bitty' responses (Braun & Clarke 2013) or thin rather than thick data, one of the negatives of using qualitative surveys (Elliott & Timulak 2021). This limited the range of qualitative analytic techniques. The ultimate focus in interpretive research however, is the intersubjective creation of understanding and meaning (Angen 2000) and that may mean researchers employ "ingenuity and flair to grasp the full range of uses of a single source" (Tosh 2009, p.141).

Côté-Arsenault (2003) conducted a secondary data analysis on qualitative data gathered from four separate qualitative studies. This data was collected via different data tools (questionnaires, interviews, focus groups, and participant observations in the form of transcripts, field notes and short responses to specified questions) but treated collectively as personal accounts. This is a useful way to consider the primary data sources collected in this study, for three reasons. First, the same set of questions were asked to all living participants though there were four options for completing the survey questions. The manner of completion did not alter the questions asked – all participants worked from the same topic guide and the researcher was not directly engaged. Second, this study uses eyewitness testimony drawn from historical records, these contributors cannot consent thereby they cannot be considered 'participants' which suggests a degree of agency. Characterising primary sources as archive records, entries or survey responses depersonalises all contributors, and the term 'personal accounts' better represents the humanistic aspect of qualitative research. For similar reasons, the term 'contributor' is preferred over 'participant' though participant is used in the above section as this is recognised terminology in health and social sciences research. Finally, by characterising this data as personal accounts, it means the data can be analysed in a comparative way.

Treating past and present data as personal accounts creates coherence in the dataset, and allows for a comparable thematic structure to be applied, resulting in a more comprehensive interrogation of social norms and socially located experiences (Braun &

Clarke 2013). Other forms of historical data require a different approach, as the mechanism for categorisation and analysis of historical data can be challenging (Marshall & Rossman 2016).

History involves a process of gathering, synthesising and reporting data as chronological developments (Renjith *et al.* 2021). Using systematic analysis of documents to reconstruct the past, historians present their work chronologically and thematically (Dunne *et al.* 2016). To respect the contextual nature of qualitative data, requires an iterative weaving in and out of the detail (Thorne *et al.* 2004), the same applies to history. Analysts should avoid excessively detailed coding (i.e. word by word/line by line), as this can diminish the ability to "see patterns, follow intuitions, and retrace a line of logical reasoning among and between pieces of data" (Thorne *et al.* 2004, p.7).

The basic historic process is both descriptive and interpretive (Sarnecky 1990). This is similar to other qualitative interpretive descriptive approaches which can only yield constructed truths (Thorne *et al.* 2004). The degree to which these 'truths' are plausible is contingent on the skill of the researcher to transform raw data into something meaningful, thus interpretation depends on the process of intellectual enquiry more than on sorting, organising and coding data (Thorne *et al.* 2004).

The first hurdle in using multiple data sources, is finding analytic techniques that work for the type of data and form of research. Though the historical method outlines a process of doing history which includes finding, synthesising, and interpreting data (Lusk 1997; Sarnecky 1990), and Collingwood (1928, p.219) maintains historical thinking is simply a case of interpreting the evidence with the "maximum degree of critical skill", as a non-historian this seemed vague. Adopting transparent procedures felt necessary, and so documentary and thematic analysis were selected, as each have an explicit mechanism for doing research.

Marshall & Rossman (2016, p.313) maintain that oscillating between contemporary and historical interpretation creates a "dialectical tension". This tension extends to the presentation of data. History, relying on monograph, has more choice over its stylistic presentation, space to deliberate, elaborate on complex relationships and provide conceptually fuller depth and detail (Strauss & Corbin 1998). Dissertation formats are more restrictive, emphasising findings rather than the fuller analytical argument presented in monographs (Strauss & Corbin 1998). As this study is informed by historical methods and word count is restricted due to the conventions of social

research, the presentation of findings adheres to a sociological presentation, rather than being a pure history.

In qualitative research, findings are typically presented in two ways. Replicating the system frequently used in quantitative research, key findings are reported under a main theme or category, with illustrative quotes to support the theme (Burnard *et al.* 2008; Braun & Clarke 2013). This descriptive way of presenting data, is followed by a linked discussion chapter which connects the findings to the literature (Burnard *et al.* 2008). This is used to analyse the personal accounts from living contributors. The alternative is to blend findings and discussion; this is an interpretive and descriptive analysis aligned to constructionist research that looks for latent meaning (Burnard *et al.* 2008; Braun & Clarke 2013). This is the approach used more broadly here as it mirrors the more contextual narrative structure used in history.

4.6.1 Analytic Techniques

4.6.1.1 Thematic Analysis

Themes are simply patterns across datasets that relate to specified research questions and describe the phenomenon under exploration (Newnham & Rothman 2022). Thematic analysis is the basis of all qualitative data analysis (Pope *et al.* 2020), though there are different forms (Braun *et al.* 2019). Thematic Analysis as used here is combined with Documentary Analysis, to highlight similarities and differences, summarise key features in the large dataset and generate unanticipated insights (Nowell *et al.* 2017).

The basic analytic task is called coding, how coding is completed depends on the study and the research problem (Gerson 2017). Coding can be deductive, derived from scholarship or other analytic models; or inductive, meaning it is derived from the data (including *in vivo* or naturally occurring terms from within the data) (Green & Thorogood 2004; Marshall & Rossman 2016). Coding simply organises data into useful segments that are easily retrievable. Small meaning units can be labelled as codes, codes can be grouped based on shared concepts to form categories, and categories can be clustered, sometimes this is presented in a graphic or schematic form (Renjith *et al.* 2021) of meaning. The challenge here was not all data can be analysed in the same way, as outlined above. Even within the personal accounts, the data presented three challenges. First the data was thinner than anticipated; it was also quite "meaning dense" (i.e. concentrated within a few words) so it was difficult to analyse (Elliott & Timulak 2021, p.40); and the personal accounts were not all contributed by the same

type of people – they were comprised of parents, adult children of bereaved parents, or other members of society with either direct or indirect experience of perinatal death. Similarly, the NFC and other historical data was not evenly distributed, so for example, though in excess of 1,200 records were collected, what they referred to differed, e.g., some referring to birth, others referring to burial or clergy e.g. This fragmented way of coding data is more akin to creating a mosaic, building towards a 'theme' rather than breaking down interview data to assign into meaning units and categories.

4.6.1.2 Documentary Analysis

Essential for both the contemporary qualitative and mixed methods researcher, historians of medicine and health, and health researchers, are documentary research skills (Dalglish *et al.* 2020; Gorsky & Mold 2020). Coffey (2014) notes that qualitative researchers overlook the analytical capacity of documents. This view is supported by Dalglish *et al.* (2020) who maintain social and health researchers marginalise documentary analysis, privileging verbal interview data over documentary research in social and health science. Document Analysis (DA) is a method of evaluating documents to provide context, supplement other forms of data, triangulate or corroborate other data sources, and track change over time (Dalglish *et al.* 2020).

DA (also known as documentary review) is the close reading of texts by qualitative researchers (Dalglish *et al.* 2020). Earner-Byrne (2017) felt that placing the close reading of letters at the centre of her work on twentieth century poverty, would push the boundaries of historical methodological analysis to a point historians were uncomfortable with. This suggests that qualitative researchers employ close reading in a slightly different way to historians. Close reading requires being alert to language and meaning and the systematic choices made in sampling, creation, archiving and preservation (Marshall & Rossman 2016; Dalglish *et al.* 2020; Gorsky & Mold 2020). Through the process of DA a dialogue occurs between the source and the researcher, and so for Lincoln & Guba (1985), this represents interaction. This means that DA is relevant for understanding socially constructed meaning (Dalglish *et al.* 2020).

4.6.1.3 Analytic Framework

The central organising themes for this thesis are predominantly deductive, or theory-generated codes (Marshall & Rossman 2016), derived from an analysis of the scholarship (secondary sources) and the evidence (primary sources), to create specified areas of focus. The reason for taking this approach is due to the:

- Complexity of the topic
- Contentious and complicated history regarding infant death and burial
- Fragmented nature of the historic data collected
- Need to provide a clear baseline ‘story’ or chronology of events which is absent due to the paucity of historical and sociological research relating to perinatal death and burial specifically, in both international and Irish contexts

The use of an organising framework, helps to structure content, which is helpful in the interpretation and presentation of findings (Lusk 1997; Lewenson 2010b). As discussed in the literature review, there is no agreement in the scholarship as to what constitutes a funeral or its benefits; the analytic framework used here relies on Howarth’s (2007a) broader explanation of mortuary ritual. This gives an organising framework incorporating

- Social rituals at birth (in this case baptism, which for any death defines the use of religious rites)
- Social rituals at death
- Preparation of the body
- A wake (or the time between death and burial)
- Religious rites
- Funeral
- Committal of remains (burial and any associated rituals or religious rites)
- Post-funeral activities (ways in which people remember)

Though a deductive framework is being used here, the thesis also supports the use of inductive themes derived from further data analysis (Kahlke 2014).

4.6.1.4 Unit of Analysis

The unit of analysis in this study is mortuary ritual that is socially expressed.

4.6.1.5 Analytic Steps

The whole analytic process was iterative and comparative, moving between historical and contemporary data. Putting all the above together, the analytic steps can be summarised as follows:

1) Define Research Topic
2) Determine Research Design

3) *Collect Data*

Conduct literature review

Review historical scholarship, examine footnotes and trace back

Look for eyewitness accounts in biographies and autobiographies

1. Primary source 1: National Folklore Collection

   Iteratively sample and analyse the NFC

2. Primary source 2: Personal Accounts

   Gather personal accounts from living participants and historic archives

3. Additional primary sources:

   North Inner City Dublin Folklore

   St Andrews Heritage Project

   Autobiographies

   Newspapers

   Official reports & Civil records

4. Additional secondary sources

   Biographies and oral histories

   Scholarship

   Newspapers

   Reports

4) *Organise Data*

Clean data, anonymise, and remove duplicates

Organise methodically and check for negative data

5) *Immersion*

Skim reading to get an overall sense of the documents

Generate notes and form initial theories

Extract data based on initial coding

6) *Develop Analytic Framework*

Iteratively collect, analyse, and code data

Deductive Themes

7) *Code Data*

Data reduction: Refine data and initial theories

Inductive Themes

8) *Synthesis*

Group data by source, theoretical and analytical categories

Present findings with quotes

Logically sequence data so it is chronological

9) *Interpret*

Frame findings according to research questions

4.7 Authenticity

4.7.1 Researcher as Research Instrument

Conventional primary data in health and social sciences research are generated by the researcher, oriented towards answering specific research questions (Ang *et al.* 2013). Thus, in qualitative research the researcher is the research instrument so issues of reflexivity, ethics, fieldwork, sampling strategies, participant recruitment and data analysis must be outlined in addressing methods and methodology (Marshall & Rossman 2016).

Qualitative research replaced the positivist traits of quality, appropriateness of method and generalisability with credibility and trustworthiness; a reflection of the actual researcher as the research instrument (Marshall & Rossman 2016). The trustworthiness and soundness of research should not be just based on the competence of its design but also by the ethical engagement of the research, moving beyond procedure to focus on the people within the study (Marshall & Rossman 2016). This element was important in this project, as I was aware that participants may never have shared their stories before. Additionally, as I had no opportunity to engage directly, the creative execution of the recruitment strategy was critical in terms of attracting participants in the first instance and imparting the sense their stories would be treated respectfully.

4.7.2 Interpersonal Validity

Ethical dilemmas in social research are resolved through considering the rights, privacy and anonymity of participants, with sound ethical research based on the principle of 'do no harm' (Flick 2009; Marshall & Rossman 2016). The principal of 'do no harm' means researchers need to consider and attempt to negate potential downsides for participants; being explicit about the advantages and disadvantages for participants enhances the "interpersonal validity" or trustworthiness of the researcher (Marshall & Rossman 2016, p.139). This was addressed in the PIL and included support services and caution to consider before participating. Part of the rationale for allowing four modes of participation was to allow people space and time to reflect on their story. In interviews, sense-making can occur during the interview (Morse 2017) and there was a similar expectation that asking questions might elicit the same response in qualitative surveys.

This principal of harm though weighed heavily. The profession of nursing has an obligation to ensure its research findings are above reproach (Thorne *et al.* 1997). This is echoed by the International Confederation of Midwives who believe women deserve "culturally relevant" research, and that midwives have a responsibility in advancing research to improve both women's health and that of their families (McCarthy, 2003). This sense of professional responsibility was omnipresent throughout the study. Though I am not a clinician, I am based in the School of Nursing & Midwifery and felt the weight of ensuring that this work would not reflect poorly on the profession or the School. The issue of institutional histories though, weighed more heavily. Ireland is coming to terms with an intergenerational legacy of institutional abuse. Controversial burials at Tuam, located at the site of the old workhouse which functioned for a time as a Mother & Baby Home, have been the subject of much public anger and were the catalyst for a Commission of Investigation, which released its reports in 2021.[73] This project does not focus on residential institutions but nor can it escape them, as they are closely aligned to the development of hospitals. In this study, I focus on the 'normative' experience of baby loss – what was it like for the majority of people but I am also fully aware that what occurs here may not resonate with other social histories. It is the intention that some of the work contained here will fuel other lines of historic inquiry.

4.7.3 Holistic and Humanistic Research

The difficulty is how do we capture, understand, and then locate people's experiences without diminishing them. This represents Laite's (2020, p.978) concerns about historians commodifying individual lives in books and articles that "feed into our academic appointments… and our publishing revenue". There is no easy answer to this dilemma, it is a feature of both the research cycle, and the nature of interpretive enquiry.

The authenticity of human experience is frequently a strong feature in qualitative research (Silverman 2013) and this is often construed in terms of co-creation or co-construction with member-checking or verification of some kind being used to support this idea. Rowling (2009), as cited by Šmídová (2019b), emphasises the importance of collaborative non-exploitative approaches, echoing the empathic approach to loss and grief established in Rowling's (1999) earlier work. This is a slight contrast to Flick's (2009) assertion that researchers are meant to collect data, not work with participants on ways to cope with their situation.

[73] *Final Report of the Commission of Investigation into Mother and Baby Homes* (Murphy *et al.*, 2021)

This tension raises commodification as a feature of the researcher and researched relationship, so the parameters of that engagement must be explicit. The more critical point is that as researchers, doing interpretive analysis, we may tell a different story than the story gathered from our participants (Braun & Clarke 2013). With theoretical positions, we take participant data and analyse it – what we end up writing is our story, our interpretation of that data and so our story may differ from our participants stories (Braun & Clarke 2013). The role of researcher is always to interpret in context - whether facts matter or not, whether detail is relative or metaphorical – these features of interpretation lie with the wisdom and skill of the researcher to determine (Morse 2017).

This similar tension exists for historians and documentary analysts. When it comes to history, archivist Catriona Crowe implores researchers to "complicate the narrative" (RTÉ 2020), meaning that historical analysis offers no binary solutions. The task of research though is to make sense of these complicators; the role of researcher is one of "active constructor of meaning", treating documents as problematic sources of specific data requiring "context to be understood" (Gorsky & Mold 2020). Histories, just as narratives, are reconstructions of past facts for Polkinghorne (1988) but do not produce conclusions of certainty. This feature is present in all research – we construct the map of how we arrive at our conclusions but it is open to contest, holding true only to the point of falsification.

Developing new ways to consider the dynamic between data, digital sources and the way in which this evidence is used to tell people's stories is more vital than ever (Gorsky & Mold 2020; Laite 2020). Particularly when many studies have historical context as Marshall & Rossman (2016) maintain, systematic historical analysis boosts their trustworthiness and credibility. What gives historical analysis these features is the attention the researcher gives to data selection, interpretation, authorship, and their caution in deriving conclusions without corroboration (Gorsky & Mold 2020). What this means is that historical analysis becomes the foundation for all other research and the role of historical and documentary interrogation is more pronounced. However, as historical researchers move to contemporary data collection, particularly from living participants, historians must attend to the same protocols assigned to social researchers, to which Tosh (2009) alludes. Historians must conform to the expected standards of social research and be explicit as to the rationale, method and methodology applied to such data. For example, a historical study published using interviews from Irish mothers on limbo by Kennedy (2021) lacks the clarity required for

social research, regarding the sampling strategy expected in the context of scientific or empirical research. Though the author contends it is not statistically representative, this is to misunderstand the nature of qualitative research, ignores the same principles that historians apply to historical data sources, and overlooks the degree of sensitivity social researchers apply to the creation of their data sources.

4.7.4 Trustworthiness

Shifting away from a positivist paradigm, and associated research language of quantification (objectivity, reliability, and internal and external validity), Lincoln & Guba (1985) reframed qualitative research within the concept of trustworthiness. Trustworthiness refers to issues of reliability and validity which are baked into the research process (Morse 2017) contained within methodology (Marshall & Rossman 2016). Reliability, for Polkinghorne (1988, p.174) refers to the dependability of the data in narrative research, and validity to the strength of its analysis.

Trustworthiness or "goodness", raises issues regarding objectivity, generalisability, credibility, evaluation, and usefulness of evidence - whilst systematic historical analysis enhances trustworthiness (Marshall & Rossman 2016, p.313). This, if we understand what Marshall & Rossman (2016) intend, suggests that trustworthiness is first comprised of many moral values, and second that they are interlinked, contingent on each other.

4.7.5 Soundness not Validity

Validity speaks to issues of credibility and quality in qualitative research, validity being replaced by the modern term of "soundness" (Marshall & Rossman 2016, p.121). There are three ways to improve accuracy and validity of research, according to Creswell & Poth (2017): via member checking (referring back to the interviewee), though in health research this can impede epistemological integrity (Thorne 2014); triangulation of evidence drawn from different data sources (Mays & Pope 2020); and by transporting readers to the research setting through rich, thick, descriptive findings (Geertz 1977). This is similar to the triangulation of multiple data sources to enhance validity posited by Leavy (2011) and Silverman (2013). In contrast, Denzin & Lincoln (2013, p.10) maintain triangulation is not a tool or strategy of validation but an alternative to it. They maintain that a combination of multiple methods is a strategy to add rigour, breadth, complexity, richness, and depth.

For health researchers Green & Thorogood (2004), the most basic form of validity is the authenticity of a document. Scott (1990) as cited by Flick (2009, p.6), offers four criteria for documentary validity – again, authenticity (meaning genuine), credibility, representativeness, and meaning. Documentary researchers Gorsky & Mold (2020) suggest detailed, clear referencing offers validity, as this provides the breadcrumb trail for researchers to follow in order to confirm or contest the findings. Polkinghorne (1988, p.174) perhaps is most succinct – valid findings in narrative research rely on the general understanding of validity as a well-grounded conclusion, the research illustrating logic and reasoning as to how the results have been derived.

In this study, trustworthiness is demonstrated through the multiple methods in use in data collection and analysis; triangulated sources of data; and rich, thick description meaning defining the critical information about the study participants, documentary sources, and research process (Polit & Beck 2010).

4.7.6 Generalisability

The concept of generalisation or applicability matters in health settings which rely on evidence to inform practice, thus generalisability is a vital marker of rigour (Polit & Beck 2010; Varpio *et al.* 2021). Generalisability in quantitative research refers to statistical-probabilistic generalisation, meaning the ability to apply results from a representative sample to a bigger population or different context. This form of generalisability does not apply to qualitative research, instead qualitative enquiry aims to provide contextual understanding of a specific aspect of human experience (Polit & Beck 2010; Smith 2018).

Generalisation is based on reason; drawing conclusions about what can be observed and inferring what is not, to arrive at a logical explanation - similar to Polkinghorne's (1988) definition of validity as outlined above. This idea is carried through naturalistic generalisation (referred to as case-to-case generalisation or transferability) which simply means the extent to which research findings will resonate with readers (Tobin & Begley 2004; Stake (1978) as cited by Polit & Beck (2010); Smith 2018; Thorne *et al.* 2004). Analytical generalisability, similarly, refers to the concepts or theories that are derived from the research which can be deployed outside the context or population (Polit & Beck 2010; Varpio *et al.* 2021), and better understood as ideas for making sense of the world (Smith 2018). This form of generalisability is resonant with historical research which, according to Marková (2012), seeks to apply the same transferability to other historical events.

5 The Discovery of Perinatal Grief

5.1 Introduction

This chapter provides a brief social context to perinatal death in Ireland. The chapter then explores the historical development of psychological theory following perinatal loss, which resulted in changes to birth protocols in hospitals and consequently the recommendation for funeral as an intervention. The focus here is on the mid-twentieth century as this marks the point at which increasing hospitalisation of birth and concomitant twentieth century psychological theories align, and influence mortuary rituals.

5.2 Background to the Topic

In contemporary Ireland, three key issues propelled perinatal death into the public domain within the last ten years. In 2014, burial practices at the former Tuam Mother & Baby Home made headlines around the world.[74] Due to public pressure, the Government established the *Commission of Investigation into Mother and Baby Homes* (Murphy *et al.* 2021), of which burial practices became a prime focus – analysis of this report is outside scope for this thesis.

Parallel to this ran two other investigations into maternity care in Ireland.[75] The death of Savita Halappanavar in 2012, following a hospital refusal to terminate her second trimester pregnancy, gained international media coverage, and became a catalyst for social and system change (Holland & O'Dowd 2022). One outcome of the subsequent investigation into Halappanavar's death was the recommendation to offer psychological bereavement supports to family members (Arulkumaran 2013). The report states:

[74] See Boland (2014); Van der Horst (2014) BBC News (2021) for more detail on Tuam. Child abuse in institutions was the focus of activists during the 1990s, resulting in the publication of the *Ryan Report* (Ryan, 2009). Protestant Bethany Mother & Baby Home was also the focus of activity by Derek Leinster, who was fostered out of the Bethany Homes and worked with Dr Neil Meehan on institutional records, eventually establishing a monument to children who died at the home, at Mt Jerome Cemetery in the 1990s. This work has latterly been taken up by Dr Sarah-Ann Buckley (Buckley, 2021)

[75] There are other maternity related investigations which shocked the public at the time, these include investigations into missed miscarriages where women were incorrectly told of the demise of their foetus (Ledger & McCaughan 2011); the use of contaminated blood (anti-D) for pregnant women resulting in hepatitis (Finlay 1997), the unnecessary use of symphysiotomy and subsequent investigation into surgeon Michael Neary (Inglis 2008; Harding Clark 2006), and the postmortem retention of foetal/newborn organs (Madden 2006)

Incidental factor 2:

The investigation team established that counselling is provided after miscarriage occurs rather than when an inevitable miscarriage has been diagnosed.

Recommendation to address incidental factor 2 (National):

Ensure that the psychological impact of inevitable miscarriage is appropriately considered and that a member of staff is available to offer immediate support and information at diagnosis. Members of staff should also advise of the availability of counselling services for women and partners at diagnosis. Care given, including counselling and support, should be documented. The availability of counselling services for women, partners and families who have suffered any incident or bereavement in childbirth should be reviewed, considered and developed as appropriate at each maternity site. (p. 80)

Unexplained baby deaths and standards of maternity care at Portlaoise regional hospital became the focus of another government investigation. This inquiry found that appropriate size coffins were not always available for infants, and that perinatal infants were transported in the boot of a taxi for post mortem examination at Tullamore Hospital (Holohan 2014). The outcome from this report, and these unsatisfactory deathcare practices, contributed to the commitment to improve woman centred maternity care and the creation of the National Maternity Strategy (Langford, 2016).[76] In turn this led to new clinical standards, the *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (Browne 2016), yet gaps in postmortem standards of care remain. In 2017 at Letterkenny Hospital, one mother was horrified to discover her son remained unburied in a room off the gynaecology ward for four weeks, though she had been told he had been buried in an angel plot (a designated burial area for children) (RTÉ 2017). As recently as April 2020, it was discovered that the organs of eighteen babies had been incinerated as clinical waste in 2018, without the knowledge or consent of their parents (Moloney 2021).

[76] The National Women and Infants Health Programme (NWIHP) was established in 2017 by the Health Service Executive to lead and manage the improvement of support services for women who experience baby loss.

5.3 Relocating Birth & Death

Whilst the 1960s to 1970s is referred to as the era in which pregnancy loss finally was finally acknowledged as a grief producing event (O'Leary & Warland 2013) this is a slight misnomer. As per contemporary studies, distress following stillbirth was recorded for both mothers and the doctors and midwives attending them, during the nineteenth and early twentieth centuries (Marland 2004; Hunter & Leap 2014; Breathnach 2018). Earlier publications did in fact acknowledge implicitly, if not explicitly, the distress caused by stillbirths, and emphasised the need for stillbirth to be on public health agendas (Ballantyne 1902; Peller 1948; Sutherland 1949; Deeny 1955). It should be remembered that psychological theories were also emerging at this time, relating to grief, in the face of overwhelming death following two closely run world wars.[77] If, as Jalland (2013) maintains, nearly everybody had to navigate their way through the post-war world without bereavement theories, counsellors, or books to guide them, how could it be expected that perinatal death and bereavement would be any different? Further, births in hospitals had still not reached a critical mass until the late 1950s in Ireland (see below). Death too was shifting towards hospital, but the majority of people continued to die at home, and as discussed further below, both processes were dehumanised in doing so.[78]

5.3.1 Dehumanising Birth

The move from home to hospital birth by extension means the relocation of perinatal deaths from the private to public sphere, into a system in which it must be managed. Birth, according to social worker Cooper (1980, p.68), became a "public and professional" event, which required a humane response from all healthcare professionals inside and outside the hospital. This pull on professional resources was a feature in Yamazaki's (2010) study which identified significant sociocultural factors impacting parental bereavement, e.g. the post-war reduction in Japanese family size

[77] Lindemann's (1944) work defined normal grief (expressed) and morbid grief (repressed), viewed grief as a medical problem; Bowlby (1998) developed attachment theory of maternal bonding in the 1950s and applied it to grief theory; Parkes (1970) work began in the 1950s on widowhood, he worked with Bowlby to define the four phases of grief; Kübler-Ross (1969) devised the popular five stages of dying, which was adapted to bereavement; Worden developed the four tasks model; Stroebe & Schut (1999) published the Dual Process Model, with grief oscillating between loss and restoration activities. These are all known as stage or phase models of grief (Worden 2015). Continuing Bonds theory was detailed in 1996 by Klass, Silverman & Nickman; Meaning Reconstruction appeared in the late 1990s by Neimeyer and colleagues (Gillies & Neimeyer 2006) which considered grief as the process of reconstructing a world of meaning shattered by loss (Worden 2015)

[78] In 1930 73% of people died at home; by 1940 this declined to 66% indicating a slow trend toward hospital and institutional assistance in Ireland (CSO, 1930; CSO, 1940)

resulting in nurses becoming a proxy for family support; this creates clear implications for health policy as it increases the nursing burden and cost of service delivery. Significantly, it also points to a lack of available social supports frequently identified as important for bereaved parents (Malacrida 1999; Brierley-Jones *et al.* 2014).

When considering the drastic reforms advocates were clamouring for with regard to perinatal death interventions in the 1960s, it should be mentioned that no attention was given to those regarding birth. Women's recollections of hospital births during this transition period are not always favourable with one Irish respondent asserting "at the beginning when women had babies in hospital, they were treated like animals" (Ferris *et al.* 1992, p.29); or in 1950s America where women were 'tied and trussed to delivery tables like trapped animals' with their most 'intimate parts' on public view (Wertz & Wertz 1979, pp. 171–172). The assembly line of hospital birth was dehumanising for women and dangerous to their babies, and by the 1950s women were disempowered, isolated, and alienated from their bodies, their partners, families, friends, and communities (Wertz & Wertz 1979). Following allegations of cruelty in American maternity wards, the *Ladies Home Journal* in 1957, published letters in which women wrote of their terrifying ordeals in hospital, detailing how when mothers were ready to deliver their babies, the staff did not attend them (Wertz & Wertz 1979). One mother wrote how she was strapped to a table, her legs tied together until it was more convenient for the staff to deliver her baby; soon after birth she was told her baby was unlikely to live - this was not an uncommon story (Wertz & Wertz 1979). Twenty years later, Cooper (1980) found perinatally bereaved parents in the UK, described an impersonal hospitalisation and birth experience. Women felt "like a piece of meat – no longer human", parents described birth as a conveyor belt, with loss of autonomy and unconsented procedures, alongside expectations of compliance, during a period of "high drama and tragedy" – these experiences resonated longer than the baby's death (Cooper 1980, p.64).

Hospital routines arose from nineteenth century workhouse and lying-in hospitals– both originally founded for impoverished women, on whom doctors practised their birth craft (Wertz & Wertz 1979).[79] Impoverished women, in an earlier era of prudery and modesty, were seen as cases rather than persons, unlike private patients who were attended at home retaining far more control over their environment (Wertz & Wertz 1979). Hospital charity cases, especially those from the slums, were perceived as

[79] In their study of early twentieth century midwifery, Hunter & Leap (2014) note maternity units were often in the workhouse and cite this as a contributor to the reluctance of mothers to use them

infection risks,[80] carrying lice and filth – cleaning, purging, and shaving the patient constituted cleanliness and preventative treatment (Wertz & Wertz 1979).[81]

5.3.2 Traumatic Birth

Birth was an emotionally traumatic and physically invasive experience with multiple interventions e.g. the use of forceps (Loudon 1992).[82] Pregnancy and birth were not typically spoken about, even for married women, and there was little sex education in the early twentieth century meaning first pregnancies and births were often a "total shock" for mothers (Hilliard 2004; Hunter & Leap 2014, pp.72, 79). The first hint of birth trauma was published in a paper on active management of labour (AML),[83] which required birth to have been achieved within a set number of hours, necessitating interventions to achieve this. The authors (O'Driscoll *et al.* 1973, p.136), maintained "a first labour is a unique experience which may cause permanent damage to a woman's personality when unduly prolonged"– completely missing the point that the source of distress may be AML, lack of knowledge regarding birth, or indeed any hospital birth procedures. More recent research confirms that caregiving during labour and obstetric interventions are consistently associated with acute trauma symptoms (Creedy *et al.* 2000; Falk *et al.* 2019), with maternal prevalence of self-reported traumatic births estimated in the range 33% (Creedy *et al.* 2000) to 45% (Beck *et al.* 2018); 4% of mothers are clinically diagnosed with Post-Traumatic Stress Disorder (PTSD) as a result of traumatic birth (Yildiz *et al.* 2017). Healthcare workers are not immune to birth trauma either; up to 36% of midwives who witness traumatic births are at risk of Secondary-Traumatic Stress Disorder (STSD) or PTSD (Beck *et al.* 2015).[84]

[80] Particularly for puerperal fever which had no treatment until the introduction of sulphonamides and penicillin from the 1930s/40s (Wertz and Wertz, 1979)

[81] From the late 1800s, a variety of labour procedures were introduced in the name of infection control, including repeat enemas and vaginal douches; head washing with kerosene, ether and ammonia; treating nipples and umbilicus with ether; shaving of pubic hair; and by 1920 the standard use of forceps, episiotomy, and lithotomy; and depending on the hospital/time period, variable use of anaesthesia and analgesia for labour or perineal stitching (Wertz and Wertz, 1979).

[82] Cascading interventions are those where one intervention necessitates the use of another as it disturbs normal physiological birth, these include e.g. the routine use of intravenous fluids, continuous electronic foetal monitoring, augmentation of labour, epidural, episiotomy, restricted movement and/or food and drink (Lothian, 2014)

[83] AML was introduced in Holles St maternity hospital in the late 1960s in part due to staffing shortages; Irish nursing staff were dealing with three times the numbers of births as their UK counterparts (O'Driscoll *et al.*, 1973)

[84] Ravaldi *et al.*, (2021) similarly found in their study of midwives that up to 24.5% exhibited symptoms of PTSD following attendance at perinatal deaths, this can manifest as avoidance and numbness. Burnout, anxiety, depression and stress were also features of caregiver PTSD noted by Ravaldi et al. (2021)

Bourne's (1968) motivation towards clinical improvement in bereavement care was thus well intentioned and necessary, but it also occurred against a much larger social issue regarding birth interventions – which, as described above, in themselves were deeply distressing for mothers, and those witnessing traumatic births. More importantly, it calls into question some of the psychological theorising regarding hospital based perinatal death – particularly as Kirkley-Best & Kellner (1982) had already flagged that better controlled studies were necessary or research was in danger of following populist fashions. If birth itself, regardless of outcome, could be traumatising and result in similar symptomatology to those experiencing perinatal death,[85] could it be the psychological theories underpinning protocol changes were flawed?

The capacity of talk therapy to resolve trauma is the bedrock of Freudian psychoanalytic theory, however, trauma is often impossible to put into words - for all people, not just those suffering PTSD, this is true (Van der Kolk 2014). Van der Kolk (2014) explains that traumatic memories are dissociative, like mismatched jigsaw pieces, they do not assemble into a coherent story. After a traumatic event people are overwhelmed – in essence they experience a sensory overload; it takes time and familiar people, places and spaces to enable them integrate their story with meaning (Van der Kolk 2014). It is this integration that allows them to move on from their trauma. This calls for a reassessment of the most often used bereavement intervention post-birth, that of midwives encouraging parents to talk, as identified in Spanish maternity care by Steen (2015).

Van der Kolk's (2014) research is illuminating in the context of social support, stigma and isolation, given the sensory overload presented by trauma. Yamazaki (2010) noted how women after perinatal death were hesitant to meet neighbours and sometimes stopped going out. Cooper (1980, p.65) found that parents sought isolation in the immediate aftermath of perinatal death, needing to be in a 'cocoon', putting distance between themselves and their social networks. This self-imposed withdrawal is a feature of what Pollock *et al.* (2020, p.209) refer to as 'self-stigma', however, there is another way to consider this.[86] McIntosh (2012) emphasises that until hospitalisation of birth, mothers and midwives relationships were personal and negotiated individually

[85] Birth related PTSD symptoms include flashbacks, emotional numbness, depression, anxiety, avoidance, and distressing dreams (Ayers *et al.*, 2008) compared to perinatal symptoms which include PTSD, depression, anxiety, guilt, and shame among other psychosocial sequelae (Cacciatore, 2013)
[86] What Pollock is referring to here as 'self-stigma' is referred to as psychological disenfranchisement by (Howarth, 2007a)

– this dynamic became depersonalised and distant with increased regulation and hospitalisation.[87] 'Root shock' is used to describe how erasure of place affects people's emotional ecosystems (Fullilove (2004) as cited by Hynan 2021, p.298), and Hynan (2021) applies this concept to place of birth. Hynan (2021) argues that the removal of birth to hospital results in a similar disruption for women and their families and threatens their emotional ecosystem. For perinatal death, this means a highly emotive experience occurs among strangers with whom parents may have no pre-existing connection.

Murphy-Lawless (1998, pp.252–253) cites three examples of perinatal death, two occurring in hospital with only one a homebirth and by extension, a homedeath. 'Niamh', the bereaved mother refers to home as "the natural place" for birth and death and further describes it as "a positive empowering experience". Home is characterised as the fitting place for death "more ordinary, more everyday".[88] The point Murphy-Lawless (1998) makes is that death, wherever it occurs, is shocking but that death progresses at the mother's pace until hospitals interfere, the hospital creating 'root shock'. This is critically important because if death is mediated by hospitals, then the mediation of grief by the same institutions must also be considered. Further, this instance of homedeath as 'empowering' is essential to consider in the context of new care pathways. Another mother recounts her homedeath as strangely peaceful, without the euphoria of normal birth but equally without despair (Dybisz 2016); this raises the potential for pre-diagnosed stillbirths to be routinely routed for homebirths. It also begs the question of whether adverse maternal reactions to perinatal death are created simply by virtue of occurring in hospital. This is precisely what Lewis (1979a; 1979b, p.306) believed, that hospital culture regarding stillbirth impeded the "normal healing process" and that hospital stillbirth management was so bad that parents left to themselves would fare better – even more so, if it were a home birth.

In the context of perinatal death, collectively these points indicate that place of birth may have an even bigger impact on bereaved parents whose emotional ecosystem is under threat. It suggests that homebirth/death may offer a protective factor to parents due to continuity of care with a known midwife at home and an environment in which parents retain more control over birth and their infant's body. It indicates that parents

[87] The replacement for this relational model is continuity of care, designed to be a trust based partnership between mother and midwife (Pace *et al.*, 2021) in reality this model does not guarantee a known healthcare provider during labour

[88] Midwives in early twentieth century Britain asserted that particularly with perinatal deaths, parents were better off at home (Hunter & Leap, 2014)

may need physical and emotional space away from others to make sense of their experience – home offering a comforting retreat that hospital does not provide. Finally, it suggests that a social buffer is necessary following perinatal death rather than a funeral which requires confronting other well-meaning people.

5.3.3 Dehumanising Death

As with birth, by the 1950s, deaths in hospitals were the norm in American culture - this was not the norm in Ireland until decades later.[89] It is in this context that Kübler-Ross (1969) and Glaser & Strauss (1965) conducted their research on the medical dehumanisation of the dying with commentators concluding that death in hospital was undignified (O'Mahony 2017). This is the basis for much of the academic scholarship which followed. Death in hospital disrupted the community acknowledgement of loss and altered the way in which patients died and families grieved (Howarth 2007a). The medicalisation of birth and death then dehumanises the person experiencing either, the hospice movement emerging as a way to reclaim and rehumanise death (Jalland 2006).

As many authors concur, the social script for death, generally, is disrupted by its medicalisation in hospital leaving the bereaved disoriented (Kübler-Ross 1969; O'Mahony 2017; Mannix 2019; Sallnow *et al.* 2022). As recently as 2022, this unbalanced approach to death has become the focus of a new series of articles in *The Lancet* (Sallnow *et al.* 2022),[90] following the work on disrupted bereavement during the pandemic by Selman *et al.* (2021). Disrupted bereavement includes the inability to say goodbye, the absence of the corpse, absent post-death customs, missing social supports including wakes and religious rites and the lack of physical contact with mourners (Selman *et al.* 2021) – features which were common in perinatal deaths prior to the 1980s.

[89] In 1949, 49.5% of American deaths occurred in institutions, by 1958, it was 61% and by 1980, it was 74% (Field & Cassel, 1997); in Japan in the 1950s 80% of people died at home, by 1975 most people died in hospital and by 2010 only 12.6% of deaths were at home (Shimane, 2018); in Ireland, in 1950 only 37% of people died in hospital institutions (general, special and mental hospitals, and county homes), rising to 49% by 1960 (CSO, 1950; CSO, 1960) – today 23% of people in Ireland still die at home (Matthews *et al.*, 2021)

[90] Sallnow *et al.*, (2022) list five aims for how death, dying and bereavement should be approached. These include social determinants of death and grief; understanding death as a spiritual and relational process rather than purely physiological; support systems; everyday discussion of death and dying and grief; and that death is recognised as having value.

5.3.4 Reforming Perinatal Death Protocols

As Withycombe (2018) observes of nineteenth century miscarriage in America, women did not have universal grief responses to pregnancy loss, miscarriage was not deemed a failure of femininity or motherhood, and pregnancy did not make a child – birthing did. Critically, Withycombe (2018) finds neither the language of failure or blame within women's accounts or medical discussions of pregnancy loss at this time, concluding in the nineteenth century the pregnant body was not a maternal body, pregnancy did not include another person (i.e. the foetus) and that cultural silence regarding miscarriage emerges only in the twentieth century.

Reagan (2003), drawing on reproductive social movements when analysing twentieth century miscarriage, tracks its social significance through the century from hazard (causing physical harm), to blessing (good fortune), to tragedy (emotional devastation), noting that by the 1990s miscarriage had been constructed as a significant event infused with tragic meaning. This new pregnancy loss movement, as Reagan (2003) defines it, was comprised of middle-class white women in America and Europe who equated miscarriage with death of a child, labelled the pregnant woman who miscarried as mother, and expected her to grieve in a public ritualised way. Reagan (2003) questions this uncritical adoption by hospitals, health professionals and therapists which as Layne (2003) notes, leaves women and men floundering in the formation of parental identity and struggling to define their loss as child. This is evident in Malacrida's (1999) assertion that perinatal death is contested terrain as medical definitions of miscarriage compete with parental support groups in recognition for all perinatal loss to be acknowledged. This view is supported by other authors who contend perinatal loss constitutes all forms of pregnancy loss at any gestational age from 0-40 weeks gestation, plus the death of a baby up to 28 days post-birth (Côté-Arsenault 2003; Lang *et al.* 2011). This expansive interpretation of perinatal death reflects a gradual extension outside the parameter and discipline for which it was initially defined by Peller (1948), and further clouds the role and significance of perinatal mortuary and/or funeral ritual.

The nurturance of grief following miscarriage, is represented in increasing consumerism and active mourning rituals – the cumulative effect of these behaviours, according to Reagan (2003), manifests in hospital protocols which frame and tell women how to feel, instead of listening to them. The prescriptive quality emerging from pregnancy loss/stillbirth social activism promoted by hospitals then becomes bound in legal officialdom, in defining what stillbirth is and appropriate parental behaviours, this

becomes a bureaucratic overstep into private rites and responses (Sanger 2012). The bigger problem for Reagan (2003) is that such prescriptive behaviours create an expectation of *universal* emotional responses. For example, the question of mourning and grief evoked puzzled reactions from the parents in Cooper's (1980) study; medically and legally there was a death but socially and culturally, stillbirth was a failure to give life – thereby it was not *socially* perceived as a bereavement, despite parents clearly having emotional responses. This was also identified in Peppers & Knapp (1980, p.128) study, where one mother thought it was "ridiculous to make us go through a funeral" for her twins, a funeral being "senseless" as her babies were so premature. Yet, funeral was the recommended intervention by the 1980s.

5.4 Psyched: Funeral as an Intervention

By the late 1960s, hospital protocols for perinatal death had already become a rallying point for social reform. When a baby died, parents did not get to see, hold, or care for their baby before it was hastily taken away (Bourne 1968). Today, these parents seek the burial place of their children and express distress over not being able to see or hold their babies at that time (Koopmans *et al.* 2013). One retrospective study found that 33% of women had symptoms of Post Traumatic Stress Syndrome (PTSS), and 13% were indicative of PTSD, up to eighteen years after their perinatal loss (Gravensteen *et al.* 2013).

The work of Bourne (1968) and Lewis (1976) and their contemporaries is pivotal in the development of clinical theory and practice regarding perinatal deaths.[91] Their influence ultimately came to define perinatal death pathways in hospitals and accelerated a change in the professional and emotional responses to perinatal death. Bourne's professional interest in stillbirth arose from his clinical psychiatric practice with bereaved mothers in the 1950s (Lovell 1997). Through the 1960s, Bourne (1968; 1977) and Lewis (1979b), amongst others, campaigned to improve the emotional management of stillbirth. This in Bourne's (1968; 1977) opinion was a professional problem requiring a change in clinical practice. There was some direct resistance, in

[91] UK Drs Emanuel Lewis and Stanford Bourne (both psychiatrists and psychotherapists) were based at the Tavistock Clinic in London (Kraemer 2017; Warren 2021) - the Tavistock Clinic were contributors to the RCOG *Working Party on Stillbirth and Neonatal Death* and *Management of Perinatal Deaths*, 1978-1986; Dr Hugh Jolly was a paediatrician (Jolly 1976); Dr David Morris was a paediatrician and one of the first to write on the emotional dimensions of stillbirth (BMJ 1989); US Dr Marshall Klaus was a neonatalogist married to Dr Phyllis Klaus, a social worker and psychotherapist (Roberts 2017); Dr John Kennell was a US paediatrician and collaborator of Dr Marshall Klaus (Vitello 2013).

part, to the new ideas put forth by Lewis and Bourne.[92] Ultimately, these new ideas were cemented into best practice guidelines issued by the Royal College of Obstetricians and Gynaecologists (RCOG) in 1985. These guidelines informed new obstetric and midwifery practices which have remained virtually unchanged since that time (RCOG 1985).

In summary, the guidelines were based around better hospital management, heavily informed by the psychotherapeutic idea of confronting reality. Healing could be accomplished via the facilitation of 'normal mourning' – achieved by following certain methods (Lewis 1976; Lewis & Page 1978; 1979b). These methods included seeing, holding, and laying out the dead baby; naming the baby; photographing the baby; a post-mortem to facilitate genetic counselling; and registering the birth or stillbirth (Lewis 1979b). Most significantly, parents were advised to hold a "memorable" funeral as funerals were the way society marked the "significance of death" (Lewis 1976; 1979b). Further, parents were cautioned against burial in a "common and nameless grave" (Lewis 1979b, p.304), encouraged to have extended families to the funeral, and mark the grave. Paediatrician Jolly (1976, p.33), was generally supportive of these new ideas noting "a dead baby is not someone to be hustled away without a proper funeral", concluding that parents and siblings should take part in the funeral which should wait until the mother could attend post hospital discharge. Mourning as far as Jolly (1976) was concerned took time, and for adequate mourning to take place required meeting the person *to be* mourned. It should be remembered that all the new ideas of the mid-century theorists refer to stillbirths or postnatal losses of 28 weeks gestation or more.[93]

Across the Atlantic, Kennell *et al.* (1970) were implementing similar changes for similar reasons. Their study encouraged rituals around death but were not explicit to the extent of their UK counterparts. They also recommended hospital policy changes to benefit mothers (accommodating mothers in private rooms e.g.). What is really important in this work are three things: first they wanted to ensure it was psychologically safe for mothers to touch their infants – this was hugely controversial at the time,[94] secondly, they identified affectional bonding preceding contact with the infant; thirdly, they counselled parents that grief intensity would decline between one

[92] See letters to medical journals (Swinton 1977; Currie & Currie, 1979)

[93] Jolly (1976) saw no reason why parents could not arrange funerals for infants under 28 weeks if the parents sought it – in practice due to hospital pathways for the body this was not always as easy to arrange in practice

[94] As the authors note, to this point hospital policies of separation of mother and infant after birth were historically located in infection control, when mothers were seen as sources of contamination – and for fear of distress should the baby die; see Wertz & Wertz (1979) for further discussion of historic practices

and six weeks, be minimal at six months, recurring periodically thereafter.[95] Kennell *et al.* (1970) identified that maternal grief was not linked to the length of a neonate's life. A decade later, building on this study Peppers & Knapp (1980) determined that the intensity of grief was comparable for miscarriage as for neonatal deaths. Peppers & Knapp's work heralded a radical change in the theory of grief and a dismantling of grief hierarchies. The extent of maternal grief, they determined, was the same for miscarriage, stillbirth, or neonatal death. Their 1980 book, *Motherhood & Mourning* would go on to be described as one which would bring parental experiences of perinatal death 'out of the dark ages' (Menke, 1981).

At the same time Bourne, Lewis and Jolly were advancing their theories, Cooper's (1980) findings lay in sharp contrast, with birth trauma evident in her study. Conducting repeat home visits with bereaved parents, Cooper, a social worker, recognised that parents felt disempowered during hospital birth, with their parental decision-making stripped of them. The parental consensus in her study does not align for the most part with her psychotherapy informed medical colleagues' recommendations. Parents in Cooper's (1980) study felt seeing and holding the baby would induce further shock at a vulnerable time. Where this had been suggested or imposed, the women confirmed they were too confused, shocked, or sedated for genuine consent to be given.[96] Further, all parents expressed relief at not having to name the child or arrange a funeral, nor did they attach religious significance to any burial ceremony. Parents felt the responsibility for burial arrangements rested with the hospital (though collectively parents disliked the term 'disposal of remains') (Cooper 1980).

Reform operated on the basis of what Harvey (2008) refers to as compassion-led interventions or best endeavours which are always challenging in relation to evidence-based bereavement care. Though operating within the intellectual frames of their time, one which insisted on 'confronting reality' the psychotherapeutic view was it was essential for mothers to confront the death (particularly if they had been sedated during birth). Recalling Cooper's (1980) remarks that parents were not in a position to give genuine consent at time of birth, and considering the labour practices at that time which may have contributed to birth trauma, the insistence of confronting reality seems unwise. Further, the professional view was also one in which grief intensity was short-

[95] This finding was consistent with Parkes (1965, quoted Kennell *et al.* (1970)) which is unsurprising as his variables were used to inform the study. Giles (1970) also found mothers grieved in a similar way to people experiencing the death of an older loved one.

[96] Montgomery (1978) as cited by Raphael (1984) notes that bereaved Australian mothers were often heavily sedated during and after labour and distressed at not knowing what had happened to their baby's remains

lived and minimal (Kennell *et al.* 1970). Nonetheless, the outcome was between the 1960s and 1970s, the funeral starts to be emphasised as crucial in the resolution of grief. Doing so forced the creation of tangible memories via the funeral, as something parents could return to during mourning. Yet if we consider Van der Kolk's (2014) earlier remarks that avoidance is initially a pre-requisite for reshaping traumatic experience, whether this applies to birth and/or perinatal death, this action now seems imprudent. Critically, the flaw in Lewis' (1976) approach rests on his assertion that long lost ancient bereavement rituals provided "normal mourning and recovery". What these ancient rituals are or the culture these belonged to is not made clear but given the explicit instructions, it would suggest a middle-class English funeral of ambiguous origin.

5.5 Chapter Summary

This chapter has traced the emergence of funeral as an intervention, and the psychological theories that shape clinical practice and parental responses. Hospital reforms implemented in the late twentieth century focused on funerary ritual to expedite parental grief. The rationale for this was embedded in psychotherapeutic approaches popular at that time, which centred on the funeral as a restorative function which would facilitate normal mourning and by extension, resolve normal grief. The benefits of this approach, as far as can be ascertained, have never been evaluated and lead us to consider the role and significance of funerary ritual in the context of perinatal death and bereavement.

Whilst any of these topics are subject to further exploration, there are four points to bear in mind. First, as Durbach (2020) notes, legal definitions of viability at 28 weeks gestation, do not always reflect medical practice or birth intervention. Interventions at birth rested with the clinical judgement of doctors, and their medical judgement determined (by the twentieth century) the disposal pathway for foetal remains and perinatal bodies, particularly once hospitalised birth was the norm. Hospital protocols developed based on bureaucratic responsibility and institutional need to dispose of infant bodies, with 28 weeks defining the pathway for the treatment of remains, for most of the twentieth century. When hospital is not the primary place of birth, these judgements may be applied differently or indeed not at all, or other belief systems may dominate.

Second, parental distress was recognised by clinicians though this may have been minimised or ignored. A major shift happens in the mid-twentieth century as hospitals

become the primary place of birth and death both psychologically, and in the protocols for perinatal death. The development of psychological grief theory influences the way in which perinatal deaths are managed and result in the creation of foetal personhood via an overt reliance on funerary ritual, and the psychoanalytic basis for healing which lay in confronting reality.

Third, the recommendation of funeral as outlined, was derived from the medics middle-class status. This totally ignored the financial practicality of providing the recommended form of mortuary ritual, particularly in an era where recurrent deaths were common. As Malacrida (1999) notes, funeral costs can be expensive and recommendations for specific rituals put an economic barometer in place, which can in effect disenfranchise parents if they cannot meet these costs.

Fourth, and perhaps most significantly, there was a flimsy evidence base for the introduction of funeral as a bereavement intervention. Though the new hospital protocols had their detractors, and some scholars were requesting better evidence, a specified funeral ritual was introduced as the primary bereavement intervention with no evaluation of its effectiveness, and without consideration of the impact of birth trauma. This is where midwifery practice intersects with psychological theory as midwives become responsible for managing both the perinatal body, and the psychological wellbeing of bereaved parents at time of birth and/or death.

6 Personal accounts 1945-1999

6.1 Introduction

In this chapter the findings are presented thematically, the discussion of these findings is in the following chapter. The central organising themes for this thesis are predominantly deductive, derived from analysis of the scholarship, popular media, and prior research, to create specified areas of focus, as detailed in Chapter 5.

Following changes to this research project, prohibiting face to face interviewing (see Chapter 5), remote data collection was pursued. A digital qualitative survey was distributed via social media platforms. This resulted in a total of 24 respondents providing their family stories of perinatal death and burial, comprised of parents (n=16) and adults whose parents had a perinatal death i.e., adult children or surviving children (n=8). As data collection was completely anonymous, with no IP tracking, it is not possible to identify if there are any parent-child pairs in these data sources. Of the adult children entries (n=8), all entries were from daughters of bereaved parents. A total of seven (n=7) entries were included, one was discounted as it came from a UK based participant, i.e., outside Ireland. This entry was received after the study featured on a UK news media outlet, following publication in the *Irish Independent* (2021).

A total of sixteen parents (n=16) took part, three (n=3) were discounted as they were outside the period under review (1900 – 2000). This gives a total of thirteen parents comprised of fathers (n=2) and mothers (n=11). The combined data sources (n=20) give rise to an age range between 30 (the youngest) and 90 (the oldest) years old (see Table 3 and Table 4 for breakdown). The time span of the stories collected covers the period 1945 to 1999. The twenty stories refer to 22 babies; one father refers to two deaths, one adult child also refers to two deaths. Ten of the babies were live born (n=10) and twelve babies were stillborn (n=12). Sixteen of twenty participants provided a name for the babies they were writing about.

The split between Dublin (urban location) and areas outside Dublin (which could be urban or rural) was 50% (n=10 for Dublin, n=10 for outside Dublin). Capturing geographic location was a demographic question included to distinguish differences in regional mortuary rituals, or between urban and rural settings. This turned out to be more complicated than expected. For example, one participant living in the North-West was transferred to a Dublin hospital and then buried her son in her West of Ireland

hometown – so linking mortuary ritual with any local custom was not possible. Thereby, to enhance anonymity, regional rather than county level data is satisfactory.

How data is collected differs from how data is both analysed and presented. Some of the data was thin and lacked the anticipated rich detail (Elliott & Timulak 2021). For example, caregiver interactions are discussed in this chapter and contributors indicated that their birth experiences could be positive or negative. Contributors sometimes ticked a question box without providing qualifiers, or a relevant qualifier was found elsewhere in the account. Equally, the small number of words whilst specific and to the point, resulted in 'dense data', a pitfall of using qualitative surveys (Elliott & Timulak 2021). This meant that data was hard to understand without the benefit of a broader context (Elliott & Timulak 2021). Further, as the data was dense with limited details, it meant being careful about how to use the available quotes to optimise meaning without repeating the data. The fully written accounts uploaded to Qualtrics, though concise, had the most information power (Malterud *et al.* 2016); these were easier to work with, though the same issue of limited text for illustrative quotes applied.

This chapter considers two data sources gathered from parents and adult children collectively, what are referred to as personal accounts (Côté-Arsenault 2003). Parents can give us insights into their own emotions, their decision-making, their direct experiences. The oldest participant from the North-West for example, is a bridge between an 'old' and 'new' Ireland – his first baby being born in the county home (originally a workhouse hospital) in 1959, with his second child being born in a new urban modern hospital five years later. His story directly represents an intersection between tradition and modernity e.g. family grave digging which is now professionalised. These are unique perspectives which are scarce in historic records. Adult children generate different insights – theirs is not always eyewitness testimony. Legacy issues, parental end of life, continued use of ritual or what can be 'factually' shared regarding a time where little has been written about perinatal loss, provides a different vantage point. This chapter explores how the absence or presence of ritual manifests. It is a 'point in time' evaluation, it is about identifying what parents did, what influenced their actions, and what emotional impact this had.

TABLE 3: PARTICIPANT CHARACTERISTICS: PARENT AND CHILD DATA

Data Provided via	Pseudonym	Relationship to baby	Participant Age Now	Birth Year	Years since Death	Parent Age Then	Gestation weeks = W Days since birth = D Fullterm = Term	Place of Birth	Stillborn or Liveborn	Baby Named
PARENTS										
upload / online	Patrick (child 1)	Father	90	1959	63	27	Term	County Home	Stillborn	Yes
upload / online	Patrick (child 2)	Father	90	1964	57	32	Term	Hospital	Stillborn	Yes
survey	Mary	Mother	82	1970	52	30	34 W	Hospital	Stillborn	No
upload / online	Betty	Mother	69	1975	47	22	28 W	Hospital	Stillborn	Yes
survey	Gillian	Mother	66	1980	42	24	39 W	Private Nursing Home	Stillborn	Yes
survey	Susan	Mother	56	1982	40	16	-	Hospital	Liveborn	No
survey	Anne	Mother	59	1992	30	29	24 W	Hospital	Liveborn	Yes
survey	Lisa	Mother	50	1994	28	22	16 D	Hospital	Liveborn	Yes
survey	Sandra	Mother	67	1994	28	39	17 W	Hospital	Stillborn	Yes
survey	Michelle	Mother	51	1996	26	25	27 W	Hospital	Stillborn	Yes
survey	Carol	Mother	48	1997	25	23	32 W	Hospital	Liveborn	Yes
survey	Aidan	Father	53	1998	24	29	23 W	Hospital	Liveborn	Yes
survey	Louise	Mother	40	1999	23	17	-	Hospital	Stillborn	Yes
upload / online	Kate	Mother	49	1999	23	26	Term	Hospital	Liveborn	Yes
ADULT SIBLINGS										
upload / online	Monica	Sister	-	1945*	77	-	-	Homebirth	Stillborn	Yes
upload / online	Patricia	Sister	61	1955	67	39	Term	Private Nursing Home	Stillborn	Yes
survey	Geraldine	Sister	-	1970	52	30	35 W	Hospital	Stillborn	-
survey	Sharon	Sister	44	1975	47	26	27 W	Hospital	Liveborn	No
survey	Linda	Sister	37	1982	40	31	28 D	Hospital	Liveborn	Yes
survey	Elaine (child 1)	Sister	41	1987	35	-	49 D	Hospital	Liveborn	Yes
survey	Amanda	Sister	30	1995	27	39	7 D	Hospital	Liveborn	Yes
survey	Elaine (child 2)	Sister	41	1999	23	-	Term	Hospital	Stillborn	Yes

** Estimated year – uncertain whether before or after another sibling birth in 1947*

Stillborn denoted as SB; Liveborn denoted as LB on in-text citations, along with gestation/age and additional tables from here on

TABLE 4: PARTICIPANT DEMOGRAPHIC DATA

Pseudonym	Relationship to baby	Participant Age Now	Birth Year	Years since Death	SB LB	Location	Children at the time	Shared Information with children	Parental Relationship Status Then	Parental Relationship Status Now
PARENTS										
Patrick (child 1)	Father	90	1959	63	SB	North-West (NI)	No	When Children	Married	Married
Patrick (child 2)	Father	90	1964	57	SB	North-West (NI)	Yes	When Children	Married	Married
Mary	Mother	82	1970	52	SB	East (Dublin)	Yes	When Adults	Married	Married
Betty	Mother	69	1975	47	SB	East	-	-	Married	Ended
Gillian	Mother	66	1980	42	SB	East (Dublin)	Since Then	When Children	Married	Ended
Susan	Mother	56	1982	40	LB	South	Since Then 4 x Miscarriages	-	Unmarried	-
Anne	Mother	59	1992	30	LB	East (Dublin)	Yes	When Children	Partner	Ended
Lisa	Mother	50	1994	28	SB	North-East	Since Then	When Children	Boyfriend	Married
Sandra	Mother	67	1994	28	SB	East (Dublin)	Yes	When Children	Married	Married
Michelle	Mother	51	1996	26	SB	East (Dublin)	Since Then	When Children	Partner	Ended
Carol	Mother	48	1997	25	LB	-	X	X	Married	Married
Aidan	Father	53	1998	24	LB	East (Dublin)	Since Then	When Children	Married	Married
Louise	Mother	40	1999	23	SB	East (Dublin)	Since Then	When Children	Boyfriend	Ended
Kate	Mother	49	1999	23	LB	North-West	Since Then	When Children	Married	Married
ADULT SIBLINGS										
Monica	sister	-	1945	77	SB	Midlands	Siblings	When Adult	Married	-
Patricia	sister	61	1955	67	SB	North-East (NI)	Siblings	Teenager	Married	-
Geraldine	sister	-	1970	52	SB	East (Dublin)	-	-	Married	-
Sharon	sister	44	1975	47	LB	North-East (NI)	Siblings	Knew As Child	Married	-
Linda	sister	37	1982	40	LB	South	Siblings	Knew As Child	Married	-
Elaine (child 1)	sister	41	1987	35	LB	East (Dublin)	Siblings	Knew As Child	Married	-
Amanda	sister	30	1995	27	LB	Midlands	Only Child	Knew As Child	Married	-
Elaine (child 2)	sister	41	1999	23	SB	East (Dublin)	Siblings	Teenager	Married	-

TABLE 5: SUMMARY BIRTH INFORMATION

Pseudonym	Birth Year	Baby Age	SB LB	Location	Place of Birth	Birth Partner	Any significant event	Seeing	Holding	Care of Body	Overall Birth
PARENTS								Care of Infant Body			
Patrick (child 1)	1959	Term	SB	North-West (NI)	County Home	No	-	✓	✓	✓	-
Patrick (child 2)	1964	Term	SB	North-West (NI)	Hospital	No	Cord Strangulation	✓	✓	✓	-
Mary	1970	34 W	SB	East (Dublin)	Hospital	No	Foetal Death three weeks prior, not identified	x	-	-	x
Betty	1975	28 W	SB	East	Hospital	No	-	x	-	-	x
Gillian	1980	39 W	SB	East (Dublin)	Nursing Home	No	-	✓	-	-	
Susan	1982	-	LB	South	Hospital	No	C-Section; Teen – self-identifies as 'victim'	x	-	-	x
Anne	1992	24 W	LB	East (Dublin)	Hospital	Yes	-	✓	✓	✓	✓
Lisa	1994	16 D	SB	North-East	Hospital	Yes	Undiagnosed congenital abnormality	✓	✓	✓	✓
Sandra	1994	17 W	SB	East (Dublin)	Hospital	No	Miscarriage	x			
Michelle	1996	27 W	SB	East (Dublin)	Hospital	Yes	Placental Abruption due to Pre-eclampsia	✓	✓	✓	x
Carol	1997	32 W	LB	-	Hospital	Yes	Pre-diagnosed but cause not provided	✓	✓	✓	✓
Aidan	1998	23 W	LB	East (Dublin)	Hospital	Yes	Near Death of mother	✓	✓	✓	x
Louise	1999	-	SB	East (Dublin)	Hospital	Yes	Teen – Trisomy 18	✓	✓	✓	x
Kate	1999	Term	LB	North-West	Hospital	Yes	C-Section; Anencephaly	✓	✓	✓	✓
ADULT SIBLINGS											
Monica	1945	-	SB	Midlands	Homebirth	Yes	Indicates unattended birth	-	-	-	-
Patricia	1955	Term	SB	North-East (NI)	Nursing Home	No	Cord Strangulation	-	-	-	-
Geraldine	1970	35 W	SB	East (Dublin)	Hospital	No	No cause of death, no post-mortem	-	-	-	-
Sharon	1975	27 W	LB	North-East (NI)	Hospital	-	Cervical Insufficiency (cervical incompetence)	-	-	-	-
Linda	1982	28 D	LB	South	Hospital	-	C-section; Sudden Infant Death Syndrome	-	-	-	-
Elaine (child 1)	1987	49 D	LB	East (Dublin)	n/a	n/a	Sudden Infant Death Syndrome	-	-	-	-
Amanda	1995	7 D	LB	Midlands	Hospital	No	Cause of Death via post-mortem (not provided)	-	-	-	-
Elaine (child 2)	1999	Term	SB	East (Dublin)	Hospital	-	No Cause of Death; Organ Retention	-	-	-	-

6.2 Hospital as Place of Birth

In the twenty accounts provided, seventeen occurred in hospital, two were in a private nursing home, and one was a home birth (see Table 5 above). Birth experiences are briefly explored as they relate to the control and care of the infant body. Where times are provided, labour ranged from less than four to a maximum of twelve hours. There is a ten-year gap in this dataset between 1982 and 1992, and as noted below, a comparable difference in birth experiences (see Table 5 above for summary).

6.2.1 Caregiver Interactions

Caregiver interactions could have a positive or negative effect on parents. Patricia's mother's pregnancy worries were rejected by her GP, prompting her to change place of birth from home to hospital

> [Aunt] explained that in those days home births were the normal. Two weeks before D's birth my Mum felt something wasn't right. She went to the Doctor who basically ignored her feelings… they decided to have the birth in a private nursing home as there would be more care provided. D was born… unfortunately the cord was around his neck and he did not survive. (Sibling, Patricia, Term, SB, 1955)

Mary's baby had died three weeks prior to birth but she was not aware of this at the time she went into labour, when her child was born she says

> I felt dismissed, I was told it was nature's way of disposing, that it was unpleasant. Was told it was 'Just One of Those Things' (Parent, Mary, 34w, SB, 1970)

Gillian was distressed at the insensitive care of her daughter's body. As a consequence, her baby was removed, illustrating how the staff were uncomfortable with Gillian's emotional expressiveness

> [the] staff kind but not very talkative... Almost as if I was a patient only... No deep discussion about baby… [saw her] very briefly... she was in a metal dish... did not hold her... Taken away when I got upset... Never saw her again (Parent, Gillian 39w, SB, 1980)

Some parents never saw their babies and were left ill-informed by staff

> It was devastating for my mother and father not to see the baby. My mother still talks about this over 50 years later. Some cold doctor said to her that nature has a way of looking after things like that. She will never forget that. She has no idea what was wrong with the baby if anything… It seems in 1970 that mothers and fathers were left in the dark. It was very cruel

how my mother was treated; she had no idea what was wrong and never saw the baby (Sibling, Geraldine, 35w, SB, 1970)

Betty only briefly saw her son before he was taken away, she was left wondering what had happened to him

My son was born at 7 months… After his birth I saw him for about 10 seconds before they took him away. They said they were waiting for an ambulance to bring him somewhere; they didn't say where. About 2 hours after his birth a nurse came to my bed and took a single white flower from my locker and left without a word.

Another patient had to get a wheelchair and bring me to the nurses station to ask how my baby was and then told me he died. I asked to see him and was told he was in the sluice room of all places, so I went there on my own and all I could see was some kind of dish covered over with a cloth. I couldn't look and was so distressed that I was left on my own to do this with absolutely no compassion from the nurses. (Parent, Betty 28w, SB, 1975)

Outside of the labour unit, staff could be insensitive regarding baby loss, Betty continues her story

Two days after his birth a nurse met me in the corridor on my way back from a bath and said, "you have no baby so can you feed some of the babies in the nursery as we are very busy". Beyond cruelty. (Parent, Betty, 28w, SB, 1975)

Despite the sensitive care shown to Kate by the midwives during surgery, the comments of another staff member on the postnatal ward upset her

Even one of the hospital staff made me feel like crap when she came to take blood one morning… She asked where my baby was, and I explained he had died and named the condition he had. Her words were ‘Oh I saw a baby like that once and it had an awful effect on me’. She proceeded to tell me that her nephew lost a baby but ‘there was nothing wrong with his baby’. I was very shaken up by her comments and felt that she almost thought J deserved to have died because he wasn’t perfect in her opinion. (Parent, Kate, Term, LB, 1999)

Some mothers were aware their baby would die at or around birth, leaving them time to prepare

My son… was christened directly after his birth which I had in my birth plan as I knew he would not live very long… if he survived the birth at all. Staff were very kind which helped

> the situation, I did have one experience with one midwife who was stern & didn't seem to understand but overall it was positive (Parent, Carol, 32w, LB, 1997)

Other parents were thrust into stressful situations, for example, Aidan knew his son would die and his wife's life was in danger.

> The doctor told me the baby would die and that it was touch and go for my wife. My wife held the baby when it died and the midwife told us the time of death. I got to hold baby just before he died. I didn't want to let go. (Parent, Aidan 23w LB, 1998)

Aidan supported his wife through labour, him knowing and her unaware of how precarious both her and their baby's situation was. When asked what his strongest memory of this time was, Aidan referred to the moment of his son's death

> [I was] holding him in my arms wrapped in a tiny blanket and seeing him struggling to take his last breaths… (Parent, Aidan 23w LB, 1998)

That this is Aidan's strongest memory is indicative of the lasting effect witnessing his son's death has had.

Depending on the situation, babies could be separated from their mothers, as in Lisa's case when her baby was transferred from a regional maternity unit to Dublin for specialist treatment, where he later died. Lisa only realised how ill her baby was during labour

> Health care staff were very good and caring and our baby was treated so well and transferred to [Children's Hospital] within three hours of delivery.... [where] heath care professionals treated us all very well. We were in [Children's Hospital] when he died and were treated with great care and respect. Chaplain was so caring and gave us guidance about organising his funeral. Only issue was staying in post-natal ward with no baby.....as he was in [Children's Hospital]. (Parent, Lisa, 16d, LB, 1994)

Despite many parents describing both negative and positive features of their births and deaths, it is clear there was a failure to meet their needs, at the time. Parents felt medical professionals would benefit from additional training and that universal models of care were inadequate

> Hospitals should conduct surveys of parents experiences. Treatment received at a time of trauma can make a huge impact, positive and negative. Even now, 24 years later, I remember a lot about how I and my partner were treated at the time. Time lessens the hurt, but the memories live on forever and it is important that hospital staff bear that in mind when

> dealing with parents in these situations. should be compulsory to learn about for any medical staff dealing with stillbirths and neonatal deaths Also I did [the study] in memory of my daughter S, born an angel on DDMM 1996 (Parent, Michelle, 27w, SB, 1996)

> It might help other parents get through a similar experience and know that they will get through it. It might also help medical professionals understand that a one size fits all approach isn't ideal (Parent, Aidan 23w LB, 1998)

Parents experiences could also compel radical change, for example, Gillian joined forces with other parents and founded a parent support group, with the aim of educating clinicians, and to lobby for legal changes which would ultimately result in the introduction of civil registration for stillbirth in 1995

> Was founder member of [Parent Support Group] so battled with all founders to get register established. Until then there was no official way to acknowledge the pregnancy or baby... Legally or religiously. (Parent, Gillian 39w, SB, 1980)

6.2.2 Control and the Infant Body

Prior to the 1980s, in the stories detailed here, fathers were not recorded as being present at birth, meaning women were isolated from their partners. The consequence of this meant mothers and fathers received the news of their child's deaths in different ways. Betty, as outlined earlier, was left with only vague information regarding her child, finding his body in a sluice room (Parent, Betty, 28w, SB, 1975). Betty at least had an answer as to where her son was, unlike Susan. Susan had no partner support. Aged fifteen at the time of her birth, Susan has been left with a lifetime of unanswered questions and emotional consequences regarding the birth, death, and burial of her baby

> I was in labour for 12 hours before The Obstetrician delivered the Infant by Section. The Professionals dismissed me when I tried to speak about what happened. The Silence, so much silence. I should have been given the chance to grieve and say goodbye as there will never be any closure for me. I never got the chance to say "GOODBYE". The hospital was supposed to [bury baby], however, there is no records of the burial… which led to Professionals believing I was Paranoid and Delusional. So Yes, It's hard to think about this baby without fear. (Parent, Susan, LB, 1982)

The lack of information regarding their babies meant for women there was an information vacuum, and when they did receive clarity, it was given in an informal, or unstructured way. In contrast, though there are few examples here, men received

information formally. Patrick, for example, had left his wife to the hospital to give birth in 1959

> In those days there were few telephones, I do not remember who brought me the sad news that our baby J was stillborn. It was probably the doctor…. I recall being brought into the office of the ward sister – who incidentally was not of our faith. I got the impression that she was apprehensive as to what my reaction would be. Would I get upset or maybe blame the staff for the loss of our baby? Being blessed with a calm nature I handled the situation in a dignified manner. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

Aidan's (1998) story, as above, details how he knew his son would die and how the doctor had imparted this information to him, as his wife was unwell. Following birth, whilst his wife was resting, Aidan repelled numerous attempts by staff to take his son.

> One thing is the nurse kept trying to take the baby when my wife was asleep, and I wouldn't let them. After I left, they told my wife they had to take the baby and they just took him even though she didn't want that (Parent, Aidan 23w LB, 1998)

Other parents described a different experience to Aidan's.

> Myself and my partner were able to spend time with A. My mother and brother were also allowed into the room to hold A. (Parent, Anne 24w, LB, 1992)

> We were holding baby in ICU when he died. Got plenty of time with him in hospital and then got to bring him home to house. (Parent, Lisa, 16d, LB, 1994)

Having had plenty of time to hold her son, Anne confirms that she felt she had enough time with him and it was time to let him go. Similarly, Lisa felt she had adequate time with her child, meaning these parents retained control over their child's body, unlike in Aidan's case where this choice was eliminated by staff who removed the baby.

In contrast to these 1990s parents, as noted earlier, Mary (1970), Betty (1975), Gillian (1980), and Susan (1982) were upset over the treatment of their babies – either not seeing their babies or being presented with their babies remains in a distressing way. These mothers had no time with their babies after birth, nor did their babies receive a hospital baptism (see Table 6). Adult children Geraldine (1970) and Sharon (1975) record similar birth experiences for their families

> My mother just wanted to see the baby. I am sure she wanted to take part in the funeral, but she does not talk about that, just seeing the baby. (Sibling, Geraldine, 35w, SB, 1970)

> The hospital disposed of the remains, and as best I understand, I think that means the body was incinerated as organic waste. There was no funeral. (Sibling, Sharon, 27w, SB, 1975)

Though these 1970s accounts are less certain about the pathway of the body, some clarity is offered by Elaine (1987 and 1999). At six years old she found her seven week old baby sister dead in the cot at home; her brother was stillborn twelve years later

> [When S died] we weren't allowed to go to her funeral, so I don't know anything about it. The social worker at the hospital advised my parents not to have their other children at S's funeral. I was close to 7 at the time, my brothers were 6 & 5 and my sister was 4. My Mam says she regretted it.
>
> For R's death I was 19, I remember everything from then. We had a funeral in the hospital chapel and then buried him with S. We had two more siblings by then who were 8 and 5. We were all included in the funeral, each of us wrote a letter or drew a picture for him to bring with him to heaven. We were encouraged to hold him or touch him but I was afraid so I never did, I always regretted that. (Sibling, Elaine, 49d/Term, LB/SB, 1987)

This example illustrates how hospital protocols were changing in the late twentieth century. In 1987 the hospital social worker advisory was to exclude the children of the family in any ceremonial farewell. This guidance in effect overruled Elaine's mother's instincts, causing regret. By 1999, the recommendation was to add personal items to the coffin and for the rest of the family to have contact with the baby.

There are some disparities in the decision making regarding funerals and burials, in these accounts. Mary explains she was presented with a bill for burial and this was the extent of her input to her child's burial

> No control over anything… told Holy Angels site in Glasnevin but no input possible. Fee of £2.10 (old money) (Parent, Mary, 34w, SB, 1970)

Betty was fortunate that her grandfather insisted on stepping in to help, thus avoiding a hospital disposal

> They asked if I wanted them to "dispose" of him. I was very lucky my grandfather insisted on buying a plot in our local graveyard so my husband took him to be buried there. (Parent, Betty, 28w, SB, 1975)

Parents could be overwhelmed by the birth and death of their child. Aidan, witnessing the death of his son and the potential death of his wife was clearly in shock, and frequently uses 'a blur' to describe this time, he was content for family to step in

> I felt least control in hospital as there was nothing I could do to protect him or change what was happening. Decision was made by family. I was in such a fog, I wasn't in a place to make a decision. I didn't know what was supposed to happen and went along with events. It felt appropriate at time. I was happy then, and now, that this decision was made by others (Parent, Aidan 23w LB, 1998)

6.3 Mortuary Rituals

Mortuary rituals in mid-twentieth century Ireland are complicated. From the accounts here, three forms of mortuary practice are apparent – hospital disposal, disposal without professional services, and disposal with assistance of professional services. Parents were asked in the survey to describe the funeral they had for their baby, and to indicate whether they felt this was similar to other funerals (i.e., typical) or whether they adapted the typical funeral in some way (i.e. modified), see Table 6 and 7 for summary.

By the 1970s, hospital disposal appears to have been common, no underpinning reason for this was identified in these data sources. Hospital disposal meant parents were excluded from all aspects of mortuary ritual – they had no part to play in arranging a ceremony, choosing a coffin, music, flowers, adding things to the coffin, accompanying their baby to the cemetery, inviting mourners, selecting a grave, or a grave marker (though this changes in the late twentieth century). Hospital disposal thus is devoid of any elements of social ritual and as the phrase suggests, is perfunctory. Within the remaining accounts there is evidence of some mortuary ritual, the formality of this differs amongst parents, as does how they categorise the funeral.

TABLE 6: PARENTS MORTUARY RITUAL SUMMARY

Pseudonym	Birth Year	Baby Age	SB / LB	Location	Place of Birth	Funeral Type: Hospital Disposal	Funeral Type: Modified Funeral	Funeral Type: Typical Funeral	Mourners: Father	Mourners: Mother	Mourners: Grandparents	Mourners: Family / Friends	Religion as important	Baptism: Unbaptised	Baptism: Baptism	Ceremony: Wake (Home)	Ceremony: Informal Religious	Ceremony: Formal Religious	Grave Type
PARENTS						Funeral Type			Mourners					Baptism		Ceremony			
Patrick (1)	1959	Term	SB	North-West (NI)	County Home		✓		✓		✓		Y	✓		✓			Angel Plot
Patrick (2)	1964	Term	SB	North-West (NI)	Hospital		✓		✓				Y	✓		✓			Family Grave
Mary	1970	34 W	SB	East (Dublin)	Hospital	✓							Y	✓					Angel Plot
Betty	1975	28 W	SB	East	Hospital		✓		✓		✓		Y	✓					New Grave
Gillian	1980	39 W	SB	East (Dublin)	Nursing Home	✓							N	✓					Angel Plot
Susan	1982	-	LB	South	Hospital	✓							Y	✓					Unclear
Anne	1992	24 W	LB	East (Dublin)	Hospital				✓	✓	✓	✓	N		✓				Family Grave
Lisa	1994	16 D	SB	North-East	Hospital				✓	✓	✓	✓	Y		✓	✓	✓		Family Grave
Sandra	1994	17 W	SB	East (Dublin)	Hospital		✓		✓	✓			N						New Grave
Michelle	1996	27 W	SB	East (Dublin)	Hospital		✓		✓	✓	✓	✓	-			✓			Family Grave
Carol	1997	32 W	LB	-	Hospital		✓		✓	✓		✓	N		✓		✓		New Grave
Aidan	1998	23 W	LB	East (Dublin)	Hospital		✓		✓	✓	✓	✓	-		✓		✓		Family Grave
Louise	1999	-	SB	East (Dublin)	Hospital		✓		✓	✓		✓	N						Angel Plot
Kate	1999	Term	LB	North-West	Hospital			✓	✓	✓	✓	✓	-		✓	✓	✓		Family Grave

TABLE 7: ADULT CHILDREN MORTUARY RITUALS SUMMARY

Pseudonym	Birth Year	Baby Age	SB / LB	Location	Place of Birth	Funeral Type: Hospital Disposal	Funeral Type: Modified Funeral	Funeral Type: Typical Funeral	Mourners: Father	Mourners: Mother	Mourners: Grandparents	Mourners: Family / Friends	Baptism: Unbaptised	Baptism: Baptism	Wake (Home)	Ceremony: Religion = important	Ceremony: Informal Religious	Ceremony: Formal Religious	Grave Type
ADULT CHILDREN																			
Monica	1945	-	SB	Midlands	Homebirth		✓		✓					✓	✓				Angel Plot/Cillín
Patricia	1955	Term	SB	North-East (NI)	Nursing Home		✓		✓		✓				✓				Family Grave
Geraldine	1970	35 W	SB	East (Dublin)	Hospital	✓													Angel Plot
Sharon	1975	27 W	LB	North-East (NI)	Hospital	✓													Incinerated
Linda	1982	28 D	LB	South	Hospital			✓						✓				✓	Angel Plot
Elaine (1)	1987	49 D	LB	East (Dublin)	Hospital			✓	✓	✓	✓	✓	✓			✓		✓	Family Grave
Amanda	1995	7 D	LB	Midlands	Hospital			✓	✓	✓		✓		✓			✓		Family Grave
Elaine (2)	1999	Term	SB	East (Dublin)	Hospital			✓	✓	✓	✓	✓	✓			✓		✓	Family Grave

6.3.1 Relevance of Religion

Few participants expressed any degree of religious faith, older parents were most likely to refer to faith and a belief in religion. Despite this, clergy did have relevance to exercise of rituals, as noted above several parents had clergy led services in their homes from the 1990s, but there is no evidence of clerical or religious formalities prior to this. This absence extended to burial, as well as performance of rites, the two often being interlinked

> I will never forget my father's face as he sat by the fire and told me about bringing his son to the wall of the graveyard… It is ironic that the wall in question is now consecrated ground as it divides the old and new graveyard. Also, that 'Limbo' is no longer in existence as far as the Roman Catholic Church is concerned…My father did not attend Mass for 14 years in the 1940s/50s and was always very sceptical about the Church and aware of its power. No wonder. No-one to help him as he did that lonely task. No compassion. Times were different yes, but suffering and loss remain the same. (Sibling, Monica, SB, 1945)

> The parish priest told me that the baby was to be buried in the designated section in the graveyard…Nowadays there would be a suitable church service for infants… For generations the church authorities got it very wrong as they did in many situations including the Mother and Baby Homes. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

> They asked if I wanted them to "dispose " of him. I was very lucky my grandfather insisted on buying a plot in our local graveyard so my husband took him to be buried there. No priest attended. It was like he was not important enough. (Parent, Betty, 28w, SB, 1975)

6.3.2 Baptism, Limbo and Naming

In the context of baptism as a feature of mortuary ritual (see Table 6 and Table 7 above), baptism was either:

- Not performed
- Performed at home, as in lay baptism
- Performed by midwife in hospital, meaning lay baptism
- Performed by clergy in hospital, meaning formal baptism
- May have been performed posthumously

Whether baptism occurred or not, sixteen of the twenty participants provided a name for the baby they are talking about. Most participants rejected limbo as having any consequence and selected the response 'the idea is nonsense'; suggesting "by 1999,

limbo was less of a thing" (Parent, Kate, Term, LB, 1999). Two participants were bothered by limbo at the time but only one is still bothered by the concept today – there was no elaboration by either person. Further, only three of the twenty participants described any adherence to religious beliefs today, most did not describe themselves as religious nor did they participate in religious rites or rituals, unless these coincidentally happened to be commemorative ceremonies, which may be religious.

6.3.3 Preparing for Burial

Mothers sometimes were not involved in funeral arrangements, due to their emotional distress, postnatal health, or simply as they were not consulted

- I was in a bad place lost in grief (Parent, Louise, SB, 1999)
- We weren't given the option (Parent, Gillian 39w, SB, 1980)
- The arrangements were made without me, people didn't want to include me, they thought they knew what was best (Parent, Carol, 32w, LB, 1997)

Duration of hospital stay was also a factor in maternal funeral participation. As Patrick notes in 1959 and 1964, his wife's postnatal hospital stay prevented her from attending any funeral for their babies

> Margaret had to remain in the hospital for the usual 9 days and I visited her every evening. Some time after Margaret came home, she asked me to take her to J's grave which I did. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

Organising the funeral can alternately be seen as an attempt to assert control and establish a maternal relationship, as Louise (1999) illustrates

> I wouldn't have let the hospital arrange it [the funeral]… [Baby is buried in an Angel Plot as] the hospital advised it (Parent, Louise, SB, 1999)

Only five accounts here refer to babies being at home prior to burial, only one (Michelle 1996), describes the delay between death and burial as a wake. These accounts do confirm however, that the infant body was brought home to be among family, even when mothers remained in hospital. In the first account, Monica describes the death and burial of her sibling, born at home in 1945

> My Father told me the story of my brother born in the 1940s who was denied burial in consecrated ground because he was classed as unbaptised… he told me how he had taken

> the infant and placed him within the wall of the graveyard as close as he could to the family plot. He said he was not allowed to put him in the graveyard as he was unbaptised due to being stillborn. He said they did baptise him at home. He said the child was 'perfect'. (Sibling, Monica, SB, 1945)

Patricia outlines an urban scenario following the death of her brother in a city nursing home

> [Two days after the birth] my Dad and Grandfather left my Grandparents home with Dad carrying D in a little coffin. D was buried in the family plot in [Named] Cemetery with his Great Grandparents and his Great Great Grandmother. (Sibling, Patricia, Term, SB, 1955)

Patrick gives a slightly more detailed first-hand account, following the birth of his son in 1959

> The next step was to get a small coffin from the local undertaker and return to [Hospital] to collect the baby. J was wrapped up in white garments and I placed him in the little coffin and fixed on the lid. I took J home in my brothers [car] which he had lent to me. The parish priest told me that the baby was to be buried in the designated section in the graveyard. I had arranged for a friend to dig the little grave for me, we placed the little coffin in the grave and filled it in. I think my father may have been present – it was all very dignified. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

This account offers a particularly valuable historical insight. Paternal responsibility for the care of the infant body, absent from the mother, is observed. This paternal responsibility required the care and dressing of the baby before coffining – a role that was denied to mothers in hospitals at this time.

These three mid-century accounts show the reliance on family rather than professional services for mortuary customs. Patricia and Patrick's accounts are clear that babies were collected from the hospital and brought home to be with family, before being brought by their fathers and grandfathers for burial. Other friends and relatives assisted. These accounts, like Betty's (1975) emphasise a reliance on grandparents for practical support at a critical time. As these stories represent both urban and rural, home and hospital, the similarities would suggest that this was normative mortuary custom up to the mid-twentieth century.

That Patricia's stillborn brother was buried with family shows that babies, though unbaptised, were buried in consecrated ground. Comparable to Monica's (1945) account, Patrick's baby was designated for burial in unconsecrated ground due to

being stillborn, suggesting the baby was unbaptised. Five years later, Patrick followed a similar process when his fourth child was stillborn

> [In] 1964 tragedy struck again with the death of daughter, M. She was born in the new [Regional] Hospital. The same procedure was followed regarding a burial but this time church regulations were changed, and infants were buried in family plots. I acquired a plot from the then sexton and there M lies at rest. Another friend dug the little grave with just myself present as far as I remember. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

The same expression of social solidarity is noted with another friend digging the grave. This time, the baby was buried in a new family grave. Though Patrick attributes this to changes in church practices (suggesting Vatican II), these updates had yet to be published. Instead, the difference in burial practice between his two children, is that in 1964, Patrick owned the grave. What the difference in practice here suggests, is a regional variation or misunderstanding regarding baptism and burial.

By the 1990s, there is more variability in mortuary customs. Michelle (1996) describes her modified funeral, defining the wake as separate from the funeral

> [Yes we brought baby home] … [Had a wake] in my parent's house and a funeral in the house also (Parent, Michelle, 27w, SB, 1996)

Lisa, living in the North-East had been transferred to a Dublin (East) hospital before bringing her baby home to the West.

> Got plenty of time with him in hospital and then got to bring him home to house. Had small family gathering and prayers with local priest. Drove to [West] with little coffin and buried him in my home church cemetery and again had prayers at graveside. (Parent, Lisa, 16d, LB, 1994)

Kate's son was born in a midlands regional hospital where she was living at the time, but the funeral went to her hometown in the North-West. Kate had advance warning of her son's death, leaving her time to plan and organise a funeral.

> We didn't feel any pressure regarding funeral arrangements as we had time to organise it as we wanted it. As far as I recall the monsignor chose the prayers. It wasn't a full mass – just a few prayers. We were going to have a small service at my parents' house the day we were discharged from hospital. The local monsignor came to the house to say prayers. J's coffin was laid on the kitchen table and many relatives arrived. There were more people there than I expected and it was overwhelming but lovely at the same time. It was lovely to think that

> so many people cared. More people turned up at the grave. At the graveyard my husband carried the coffin to the grave. I feel we had control over every part of J's birth and the days following and the funeral too and I cannot imagine I would change any part of it. (Parent, Kate, Term, LB, 1999)

These last three accounts show a strong similarity, the baby's body being at home amongst family and extended social networks, expressions of social support and an informal religious presence with prayers in the house prior to burial. The latter two accounts also emphasise how place of origin was more important than place of birth and death, both Kate and Lisa brought their babies to their hometowns, to be laid at rest amongst family in family graves.

From the 1990s, fathers still had responsibilities regarding the deaths of their babies, even if they were no longer directly coffining the body or digging the grave. Though Aidan's family organised the funeral, on the day he was still in charge of his son's body

> I also got to hold little white coffin on way to cemetery and all I felt was that I had to hold tight and protect and mind him (Parent, Aidan 23w LB, 1998)

Kate too notes the emotional distress of this responsibility for her partner.

> At the graveyard my husband carried the coffin to the grave. He stood at the side of the grave as he had done 3 years earlier when his dad died. My heart really went out to him. (Parent, Kate, Term, LB, 1999)

Mothers too were distressed about being separated from their baby

> …how small but perfect she was, how I didn't want to let her go, and how I didn't want to leave her alone in the cemetery (Parent, Michelle, 27w, SB, 1996)

In 1995, Amanda's brother funeral summarises what is still common practice

> A funeral took place in the hospital chapel with my parents and I present, as well as a nurse and the priest. The baby was then buried in the family plot in the graveyard. We got to pick the clothes he would wear. The hospital took family photos prior to the funeral. [There was a] small number of close family, friends or neighbours [and] prayers at the graveside (Sibling, Amanda, 7d, LB, 1995)

The funeral Amanda describes distinguishes it from the hospital disposal familiar to parents in the 1970s. The funeral as Amanda describes it, took place in the hospital chapel, rather than a church. Going straight from the hospital to the cemetery, informal

religious expression (through prayers at hospital chapel or graveside), with the presence of mourners was the most common practice in the 1990s. Anne (1992) describes this as a 'fairly typical' funeral, in contrast, Carol felt this was not.

> [We skipped the church and did prayers at the graveside] … The arrangements were made without me, people didn't want to include me, they thought they knew what was best. Would have liked to have my son home with me for a little while before I had to say goodbye, I didn't get to bring my baby home & wake him or bring him to a church for a proper funeral (Parent, Carol, 32w, LB, 1997)

This distinction as to what constitutes propriety or even a funeral is difficult to understand, as most parents followed similar activities. Even though Sandra (1994) partook in some aspects of mortuary ritual, she indicated on the survey that she had no funeral.

6.3.4 Social Solidarity

The term social support is frequently used in the bereavement literature to denote social responses to grief. Noted earlier were expressions of social support for men, through actions or presence of others. Patrick (1959) borrowed a car, and for each of his children's deaths, his father showed up and a friend dug the grave. Aidan (1998) relied on extended family to organise the funeral. These non-verbal expressions of social support can be better represented with the term social solidarity. These are sometimes subtle or indirect. When Kate's son died, her social circle and extended community network responded in different ways to acknowledge her loss

> J was born and wrapped in a dark green towel and he had a little hat on, crocheted by a friend of my mother's, who had sadly lost a baby to stillbirth many years previous. On the day of the funeral my father said he wanted to pay for the funeral director services. However, the funeral director didn't want payment. He just asked for a few pounds for the gravedigger. He knew our families well and it was such a lovely gesture (Parent, Kate, Term, LB, 1999)

Kate's account demonstrates the interconnected and complex dynamics within rural communities, as well as the desire of grandparents to step in and help in pragmatic ways. Grandparents feature strongly in most accounts, particularly grandfathers and great-grandfathers. Betty (1975) was relieved that her grandfather stepped in to help with burial of her baby, as recorded earlier, she felt 'lucky' that he did. Patricia's (1955) grandparents assisted when her sibling died, in much the same way Elaine's (1987/1999) family was reliant on help from both grandparents

> For S my Grandad arranged everything for my parents, he bought a grave in my father's hometown village. I think my Mam would have preferred to have S and R buried nearer our family home in Dublin. We were minded by somebody in our Grandparents home. (Sibling, Elaine, 49d/Term, LB/SB, 1987/1999)

The intergenerational links extend beyond practical help to emotional support.
Extended families could be affected by the deaths of babies

> The loss was a big disappointment to the grandparents and the many aunts and uncles. Thankfully we survived in spite of it. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

When parents babies died and their surviving children later had children, this prompted a new dynamic to their family relationships which could be either negative or positive

> The death of my daughter has brought up a lot of emotions for my mother about my sister's death. I think she has a lot of regrets about how it was handled almost 'under the carpet' and while we always knew about my sister I don't know if others outside our family do. (Sibling, Linda, 28d, LB, 1982)

> The birth of my Mam's first grandchild was very significant for her. When she held my eldest daughter, it was the first time she had held a newborn baby since R's death. Recently she told my daughter about meeting her for the first time and said, "you helped heal my broken heart". It was very powerful! (Sibling, Elaine, 49d/Term, LB/SB, 1987/1999)

> Unfortunately my son & his wife had a stillborn baby girl, E, almost 20 years to the day after I had A, I felt I was able to help them with their process. In some ways I am more heartbroken over E's death. My mother had a stillborn baby too his name is R and we would sometimes talk about all three babies (Parent, Anne 24w, LB, 1992)

Families did not always manage to effectively support parents, who could struggle to navigate their emotions

> While we had good support from family and friends it was a very difficult time and we found that people did not know what to say to us so usually said nothing at all... (Parent, Lisa, 16d, LB, 1994)

> [Baby's death] caused my parents to fight a lot and my mother drank alcohol a lot to cope. Family and neighbours didn't seem to know what to do to help. [It helps] remembering people's kindness. The nurse in the hospital and the local pharmacy staff. The local pharmacist was a big help to my parents. He wasn't afraid to ask them how they were and would listen openly to them (Sibling, Amanda, 7d, LB, 1995)

6.3.5 Ways of Remembering

Remembrance constitutes a continuing bond; commemorative or remembrance activities can be public or private. Graves and memorials exist in public spaces and thereby marking, decorating, and tending of graves can be considered public remembrance activities. Grave visiting also takes place in public, even if it is not a shared activity. Commemorative practices can include public or private (see Table 8 below for ways of remembering).

TABLE 8: WAYS OF REMEMBERING

Parents Ways of Remembering		Hospital Artefacts
• Religious item e.g. medal	• Balloon Release	• Footprints / Handprints
• Memorial Services at Graveyard	• Quiet prayer of Remembrance	• Soft Toy
• Hospital Memorials	• Birthday Party	• Lock of Hair
• Registration Certificates	• Display Photograph	• Clothing or Blanket
• Baptismal Cert	• Photo in Album/Purse	• Name Band
• Condolence Cards	• Write to Baby	• Foetal Scan
• Dried flowers from time of Death	• Christmas Tree Decoration	• Photograph by Midwife
• Items used in the care of baby at time of Death	• Planted a Tree or Memorial Garden	• Photograph by Professional
• Grave Visits	• Sun catchers	
• Grave Marker	• White Feathers	
• Grave Decoration	• Robins	
• My Own Way (not described)	• Parent Advocacy	
	• Social Media Posts	

6.3.5.1 Grave Visiting

Grave visiting was variable across the dataset. In the initial years post death, over half the mothers regularly visited the grave and over time these visits have declined so that for many these are now annual visits. In general, men were less likely to visit graves in this dataset, though there are some exceptions, as in Elaine's family where her grandfather took on a daily routine of visiting her siblings

> Before my grandfather died, he went to visit their grave every day of his life after mass. He would keep it tidy, taking away old flowers etc. That meant the world to my parents (Sibling, Elaine, 49d/Term, LB/SB, 1987)

Grave visiting links parent and child but it also has an intergenerational component, as noted above. Carol's mother regularly visits her baby's grave because, as Carol explains

> I don't like visiting the grave it hurts too much but my mother does (Parent, Carol, 32w, LB, 1997)

Linda (1982) used to visit her sibling's grave annually but now visits often which may be linked to the recent death of her own daughter, though she does not elaborate on her daughter's death. Though Elaine's parents frequently visit, Elaine (1987 and 1999) does not feel this need but expects that at some point she will take over the responsibility

> [The grave] is something they enjoy and like to maintain. I rarely visit it anymore but I would if my parents died. (Sibling, Elaine, 49d/Term, LB/SB, 1987/1999)

For adult children, who knew little of their siblings, links to grave sites take on new meaning and are a way to continue family connections with extended family.

> Two years ago I started looking into my family ancestry and this is how I discovered where D was buried. In those days it was not everyone who had a private plot and looking at records most were buried in Public Ground. My dad's cousin and I are going to visit the grave when we are allowed to meet. (Sibling, Patricia, Term, SB, 1955)

6.3.5.2 Grave Marking

All families bar one had a grave marker. Grave marking was contingent on the type of grave. For hospital burials, in Glasnevin Angel Plot, there was no grave marking for Mary (1970) whereas Gillian (1980) had her child's name added to the plaque now provided at the cemetery for angel plot burials, as did Louise (1999). Some parents had 'auxiliary' grave markers. Michelle (1996) had a marble teddy bear, for example, as her parents are still living, so she intends to add her son to the future headstone that will be on the grave. Elaine's (1987 and 1999) father made a wooden cross for his first child's grave. When his second child was buried, an engraved headstone was erected. The wooden marker became an important memorial item

> They now have a headstone but for a long time when it was just S's grave there was only a wooden cross that my Dad had made, since the headstone went in the cross has [been] kept in my Dads shed/workshop (Sibling, Elaine, 49d/Term, LB/SB, 1987/1999)

Graves could be commemoratively marked, as Patrick (1959) did for his first child who was buried in an angel plot.

> A new curate Fr. X asked me to show him around the cemetery and on seeing the spot in the corner asked me about it. When I told him he said that there should be a memorial stone on it. He asked me to arrange it and the parish would pay for it. One of our daughters – a graduate of the Art College in [City] designed the stone – showing a girl and a boy safe in the Hands of Our Lord. A local monumental sculptor made it and erected it. At the time I had published a book on the history of the church and from its sales a sizeable contribution was made to parish funds. I still had money in hand from sales and there was sufficient to pay the costs of the memorial. The way in which I handled the situation gave me a very personal interest. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

6.3.5.3 Grave Tending & Decoration

Grave decoration was variable and was subject to change over time, along with increased or decreased grave visits. Aside from a headstone or grave marker, most graves were decorated with plants, fresh flowers, windmills, or toys. As time passes, the reasons why grave visits change are both emotional and practical

> J was blessed to be buried with his grandfather, who I'm sure greeted him with open arms when he died. His name was added to the existing headstone and we also placed a small plaque with a poem engraved on it. I used to put flowers on the grave regularly. It was more difficult to keep that up once we moved to [North-West]. Once my mother-in-law died, we cemented over the grave to keep it low maintenance. We don't visit very often now as our parents have all died since, so we have no home to visit. However, if we are going to [hometown] we always visit the grave. I don't necessarily feel he is there though and like to think he is with us wherever we are. (Parent, Kate, Term, LB, 1999)

6.3.5.4 Commemorative Activities

Some parents take part in public commemorative services. These are local memorial services at the graveyard (Cemetery Sunday), or specific baby loss oriented activities such as annual memorial services or masses arranged by hospitals or parent support groups. Patrick (1959 and 1964), as outlined earlier, was influential in establishing a community memorial at the angel plot in his locality. Gillian (1980) became a parent advocate, campaigning for changes in policy and civil registration for stillbirth. Though civil registration for birth and death were possible for liveborn babies, this was not always a priority for parents

> The hospital registered the birth…. It actually took 9 years for us to get his birth cert as it wasn't something we had thought of prior to that. [Then] I discovered his death had never been registered so I had to go about organising that, liaising with the hospital again to get the relevant form signed. (Parent, Kate, Term, LB, 1999)

6.4 Representations of Parental Grief

Emotions are summarised in Table 9, from the most to least commonly selected responses.

TABLE 9: PARENT EMOTIONS REGARDING DEATH OF THEIR BABY (FROM MOST TO LEAST COMMON)

FEELINGS AT BIRTH	FEELINGS FIRST MONTHS	EVER FEEL THESE
Shock	Disconnected or Numb	Felt Alone
Disconnected or Numb	Overwhelmed	Felt Lost
Disbelief	Distraught	Felt I couldn't talk about it
Distraught	Shock	Felt others wouldn't understand
Anger	Guilt	Felt Silenced
Overwhelmed	Anger	Felt Abandoned
Conflicted: joy / sad	Disbelief	Felt Guilt
Guilt	Relief	Felt Shame
Relief	Conflicted - joy / sad	Felt Stigma
		Felt Embarrassed

All parents identified shock at time of death as their primary emotion, about half of the parents in this study had no forewarning but for those who had, this provided some benefit

> On reflection I suppose I take comfort from the fact that we had time to process the fact that J would die. It wasn't something that was thrown at us the day he was born. I recall saying 'thank God we knew' to my husband when I was in the recovery room after his birth. We'd had a bit of time to start our grieving and know that we wouldn't take him home. (Parent, Kate, Term, LB, 1999)

Though the deaths of their children caused men sadness, fathers were deeply concerned about their partners, and their relief that their partners have survived birth is apparent. The men prioritised their own feelings as secondary to the health and emotional wellbeing of their partners and aimed to protect them. Aidan believes 'as the mother her feelings were much deeper and raw' (Parent, Aidan 23w LB, 1998). Patrick notes the death of his two babies as being a 'severe cross for us to carry' (Parent, Patrick, Term, SB, 1959; Term, SB, 1964). Even today, 63 years after his son's death,

Patrick was hiding his participation in this study from his wife, as it may cause her distress

> My first thought was to go and see Margaret and be there for her in a time of need. Such a sad event is naturally more difficult for the mother than the father… I do not remember if Margaret was allowed to hold him after the birth. I will not ask her. I have not told Margaret about it [the study] as it would probably upset her. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

Fathers were eyewitnesses to birth and death, and they play an important role in creating the family memory of both. This paternal role comes with consequences

> My husband was probably more concerned about me than worrying about himself. He was a rock… He could recall every detail of the birth whereas my memories were hazy. I asked him countless times to go over it which he did. After a year he wasn't coping too well and he went to counselling. It's tough on fathers when it seems the main focus is usually on the mother. (Parent, Kate, Term, LB, 1999)

When women were absent from the funeral, fathers filled in the gaps as they were the one responsible for the care of the body. This is noted by Patrick (1959 and 1964) who brought his wife to the graves of their babies after she returned from hospital. Even when fathers were supportive at the time of death, participated in mortuary rituals and attempted to protect or help their partners, continuing bonds with the baby was a potential source of relationship conflict

> My husband, now ex, told me to get over myself and stop talking about him. (Parent, Betty, 28w, SB, 1975)

> Partner was supportive and helped in aftermath of death with funeral etc. Was a very difficult time for him as well..... My husband and myself have had a difficult relationship and he does not wish to talk about him at all… Over time I have accepted his death but has made me more emotional and I get upset easily especially when visiting his grave. (Parent, Lisa, 16d, LB, 1994)

> I suffered from depression for a long time afterwards, even after a successful pregnancy… He did not feel the guilt that I felt, and he thought that I had nothing to feel guilty about, but I didn't agree. He tried and did support me initially but found it difficult to deal with my depression and how it changed me and my personality and behaviour (Parent, Michelle, 27w, SB, 1996)

These examples show that fathers are contending not just with their own emotions after death but that they are playing a supporting role for mothers. Fathers appear ill equipped to deal with the complexity of their partner's responses and, when considering birth experiences, it may be that these families are dealing with birth related trauma, as well as grief following death.

There was a visceral reaction to grief after the death of babies for some parents

> The day after the funeral I woke up and it was like being punched in the stomach (Parent, Kate, Term, LB, 1999)

> The grief was horrific and for a split second on waking up in the morning I would 'forget' but then the grief would hit me like someone punching me in the gut. (Parent, Michelle, 27w, SB, 1996)

All parents reflected that time had impacted on their feelings. Most of the parents still expressed strong emotions regarding their babies, wondering who their babies would have grown up to be. Tears or distress could be sparked by special times of year, or even just surge out of the blue. Some parents described their feelings as less 'raw' now and that the intensity of their emotions had waned

> In the 21 years since J died, I no longer feel that sense of despair and I can think about him and talk about him without feeling upset. Time has definitely been a healer but that's not something I wanted to hear at the time and I don't think I'd ever say it to anyone experiencing a loss now. The intensity of the emotions I felt then have lessened over the years. (Parent, Kate, Term, LB, 1999)

Other parents emotional state remains static, and for some, time has not been a healer

> I just pray that, in this day and age, that these practises are not bring replicated. I am 67 now and still cry over his loss. Rest in Peace S (Parent, Betty, 28w, SB, 1975)

> My heart broke the day he died and has not fully repaired despite having other children.... Over time I have accepted his death but has made me more emotional and I get upset easily especially when visiting his grave.... I have spoken on many occasions to counsellors but still find it difficult to speak about him. (Parent, Lisa, 16d, LB, 1994)

> He left the biggest hole that can never be filled, each year without him is harder, it can leave you feeling cold at times because you don't want to feel that pain ever, ever again (Parent, Carol, 32w, LB, 1997)

> [I quite often think of my baby] I really haven't come to terms with it (Parent, Louise, SB, 1999)

Privacy was seen as a valuable attribute in some accounts. Patrick is content that as a father, he met the social expectation to take care of his babies

> The death of two babies was a severe cross to carry for us… I consider myself blessed to have been able to do all that was necessary for both burials. Naturally it was lonely but privacy to mourn and grieve in my own way was important. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

Whilst Patrick's description may be interpreted as a generational reflection of emotional repressiveness, it is similar in character to what Aidan describes.

> Yes we talk with our kids a little. Not extended family. This is only for our immediate family - it's our memory (Parent, Aidan 23w LB, 1998)

By confirming his son's death as something private to his own nuclear family, Aidan is identifying similar characteristics of isolation and privacy to mourn. It may also be read as a way to exert control by limiting the 'memory' to specified people. This disconnect between the external world and the parents internal world is best exemplified by Kate

> The hardest part is the feeling of loss and isolation at times. Unless we talked to someone in the same position then nobody could fully understand what we were going through. (Parent, Kate, Term, LB, 1999)

An additional dimension of continuing bonds is exhibited through study participation. Taking part in this study offered a sense of relief, continuity, and permanence. In the absence of a physical grave, civil registration, or public recognition, for some participants, the study provided a legitimising record and/or a way to share what has remained unsaid

> When my daughter broached the subject I was happy to talk about it - have an opening for it. A relative lost a baby recently and this brought it back to me. The opportunity to talk about it was heaven sent. I was glad to learn about some extra supports and registration (Parent, Mary, 34w, SB, 1970)

> I wanted to write this out and maybe have her life be recorded somewhere? I'm a historian, and so making a note of things matters to me. I work on people who left virtually no archival trace and who didn't get to speak for themselves, but I can still write about them by being

> ethical and careful with the sources I do have. Maybe this is my imperfect way of putting an unnamed baby girl into the record. (Sibling, Sharon, 27w, SB, 1975)

> I am trying at the moment to find the Burial details again, I just want closure. Thank you for letting me share this story with you. (Parent, Susan, LB, 1982)

For others who did have a grave and/or rituals, the study provided had both an internal and external orientation, and an outlet for emotional expression

> Giving up the time to do this is like spending time with J and focussing solely on him. It's therapeutic in a way. (Parent, Kate, Term, LB, 1999)

> Margaret is not aware that I am helping you with this project and I am not keeping any copies – it is all in your hands. You use it in whatever way suits your research. I am not saving this work and you are the only people to have it. It has been my pleasure to help you. I would expect that when on your dealings with parents who have had a similar experience as ours you will be able to quote from my account. It was the very professional approach of yourself [lead researcher] that really made it easy for me to put my experience on record. I have a strong feeling of a great peace of mind since completing it. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

None of the parents, except one, would consider sharing their experiences on social media as it was too private. The parent who did use social media only posted a simple remembrance message on her child's anniversary. For those who used parent peer supports, none were still using them as they felt it was too hard being with other bereaved people and they were being 'anchored' to the past.

> Yes support group a few weeks after, needed somewhere to express feelings. [Left as] too hard being with other bereaved people (Parent, Lisa, 16d, LB, 1994)

Parent support groups provided a valuable outlet for some parents, particularly when there was an absence of alternative or professional services. Kate's story illustrates that despite having peer support she still needed professional therapy

> As far as I recall we were not offered any type of counselling via the hospital before or after J was born. It was difficult not knowing where to turn to for help. I looked for a local support group but unfortunately there wasn't an active one nearby. It was disappointing as I felt I really needed it at that time. I was struggling being back at work. In time, when internet services progressed I found [online Support Group]. In time the need lessened. I attended counselling about 6 years after J died… wasn't coping too well. It helped at the time to talk to someone neutral. (Parent, Kate, Term, LB, 1999)

In both these examples, parent support groups provided an immediate space for parents to express themselves – but it also showed limited benefits.

6.4.1 After Death Communications & End of Life

6.4.1.1 Symbolic Communication

Communication between parents and their infants comes in two forms. The first, is parent to child communication. Kate (1999) is the 'bridge' between the living and non-living members of her family with her living children speaking of their brother J, and including him in family pictures

> [The kids] each have a photo of him in their bedroom. I'd sign J's name on our family birthday cards and the kids would write his name on Mother's and Father's Day cards. J is very much a part of the family. (Parent, Kate, Term, LB, 1999)

The second form presents as a feeling of ongoing presence or connection to their child, with half of parents confirming sense of presence. This could be subtle.

> I do feel that the spiritual guidance of J and M do have an influence of our lives. Now looking back over the years I do not see the passing of our babies as a tragedy – I see them as being so important to our lives. (Parent, Patrick, Term, SB, 1959; Term, SB, 1964)

> I often say to my kids if something goes well that we have an angel looking out for us (Parent, Gillian 39w, SB, 1980)

> I believe he has helped us through the tough times and has been there through the good times we have experienced since his death. It did take a few years to finally accept what had happened and that was a turning point. Prior to that I would have been anxious in the lead up to his anniversary but now it's not as bad. I now feel great pride and comfort knowing he is with us in spirit. (Parent, Kate, Term, LB, 1999)

Whilst only half of parents confirmed a physical sense of presence, most parents identified with traditional Irish symbols of remembrance, usually robins or white feathers. These are also symbolic connections to the dead, as Lisa (1994) says 'I feel him whenever I see a robin'.

6.4.1.2 End of Life

Many parents expressed end of life wishes relating to their baby, linking the physical and the spiritual. This demonstrates a deep unrelenting bond to the physical remains and spiritual life of their child, this was expressed in different ways

- I hope I see him (Parent, Anne 24w, LB, 1992)
- I want to be buried with him (Parent, Lisa, 16d, LB, 1994)
- I want the few bits I have belonging to her cremated with me (Parent, Louise, SB, 1999)
- I would love to be buried with J but that's not possible so my one wish for when I die is that I am buried in the same graveyard (Parent, Kate, Term, LB, 1999)

The second expression relating to end of life, is captured in Monica's (1945) mother's death, here Monica details an end of life vision but does not herself characterise it in this way

> My mother died in 1991, and in her last few days she was in bed at home and one afternoon when I thought she was asleep I heard a big bang and ran into the room. She was by the window and had pulled the curtain rail down on herself. She was very distressed. She said that her 3 babies were calling her to come and play with them and she said C was beckoning to her. Such awful suffering and no word about it. She died a few days later (Sibling, Monica, SB, 1945)

Though Monica was aware of the birth and burial story of her brother, this was Monica's first knowledge of the existence of having three siblings and she links the absent discussion of these children to hospital birth and burial practices.

> None of us ever knew anything… it is possible that while C was born at home the two girls were born in the hospital. Maybe that explains why the memory of C was so present for my father as I am sure if he had had to inter the two girls too he would have spoken about it then (Sibling, Monica, SB, 1945)

Though Monica's story recounts a rarely reported but important aspect of life long continuing bonds to which she is an eyewitness, the difficulty with adult children accounts is also clear. Here with the absence of first-hand information, Monica and her siblings are filling in gaps in their family histories, which may have no basis in reality.

7 Discussion: Personal Accounts 1945-1999

7.1 Place of Birth Impact

Birth experiences are inextricably led to death experiences. Both were variable. Changes in hospital practice were evident from 1980. Most parents in the 1990s, even when asserting negative aspects of care, still characterised their birth experiences as broadly positive. The distress of mothers pre-dating 1990 was clearly linked to their birth experience but also the care of their baby's body, and a lack of compassion exhibited by clinical staff. No parents indicated continuity of care. Women birthing without partners were far more vulnerable physically, and emotionally. From the moment mothers were in labour, they were disempowered. Both the disdain shown to their babies bodies, and towards maternal birth encounters reinforced this. This is comparable to Cooper's (1980) findings which confirm that in UK hospitals parents described impersonal care, unconsented interventions, loss of autonomy, and expected compliance. This means that for women who gave birth in hospitals prior to contemporary changes in practice, their birth experiences can be characterised as disenfranchised, or as Hynan (2021) would refer to it, women's emotional ecosystems are disrupted by hospital birth and they experience 'root shock'. Further, hospital disposal of remains removed any ritual aspects of care from parents, prevented any mourners from attending, and meant parents may only be presented with a burial bill. In these ways, the hospital did not recognise their loss as significant physically, emotionally, or ritually. This can be read as disrupted bereavement, which is consistent with Selman *et al.* (2021) study of pandemic deaths. In Selman *et al.*'s (2021) research, the features associated with disrupted bereavement included the absence of a body; absent post-death rituals and religious rites; an inability to say goodbye; and missing social supports which included wakes and contact with other mourners, ostensibly what the authors are describing are a loss of normative death traditions.

Parents had no control over the fact of their baby's death, this was rebalanced by parents in different ways. Two mothers were satisfied they had enough time with their babies after birth, for example. In contrast, Aidan's (1998) story shows how physically isolating mothers first from their partners, then from their babies was likely to increase their emotional distress as they lost control over a key feature of mortuary ritual, and birth, that is the amount of time they had with their children. In this study, not seeing the baby left some parents with a lifetime of wondering. For others, whose babies were

presented insensitively, this was a matter of continued distress. Geraldine (1970) emphasised how her mother never saw her baby and this continued expressed need to see the baby suggests that the issue of control, rather than ritual, was more significant for bereaved parents.

The presence of men influenced the way in which care was delivered – whether this was during or after birth. When men were absent, women were particularly vulnerable and information flow differed, emphasising that separation of mothers and fathers affected how they received the news of death. When men were present at birth, they were left not just dealing with the anguish of their child's death but also managing that knowledge whilst witnessing their partners in physical and emotional turmoil. As mothers physical and emotional needs take preference, men's experiences, particularly if witnessing birth and death, can also be disenfranchised, as McCreight (2004) found in her Northern Ireland study.

Emotional conflict between parents was noted, this was regardless of ritual. This may also be read as a source of disenfranchisement, but this is not 'socially' oriented. There was social recognition of distress, and there was support at time of death through some form of ritual. These conflicts are better interpreted as a legacy of birth related trauma – fathers had to contend with both the death of their child, and their partner's suffering. This is exhibited differently by the two fathers here – one who was absent at birth (Patrick 1959 and 1964) and one who witnessed death (Aidan 1998). Fathers as spectators, were a repository of knowledge whom mothers relied on to provide an 'action replay' of their births, this may well compound men's coping abilities. It may be that witnessing such events impacts a father's ability to provide the necessary emotional support, as he deals with – or avoids - his own trauma. These findings mirror McCreight's (2004) Northern Irish study of fathers, who similarly found that men were marginalised in hospitals, were ill-prepared for birth, did not anticipate what their baby would look like, and their grief was over-looked.

Most parents indicated that hospitals needed to do better with regard to care, they perceived their needs to have been unmet in some way and saw themselves as individuals with individuated responses. Parents insist there is no 'one size fits all' model of care. This contrasts with the way in which hospitals do seek models of universal care and follow systematic processes and protocols, as evidenced in RCOG (1985) guidelines, and more recent policy documents regarding national bereavement standards (HSE, 2016; O'Donoghue & Cotter, 2021). The inherent difficulty lies in tailoring care to parent needs. Further some parents felt others couldn't identify with

what they were going through, and that only other bereaved parents truly understand - this is also noted by Klass (2013). However, if this holds true, this means that in some sense regardless of how perfect care pathways become, or how receptive or responsive society is towards baby loss, there will always remain a sense of parental disenfranchisement, as Klass (2013, p.602) says, “their world is forever a poorer place”.

Though care pathways have changed since all these parents gave birth, it should be noted that the impact of these birth experiences have remained with these families for their whole lives, underlining the importance of continuing to provide respectful care during birth. This applies to all the clinical aspects of care – listening to mothers, informing parents together, providing choices, remaining neutral, acknowledging physical and emotional distress and being able, as caregivers, to sit with both.

7.2 Evidence of Rituals

Many of the babies here were unbaptised, where baptism was performed, this was predominantly lay baptism. Naming is sometimes the only feature within a parent’s control, as Mary’s (1970) testimony shows – she was excluded and disempowered in hospital, neither, seeing, holding, or caring for her baby, no baptism or post-mortem were offered, it was not possible to register the birth, death, or stillbirth, and she did not take her baby home – the hospital arranging for disposal of remains. Similarly, Patrick’s (1959 and 1964) story shows that his babies being stillborn were also unbaptised – yet he affirms their existence through the use of naming as he recounts his family story. These parents, as did most families in the accounts here, provided a name for their baby regardless of baptismal status.

Some parents maintain they had a ‘typical’ Irish funeral, others had a modified form of funeral, and some had no funeral at all, with the hospital taking control of burial and excluding parents. Hospital disposal can thus be considered a specific category of mortuary ritual which represents an institutional response to death. Though caregiving experiences were variable, excluding hospital disposals, most of the families in this group had some form of funeral. The degree of formality differs from person to person but in most instances, there was obvious ongoing support from immediate and extended family, and responsiveness to parental emotional distress. Where clergy were present, in the pre-1980s era, they defined the place of burial in churchyards. Post 1980s, clergy provided informal supernatural leadership which becomes a focal point – whether this was at the hospital, home, or graveside. All parents had mourners

– these were either the parent themselves, the parent and one or two relatives, or both parents and other family and friends. There were social expressions of solidarity through actions as well as words, by extended social networks.

Modified or typical funerals, as detailed here are, in principle, fundamentally the same. None of the parents, regardless of how they described their funeral, conformed to what would be considered normative adult funerals. Sandra (1994) did not identify her mortuary activities as a funeral (though she and her partner collected their baby from hospital and attended the burial). Despite the presence of mourners and graveside prayers, Carol (1997) still characterised her funeral experience as lacking the formality of a 'proper' funeral. Carol describes herself as not religious, does not involve herself in religious rites or rituals, yet likes religious traditions. This suggests that religious rituals provide both a sense of familiarity and formalised structure. Thus, Carol has determined that a full church ceremony provides ritual power, whilst not necessarily deriving any spiritual benefit from it. Further, the absence of a wake which she resents, is not associated with church rites. What Carol's account demonstrates is an intersection between *rites* and *traditions,* both being necessary to create a sense of propriety, in her view.

Few participants expressed any degree of religious faith, older parents were most likely to refer to faith and a belief in religion. The formality of religion – through the presence of clergy, religious rites, or consecrated burial, all provide perceived legitimacy to funerals. When any of these are absent, as with birth experience, families can see this as disenfranchising. None of the parents included here, held a formal religious service in a Church, instead informal religious services were held in hospitals, hospital chapels and homes. As noted in Carol's (1997) account above, there is a broad interpretation of religion providing a formal structure and supernatural leadership but not necessarily spiritual or faith benefits. Clergy, if present, take a ceremonial but informal role, usually through graveside prayers, from the 1990s. The absence of clergy or religious formalities extended to burial, as well as performance of rites, the two often being interlinked.

Some parents had referred to the absence of certain mortuary features, particularly, religion, as indicative of impropriety – i.e. without formal religion it was not a 'proper' funeral – this was despite the fact, they themselves had no religious inclination. Most parents had no strong religious beliefs and this indicates religion provided a sense of tradition rather than faith or spiritual sanctity. This raises a query then over why parents would continue to advocate for either baptism or funeral rites, or consecrated

burial grounds. Thus religion takes on significance but predominantly in the sense of formal ceremonial value as 'tradition'.

Burial, whether hospital or parent organised, could result in the same burial location i.e. an angel plot. Baptismal status suggests that this is what determines the burial site (Garattini 2007) but this is not the case. It is grave ownership, rather than baptismal status, that defined where babies were buried. For institutional or hospital disposal this means institutional or hospital burial sites. For Dublin maternity hospitals, hospital burials are destined for the Glasnevin Cemetery angel plot. Parents can independently choose the same designated grave space, or as appears to be most common, where possible they buried their babies among family i.e. consecrated ground.

Burial with family was seen as normal and the parents' grandparents (great grandparents of baby) featured strongly. In some instances, it was great grandparents who organised burials, and in some cases babies were buried with grandparents or great grandparents. There is only one mention of unconsecrated burials in the accounts here, relating to a rural homebirth in 1945.

As noted earlier in Patrick's (1959 and 1964) case, burial choices he attributes to church teaching regarding limbo are actually a reflection of the ownership of the grave, rather than the status of his children as unbaptised. Regardless of place of burial, as demonstrated in three accounts above, clergy were not present to perform formal or informal ceremonial duties. Further, Monica's (1945) interpretation of religious formality links the role of clergy and religious ritual to pastoral supports, the perception being that the clergy are there not to perform faith based rites but to offer emotional support at a time of distress.

7.3 Significance of Ritual

As outlined above, mortuary rituals are riddled with ambiguity, and families described their funerals as either typical or modified. Even when parents repeated the same funerary customs, what they perceived to be normative differed, some parents describing their actions as modified and others as typical. This suggests that parents have a variable conception of what a funeral is, and then compare what they do against it. This is problematic in the context of caregiving. It means a singular definition of 'normal' cannot be clarified, which in turn means there is no benchmark against which to measure the 'right' way to do things.

This requires further evaluation when considering changes in hospital practice. Following the introduction of RCOG (1985) guidelines, new models of care included parents having access to their babies (seeing, holding, caring), sensitive presentation of the baby, and time with the baby. In the data here, parents in the 1990s had the benefit of these new guidelines, most parents indicated positive caregiver interactions, many had funerals as recommended by Lewis (1979a; 1979b), engaged with support services and memorial activities, thus would suggest a positive outcome. Yet, this group of 1990s parents communicated high levels of ongoing emotional distress. Considering this against Hoy's (2021) comments that high levels of perceived social support do not always align with low levels of emotional distress, suggests that these guidelines have at best a neutral effect, or at worst a negative one.

Though today there is an emphasis on expressive grief, most parents considered their experiences to be private rather than hidden or repressed. Contrary to much of the research in this area (Murphy 2012; Murphy 2019; Omar *et al.* 2019; Pollock *et al.* 2019) shame and stigma were not dominant features in parent accounts in these data sources, only one parent identified with either emotion. Parents rejected the public consumption of their experiences on social media, perceiving their stories to be personal. Parents also considered their feelings to be private, even within the family. This is consistent with Rosenblatt & Burns (1986) study of long term perinatal grief, where some parents felt no need or desire to talk, and for others talking was too private or socially inappropriate. This is reflected in the way in which parents engage with ritual behaviours. Grave visiting, marking, and decorating are all public acts but these are still 'lone' behaviours.

Though meeting the dead baby was identified as the crucial point at which mothers started processing their grief (Üstündağ–Budak *et al.* 2015), echoing early scholarly activism which promoted stillbirth management policies to 'face reality' through seeing the baby and having a funeral (Jolly 1976; Lewis 1976; Lewis & Page 1978), the evidence here indicates differently. First, parents who did not meet their babies grieved, and still continue to do so. For parents who did meet their babies, they also grieved and continued to do so. This suggests that continuing bonds occurs irrespectively of meeting or seeing the baby or having any form of social ritual regarding death.

Whilst parents did have an immediate reactive emotional response, regardless of seeing the baby or not, this is not the same as 'processing' – in this study, the evidence for processing grief takes place over a much longer time period. The majority of

parents indicated they were in shock at the time of their babies deaths; for half, this was also time of birth. Shock, numbness, and disbelief were the top three emotions at time of death and within the immediate months following death these still featured, though a feeling of disconnect remained dominant. These reflect symptoms of birth related trauma and PTSD, as noted by Ayers *et al.* (2008). This suggests that parents are not in a position to 'face reality'. This is reinforced by the fact that grandparents (predominantly grandfathers) step in to help in significant ways – in organising funerals and emotionally supporting the bereaved parents. Further, this period of disconnect is consistent with Van der Kolk's (2014) trauma theory which asserts people need time to retreat and familiar people and places, to enable them integrate meaning into their experience and move on. The findings here suggest that the notion of 'processing' is a longer term activity which parents continue to integrate and renegotiate over the course of their lives.

7.4 Effect of Hospitals on Ritual

In the accounts here, parents identified several emotions at time of death, these included shock, numbness, disbelief, and anger. Shock, as the primary emotion, impacted on parents abilities to think and make decisions. Pre-1960s, mothers were recuperating in hospital post birth, and fathers took on the responsibility of burial for their baby. By the 1990s, some parents knew prior to birth, that their baby would not survive – this gave them time to prepare the funeral. For other parents, thrust into the suddenness of death, they did not have this comfort. In addition, parents may have been contending both with the death of their child and traumatic birth situations which threatened the life of the mother, further clouding decision-making. In most cases, extended families assisted parents in arranging funerals.

From reading accounts provided by parents, it is obvious there is no agreement as to what constitutes a funeral. What is clear is that when hospitals took charge of the remains and sent them for burial, parents were either not consulted and/or had no engagement regarding the burial process. There were no mourners, there was no clergy, and there was no ceremony, including baptism, for some babies. Hospital disposal can definitively be considered *not* a funeral.

Cooper's (1980) British study identified that in the 1970s there was a parental assumption that hospitals would organise burial for perinates. Such assumptions are less clear in an Irish context. From the accounts given here, it is not apparent why in some instances pre-1990 the hospitals assumed charge of burial, and why in other

instances parents took their babies bodies home for burial, with or without the assistance of professional services. It may be that young fathers, inexperienced with death, relied on older relatives to take the lead. Certainly there is some evidence regarding the reliance on older members of the family by young fathers, with grandparents, and more specifically grandfathers, playing an important social role. Further, the accounts here definitively contradict Prior's (1989) assertion that hospital disposals were for unwanted babies. This was most definitively not the case – these were wanted babies and yet, hospital policies dictated the management of the infant body, overruling parents or ignoring them.

What is observed in these accounts pre-dating 1965 is that hospitals appear to follow a different policy to those noted in the 1970s and 1980s. In three accounts here, between 1945 and 1965, a similar process is described. In this time period, fathers took care of their babies in death. Fathers organised coffins and collected their babies from hospital, they dressed and coffined their baby. They arranged for burial, sometimes digging this grave or relying on family to do so, they escorted their babies for burial with the company of their fathers, brothers, and friends. They buried their babies with family where possible. There was no use of professional undertakers (excepting coffin purchase). Rather than this being associated with any sense of shame, Patrick (1959 and 1964) considered himself 'blessed' to be able to do what was 'necessary' for his children. This indicates a pragmatism which reflected his own self-described working class background, amid the endemic poverty which existed in mid-twentieth century Ireland (Ó Cinnéide & Walsh 1990).

7.5 Remembrance and Ritual

As noted above, not only was there variability in funerals but post death rituals were also variable. Grave marking was almost universal in the accounts here and could take on extra significance as memorial items, for example, Elaine's (1987 and 1999) father kept his daughter's handmade wooden cross grave marker in his workshop.

Grave decoration was sometimes linked to grave visiting, when parents or family visited the grave they left plants or toys. Some families cleaned the headstone and maintained the grave, this was one way to maintain the bond with their child. Grandparents also visited the grave, sometimes doing this on behalf of parents who lived too far away or who were too emotional to visit. As time goes by, grave visiting reduced but for some family members, particularly adult children, they were concerned to know or find out where their siblings were buried.

As noted above, grave visiting, marking, and decorating take place in public, yet these are still for the most part private activities that do not involve others and thus are not necessarily social rituals. Equally, some parents saw civil registration as important and a legitimisation of their baby as a person, but for others it was not as important. Kate (1999) waited nine years to get a birth cert and only when attending to this realised her child's death had never been registered. Though registration is not a social ritual, it can also be read as an intersection between the private and the public sphere. It appears to take on new significance in the latter twentieth century, with parents using certificates as proof of life.

Symbolic communication manifested in three forms. The first was parent to child – in the example used here, Kate (1999) acts as a conduit between other family members and her dead son. Whilst this may be viewed as a way to maintain connection between her son and the rest of the family, there is a difference between keeping the *memory* of the baby alive and behaving *as if* the baby is still alive. This is a point Charrier & Clavandier (2019) raise in their analysis of hospital practices, in which they maintain midwives perform a work of 'fiction' to create a person to be mourned. One aspect of this is the performance of a funeral and commemorative rituals for the person to be mourned (Lewis & Page 1978; Lewis 1979b; Jolly 1976). Given therapists seek new ways to support parents and advise them on public and personally meaningful mourning rituals (Markin & Zilcha-Mano 2018), this finding questions whether such advice is truly beneficial, particularly, when parents may experience prolonged distress despite actually performing funeral and commemorative rituals.

The second form of symbolic communication is from the child to parent. Parents remarked on symbols of remembrance such as robins or feathers, these being seen as symbolic links to their dead children, most parents expressed comfort and familiarity with this. Sense of presence i.e. the sense that the dead are around them manifests more in the context of a spiritual presence or angel, usually a protective presence, a feature Henderson (2014) identified in bereaved parents.

The final symbolic communication comes in the form of end of life. In the context of living parents, there was a desire for their physical remains to be with those of their children. There was also a desire expressed for being united with them spiritually in the afterlife. This was observed by Monica (1945) who described her mother's death. As Monica recounts the last days of her mother's life, she explains that three children appear to her mother, one her stillborn brother, and her mother gets distressed as she attempts to join them. This phenomenon was recorded in hospice case studies by Kerr

& Mardorossian (2020), in the example they quote the dying patient was cradling her long dead baby. Though all these forms of symbolic communication are not considered part of normal social ritual today, they are significant in the context of meaning. They raise questions about what is significant in ritual responses to death and commemoration, what is understood about the benefit of performing rituals and their relevance to the afterlife.

Commemorative practices, such as memorial monuments or remembrance services, again reflect a coming together in a public space which is often anonymous, similar to the way in which Japanese parents frequent shrines to perform Mizuko-Kuyō rituals (Smith 2013). Some commemorative activities however did have a more collective response than those noted by Smith (2013). Patrick (1959 and 1964) organised a memorial and a dedication service in his rural parish. Patrick relied on his social network to perform this – his daughter did the design, he raised funds, the clergy engaged to mark the angel plot, the community attended the service. This and other commemorative practices emerge in the 1990s, consistent with similar behaviours in the Netherlands observed by Peelen (2009) and Faro (2021), thus suggesting this is part of a larger global social trend.

Finally, remembrance occurred without ritual. Though the deaths of babies were a source of distress for parents and grandparents, bringing up hidden family histories and long-dampened emotions, the collective discussion could be therapeutic. Anne's story shows how she prioritises the support of her son on the loss of her granddaughter. It illustrates the generational familiarity of loss and how this experiential knowledge can be beneficial for the newest bereaved parents, as three generations seek to make meaning from their loss individually, and collectively. A similar process occurred for Elaine's (1987 and 1999) family, when her mother held Elaine's daughter, she repaired a 'broken heart'. This intergenerational bond between grandparent, parent and grandchild can prove to be healing, and requires further evaluation in the scholarship.

7.6 Influence of Ritual on Grief Theory

Overall, disenfranchisement can be read as a series of layers starting with hospital care pathways. Disenfranchisement was more likely to occur within the hospital, in the context of caregiver interactions and exerting control, which sometimes resulted in denial of access to the infant body and any aspects of mortuary ritual. Contemporary parent accounts illustrate that observing respectful care of the body and parental

choice are the key features to avoid disenfranchisement, a feature also noted in Australian care pathways (*Stillbirth Foundation Australia* 2020).

For the parents who participated in some form of funeral, these had a broadly similar pattern with certain time periods. For funerals pre-1960, this consisted of the father making or purchasing a coffin, dressing, and coffining the baby, collecting the baby's body from hospital and returning home, bringing the baby for burial to the graveyard, and burying the baby with the help of his father, and potentially other friends or relatives. Burial in this time period relied on the assistance of others and no professional services were used. There was no evidence of baptism or funeral rites, though prayers were said by the father. Mothers were not present as they recovered from birth. In parallel to this form of ritual, hospital disposals were an alternate pathway for the infant body but it is unclear as to why this persisted or when it was applied. From the 1990s, parents followed the recommendation to have a funeral. These funerals were variable but broadly consisted of both parents attending the burial of their baby, accompanied by a number of close family and friends. In some instances baptism was performed, some parents had prayers in the hospital chapel and/or at the home, and/or at the graveside. There was social acknowledgement of death and babies were most usually buried in family graves. Grandparents helped with burial arrangements but could also take over and remove control from parents.

Regardless of rituals, all parents expressed a continuing bond with their babies. This lifelong continuing bond has received little attention to date. Not getting over it, is indicative of affirmation of parental connection, a reassurance that the baby will never be forgotten. This lifelong continuing bond is most explicit in the context of after death communications, a feature of baby loss with minimal scholarly attention. Sensory experiences of the dead (also known as After Death Communications) are common, and often deeply to the bereaved who experience them (Elsaesser *et al.* 2021). More than half of parents expressed a sense of presence, a figure consistent with Rees's (1971) study of after death communications. Symbolic connections can be ritualised, through commemorative activities but also speak to cultural symbols of spiritual connection via robins and white feathers. Further, parents wishing to be physically and/or spiritually reconnected to their babies through parental death rituals, demonstrates an enduring bond between parent and child.

The final point to be made here pertains to the absence of a funeral definition. The ambiguity among parents as to what actually constitutes a funeral, makes it difficult to ascertain the degree to which normative mortuary rituals are followed and how parents

compare them. This means there is no universally understood concept of funeral. By extension, this makes it difficult at a societal level to be precise as to whether disenfranchised grief is affected by it. In turn, this means a claim of disenfranchisement based on mortuary rituals, is difficult to sustain because it will always depend on the individual perception – when in fact, social rituals are collective and others may view it differently.

8 Ireland in Context: 19th & 20th Century Mortuary Rituals

8.1 Introduction

How was it that parent advocates came to consider institution, church, and state, as legitimising perinatal loss, as observed in the previous chapter? Was perinatal grief always disenfranchised? Was perinatal death not socially recognised or acknowledged?

As highlighted at the start of this thesis, there is a paucity of scholarship exploring traditional Irish responses to death, burial, and bereavement for the nineteenth and twentieth centuries, in general. This creates a specific difficulty for studies of perinatal death. It means that no social context is available for comparison of ritual responses to death and thus makes it difficult to ascertain if perinatal death was disenfranchised in the past through the absence of rituals. Though Albano (2011) examines nineteenth century Irish funeral customs and identifies a distinction between upper and lower social classes, and the notion of respectability, this analysis is framed from a top-down perspective. Nonetheless, how we have come to understand grief and bereavement, and more generally the significance of burial and death customs, is defined by the nineteenth century. This is, in part, due to the reliance on Victorian death rituals which, as Albano (2011) has identified, were preferred by the upper and middle classes from the latter nineteenth century.

The social history of death and burial in Ireland is very complicated, and this makes a concise record exceptionally difficult to write. This chapter briefly traces development of mortuary traditions through the nineteenth century and into the twentieth century relying on multiple sources of data drawn from contemporary accounts of mortuary ritual, documentary analysis, civil and burial records

8.2 Poverty and the Poor Laws in Ireland

The nineteenth century Victorian era (1837-1901) was devoted to social reform and built on the twin ideals of morality and respectability; this is reflected in long-standing notions of the deserving versus the undeserving poor which shaped social policy over

the nineteenth and into the twentieth century (Crossman 2013).[97] Ireland, under English colonial rule was subject to these same Victorian values and social policies, but with variable application of British legislation to its jurisdiction.[98] The colonial ruling class imposed its own language, culture, agricultural systems, economic policies, social reforms, and religion – all of these had an impact on Irish traditions, particularly those regarding death and burial. The result is two parallel strands of cultural response – and two corresponding strands of mortuary ritual. This creates the complexity underpinning the study of death and burial in Ireland.

The Irish Poor Law Act 1838[99] was the most comprehensive attempt by authorities to alleviate the distress of the largely impoverished population and remained in place in Ireland until partition in the 1920s.[100] It ultimately became the framework for local government and the vehicle for the delivery of public health, sanitation, and burial legislation through the nineteenth century. Various laws were enacted governing the ownership, layout, and rules for burial grounds,[101] with the science of cemetery management developing from the mid-nineteenth century (Rugg 2021). These were necessary to resolve the growing problem of overcrowded churchyard burials, particularly in urban areas – to this point churchyard burials had been the primary place of burial in the UK (Rugg 1992). In Ireland, overcrowded burial grounds were also problematic but were not restricted to churchyards *(Drogheda Independent* 1892; NicGhabhann 2017). With growing awareness of the role of public health and the hazard posed by miasma from burial grounds, moves were made towards new cemetery facilities (Jupp 2006).[102] This was initially through the establishment of

[97] The respectable or deserving poor were economically independent but due to misfortune fall on hard times, then requiring assistance; respectability was maintained (Crossman 2013). Conversely, the undeserving poor or paupers were those who chose not to work, relying on immoral activities to survive; this required deterrence (Crossman 2006; Richardson 2013)

[98] Although Ireland fell under the legal jurisdiction of Britain, sometimes laws excluded, were amended for, or lagged in their application to Ireland, e.g. the Medical Charities Act, 1851 introduced the public health dispensary system to Ireland, characterised as the most comprehensive free medical care in Britain (Cox 2010)

[99] The Poor Law Union was administered by a local Board of Guardians (or Poor Law Guardians) but controlled centrally via the Poor Law Commissioners with extra supervisory powers than those for England; a separate Irish Poor Law Commission was established in 1847 being replaced by the Local Government Board in 1872 (Crossman 2013). Unlike in England, due to deep religious divide, clergy were not permitted to serve on Irish Boards (Crossman 2006)

[100] At the start of the nineteenth century, Ireland's population was over 8 million, equating to 32.5% of the entire population of the British Isles, however, by 1900 this figure had dropped to10%, following famine and mass emigration (Wyndham-Quin 1907)

[101] Cemeteries Clauses Act 1847; Burial Grounds Act 1856; Poor Persons Burial Bill 1866; Consecration of Churchyards Act 1867; Burial Act 1868; Irish Church Act 1869; Public Health Act 1878; Regulation of Burial Grounds 1888

[102] Miasma was a medical term which believed noxious odours to be the source of illness (Rugg 2021)

cemetery companies under the Cemeteries Clauses Act 1847; and later through the Burial Grounds Act 1856, the charge of cemeteries was invested in the Poor Law Guardians, before finally vesting in the Burial Boards of newly defined sanitary authorities (Meghen 1952).[103]

Destitution, poverty, and hunger continued to characterise Irish life through the late nineteenth century and into the early twentieth century (Breathnach 2012). Following the Irish Civil War (1922-1923), the condition of the country was described as "appalling" by Deputy Hall (1926) as he detailed the deaths of constituents due to starvation, referring to conditions in the 'new' county homes (the former workhouses) as "anything but human". The human cost of ongoing impoverishment is encapsulated by Deputy Byrne (1925) as he simply tells the government

> I am aware of a case where a young woman gave birth to a child, and the child was stillborn. I will prove, if proof is necessary, that the woman was delicate, and that the child was stillborn because of starvation. This is a problem which the Government must make up their minds to face, and face quickly (Dáil Éireann, 1925).

Mortality rates for children under the age of five, up until the early twentieth century, represented a significant proportion of total registered deaths, reducing from almost 28% to 7% of total deaths between 1865 and 1955 (see Table 10).

TABLE 10: CHILD MORTALITY AS A % OF TOTAL REGISTERED DEATHS (VITAL STATISTICS CSO)

	1865	1910	1955
Deaths under 5 (inc under 1)	27.5	19.5	7
Deaths under 1	15	13	6

Sources: Annual Report of the Registrar General (ARRG) 1865, 1869; ARRG 1910, 1911; Report on Vital Statistics (CSO), 1950

In 1880s Dublin, the rate of death in children under five years of age was 116.9 per 1,000 for workhouse inmates, compared to 18.2 for professional classes (Grimshaw 1889).[104] By 1904, though mortality was improving, class disparities remained - the death rate for children under five years in Dublin, per 1000, stood at 14.2 for the

[103] The Burial Boards fell under the control of the Local Government Board (today known as county councils). In 1869, burial grounds that were formerly under the authority of the Anglican Church in Ireland were transferred to the charge of the Burial Boards under the Church Temporalities Act 1869

[104] Parker (1869 p.4) describes the 'miserable existence' of mothers and children in the Nursery Ward of Cork Workhouse. He puts forward the premise that children die when their mothers have poor health and having no mother results in inconsistent care with worse outcomes for children.

labouring class versus 2.5 for the middle class (Cameron 1904).[105] Tenement occupancy could significantly impact death rates, with single room dwellers dying at four times the rate of multi room dwellers, from zymotic disease (Cameron 1904).[106] Tenement life blighted Ireland into the twentieth century and remained problematic even into the 1970s (Rotunda Hospital 1982). This confirms that poverty was a key contributor to the deaths of children in this time period.

By the end of the 1950s, Ireland's failure to improve living standards, and modernise the agricultural and industrial sectors, saw continued emigration and deprivation among rural smallholders and unskilled labourers (Ó Cinnéide & Walsh 1990). With free trade and new policies the 1960s was economically brighter, though rural western communities still faced inadequate service provision (Ó Cinnéide & Walsh 1990).

8.2.1 The Visibility of Perinatal Death

Establishing the prevalence of perinatal death (or more specifically stillbirth), is difficult as there was no coherent attempt to capture this data until 1957 (*Standard Report on Methods and Quality for Stillbirths Registration 2007 Onwards* 2020). Up until the introduction of civil registration, parish registers served as the basis for civil administration recording baptisms (births), marriages, and burials (deaths) (Helmholz 2013) and continued to supplement civil registration records until the late twentieth century (*Medico-Social Research Board Annual Report* 1971).[107] Though civil registration was introduced in 1864 in Ireland (National Archives of Ireland 2022), the system was deemed deficient by the 1870s amid growing concerns over the rate of infanticides (Durbach 2020).[108] Due to these concerns, under the new Births and Deaths Registration Act 1874, birth registration was made compulsory but only live births could be registered. The burial of stillborn infants in a *regulated* burial ground, required a certificate from a qualified informant, medic, or coroner, under the Act. By 1893, political debates about the control of burial grounds indicate that regulation of

[105] Cameron (1904) attributes this to overcrowded tenements and further notes that by 1903, 39.7% of all deaths in Dublin took place in institutions, this he takes as a reflection of the level of poverty in the city.
[106] Zymotic diseases included smallpox, diphtheria, cholera, measles, and typhus, among others (Cameron 1904).
[107] In one sample of Western parishes registers in the 1960s, 7.5% of deaths went unregistered (*Medico-Social Research Board Annual Report*, 1971). 6% of deaths remained unregistered in 1977 (*Medico-Social Research Board Annual Report*, 1980).
[108] Registration of Deaths in Ireland fell under the Registration of Births and Deaths (Ireland) Act, 1863, amended by the Births and Deaths Registration Act (Ireland), 1880, but differed little from English law. Notice of every death was to be provided to the registrar within five days of death, by a qualified informant, accompanied by a medical certificate or coroner judgement (*Reports from the Select Committee on Death Certification* 1893).

death and burial was inadequate, and compliance with death registration was variable.[109] There was no legal obligation to bury the dead in a public cemetery and if desired, the body could be interred in a garden or any other private ground (*Reports from the Select Committee on Death Certification* 1893). With regard to stillborn children, similar practices existed – there was no mechanism to register the birth or death of a stillborn infant, and no necessity to formally bury or register a stillborn infant (*Reports from the Select Committee on Death Certification* 1893).[110] Reflecting a continued social concern over high rates of infanticide, the Notification of Births Act, 1907 was introduced; the Act only applied to Dublin and Belfast. The Act stipulated all births over 28 weeks gestation were to be notified to the registrar. This maintained the threshold of legal viability at 28 weeks gestation, under which the foetus was not legally a person (Middlemiss 2020). Notification was separate to registration, and confusing in practice. A further amendment in 1915, eliminated the idiosyncrasy, except in Ireland, where the 1915 Amendment was not enforced in Irish rural districts (Lawson 1917). This meant that in Ireland the requirement for birth notification was contingent on the dispensary district, and only live births over 28 weeks were registered – births under 28 weeks were legally considered miscarriages (Lawson 1917; O'Malley 1965). In 1957, compulsory recording of stillbirth from 28 weeks gestation, by maternity units, was introduced under the Vital Statistics (Foetal Deaths) Regulations, 1956. The voluntary Stillbirth Registration Act, 1994 reduced the legal viability and definition of stillbirth to a foetal age of 24 weeks and/or weight of 500g.[111] Gestational age of 28 weeks thus remained the axis point regarding the legal disposal of remains through the twentieth century.

Predating civil registration, Irish births were estimated at 218,400 for 1856, with the assertion that one third of these babies (72,800) would be dead within two months of birth (*Commissioners for Administering Laws for Relief of Poor in Ireland under Medical Charities Act* 1856, p.5). Though this extends outside the definition of perinatal death, it does illustrate the extent of early reproductive loss that parents contended with. By 1921, perinatal loss was being estimated at 25% of total births (Stopes 1921). In 1954,

[109] The Public Health Act, 1878, Section 191, stipulated the authority responsible for a burial ground was to keep a register of interments making a return of the name, address, date and cause of death of the deceased to the registrar (*Reports from the Select Committee on Death Certification* 1893).
[110] Under Section 18, Births and Deaths Registration Act 1874, only live births could be registered; a declaration from a coroner or medical certificate from a birth attendant to confirm stillbirth was required for burial in a regulated burial ground (*Reports from the Select Committee on Death Certification* 1893).
[111] Weight was preferred as a measure of viability by WHO – see Lawn et al (2016) for debate on utility of weight versus gestation; from 1988 weight was used in Irish hospitals for international data comparisons (Stillbirths Registration Bill 1994)

based on deaths over 28 weeks gestation drawn from the three Dublin maternity hospitals, the national perinatal death rate was estimated at 54 per 1,000 live births (Deeny 1995), suggesting 3,377 perinatal deaths over 28 weeks occurred, in that year.[112]

Aggregated data disguises the individual toll of perinatal death. Recurrent reproductive loss was widely experienced. This is noticeable in civil registration records (which record births and deaths, see e.g. Table 11), and burial registers (which record stillbirths and deaths, see e.g. Table 12). In this example from Cappamore, Tipperary, one neonatal and eight perinatal deaths were recorded in one family. These are traceable as their births and deaths were recorded on civil registration records, with cause of death as 'prematurity'.[113]

TABLE 11: CIVIL REGISTRATION RECORDS SHOWING REPRODUCTIVE LOSS (SINGLE CASE)

Births & Deaths in civil records for James & Annie M: Married 1910
James' profession: teacher

Year	Baby	Name	Age	Cause of Death (if recorded)		
1911	Baby Girl	Ellie	* *Survival assumed*	No death cert found		
1913	Twin A: Boy	William	1.5 days	CW	P	NMA
	Twin B: Girl	None	30 mins	CW	P	NMA
1917	Baby Girl	None	1 hour	CD	P	
1918	Baby Boy	Gerard	1 day	CD	P	
1919	Twin A: Girl	None	2 hours	CD	P	NMA
	Twin B: Girl	None	2 hours	CD	P	NMA
1920	Baby Boy	Patrick	* *Survival assumed*	No death cert found		
1921	Twin A: Girl	None	5 hours	CD	P	
1921	Twin B: Boy	William	3 months	CD	P	
1924	Baby Girl	None	1 month	CD	P	NMA
?	Baby Girl	Maureen	No birth cert found	Daughter noted as informant on father's death cert in 1950		

Prematurity (P)
Congenital Debility / Weakness (CD/CW)
No Medical Attendant (NMA)

Source: Civil Registration Records

[112] Thomson (1953) evaluated Scottish perinatal mortality rates by weight and booked patient status, between 1939 and 1951, finding weight rather than gestation was used as a measure of mortality, and that under 2.5lbs (approximating 28 weeks gestation) survival was unlikely; as weight increases, survivability increases.

[113] The absence of a first name on these records, is indicative of non-baptism. The time until death appears to be a factor in naming/baptism, and the distinction between the named and unnamed twins in 1913, suggests that this is the determining factor in what appears to be formal baptism. Also noticeable is the reuse of the name William.

Infants are recorded on burial registers, though frequently without a first name, indicating that formal baptism was not applied. The rest of the burial entry is consistent with other entries, recording age/stillbirth, father's name (or person responsible for burial), address and religion, as per legislative requirements.

TABLE 12: DEANSGRANGE CEMETERY BURIALS

Deansgrange Cemetery Dublin: Burial Registers examples							
Father: Charles A (Protestant)			Plot south/m/50	Father: John M (Catholic)			Plot north/f/42
Year		*Baby*	*Age*	*Year*		*Baby*	*Age*
27 Mar	1895	Male infant	Stillborn	14 Jul	1878	Female infant	-
4 Mar	1896	Male infant	Stillborn	22 Apr	1879	Female infant	Stillborn
16 Nov	1899	Infant Female	-	24 Mar	1880	James	7 days old
17 Jan	1904	George	3 days old				
Charles died in 1905 and was buried with his children – there is no record of his wife in this grave				*John is not buried with his children though other later burials are recorded in this grave*			

8.2.2 Pendulums of Power

Catholicism was not the defining power structure for mortuary rituals in Ireland through much of the nineteenth century due to prohibitive penal laws enacted in the post-medieval period which prevented Catholics from having burial grounds and exercising religious rites.[114] The concerted attempts to eliminate Catholicism after the Reformation (1517 – 1647) made for a skeletal Catholic ecclesiastical structure as Catholic church assets were seized and redistributed to the Established Church of England and Ireland, i.e. the Anglican Church (Barr 2018; O'Connor 2018).[115] This meant that the control and regulation of burial fell under the remit of the minority ruling class of the Anglican Church and consequently, the majority Catholic population were prevented in law from having their own burial grounds or performing funeral rites. Following the Easement of Burials Act 1824 allowing Catholic rites and burial grounds, and subsequently the Catholic Emancipation Act 1829 which repealed the penal laws, the Catholic Church gradually started a building expansion and repair programme (Consecration of Churchyards Act, 1867). The Anglican church was detached from the

[114] An extensive subject list of Penal Laws is available from University of Minnesota Law School Index (2017). In 1823, Daniel O'Connell (1775 – 1847) a Catholic barrister founded the Irish Catholic Association, in a bid to peacefully revoke the remaining penal laws, accomplished in 1829.
[115] The Reformation was a political division of the Catholic church into various Christian denominations of Protestantism; the Counter-Reformation (or Catholic Revival) was the response to the threat of Protestantism (Thomas, 1991)

Irish state under the Irish Church Act, 1869, which in turn saw some burial grounds under its charge transfer to the state burial boards established under the Burial Act, 1856.[116]

The Great Famine also had an effect on the Irish Catholic Church. The institutional Catholic Church in the early nineteenth century lacked the infrastructure and clergy to provide an adequate service, leaving the Church weak. Mass attendance was low, particularly amongst the poor, for example, and by the mid-1830s was estimated at less than 40% in rural areas (Barr 2018). The fragmented Irish Catholic clergy acted according to the rulings of their provincial hierarchy resulting in localised interpretations of Catholicism (Barry 1959). The net result of a synod in Thurles in 1850 was to bring the Irish church into line with Rome and create uniform rules relating to the administration of sacraments and the maintenance of registers (Barry 1959; Dublin Diocesan Archives 2007).

8.2.2.1 Interpreting the Canon Law

In Ireland, as observed in other Catholic countries (Peelen 2009; Bleyen 2010), perceived exclusionary burial practices for the perinatal infant are based on two dominant features: non-baptism, particularly of the stillborn infant, and the absence of funerary ritual. In general, baptism (or its equivalent) as a mark of belonging to a particular faith typically determines the mortuary rituals that apply at death, yet the study of baptism as a component of mortuary ritual is limited.

In 1917, Woywod (1917) authored a new code of canon laws (*Codex Juris Canonici*) which had taken thirteen years to compile.[117] The purpose of the new Codex was to create uniformity in the application of the canon laws and provide a handy practical guide for daily use in parish life.[118] This confirms there were variable interpretations of

[116] Burial (Ireland) Act (1868) was a pre-cursor to disestablishment, formalising the procedures for the conduct of funerary rites. The Church of Ireland was detached from the Church of England under the Irish Church Act 1869; the property of the Church of Ireland was transferred to the Commissioners of Church Temporalities and officially disestablished on 1 Jan 1871 (Anglican Church of Ireland, 2021). Disestablishment of the Church of Ireland saw Anglican property (including burial grounds) returned to the state and falling under the charge of the municipal authorities or burial boards established under the 1856 Burial Act.

[117] This was the first attempt by the Catholic Church to revise, unify and codify the entire legislation of the existing Church laws, eliminating those that were obsolete, revoked or suspended. The magnitude of the endeavour had never been attempted before, though in the Middle Ages some official collections of laws had been made, nothing on this scale had ever been considered (Woywod, 1917)

[118] The Codex superseded all other existing collections of papal laws, retaining only the relevant ones in the newly published volume. The Codex was promulgated in May 1917, to take effect from May 1918, in recognition of the time required to disseminate new information to remote locations.

Canon Law, localised according to individual clerical opinion, right up to the time the Codex was published. Seven editions of the Codex had been printed by 1943, but in 1957, an expanded and revised version of the Codex was published.[119]

By 1926, the Codex reflected developments in contemporary biomedical discourse, stating

> a woman can give birth to no other than a human being, however deformed that infant may be, even to the extent of resembling an animal rather than a human being… if the thing born is a mass of flesh… without definite shape… if life is doubtful it should be baptised conditionally (Woywod 1926, p.335)

The 1957 Codex was more explicit regarding the baptism of the foetus, whether extracted from its mother alive or dead, following maternal death, through miscarriage, or whether it was "monstrous" or took "unusual form" (Woywod 1957, pp.376–77). The 1957 Codex is definite regarding American medical interventions at birth (Woywod 1957).[120] The 1917 Canon made no such reference,[121] and this suggests that some of the Codex in this intervening period was subject to American sociocultural and/or biomedical rather than theological influences.

The complicated set of canons pertaining to baptism and burial are contradictory. Canon 1209 details that the "bodies of infants" should be buried in a plot "specially set apart for them", making no distinction as to baptismal status.[122] Infants, in this context, refers to children up to the age of seven who were excluded from ecclesiastical law (Woywod 1926; 1957). Canon 1239 expressly forbids burial of the unbaptised though Canon 1212 compensates for this exclusion by allowing burial in a "separate place well

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[119] Following Woywod's death in 1941, the revision and expansion of the text was taken over by Callistus with further revisions through to the 1960s. Both works were published via American colleges where, by 1957, hospital birth had become normal, whereas in Ireland this was not the case. By 1955, 99% of all New York city births occurred in hospitals (Pakter *et al.* 1955); in Boston in 1939, the rate was 91% (Peller 1948), whereas in the UK only 50% occurred in hospital by the late 1940s (Hunter & Leap 2014), compared to Holland in 1938 with the lowest rate of hospitalisation at 20% of births (Peller 1948). In Ireland, 65% of births occurred in hospitals by the mid-1950s (Central Statistics Office, *Vital Statistics* reports 1900 - 2000).

[120] The Codex stipulates that if a mother dies in pregnancy the foetus should be "extracted" post mortem for separate baptism. The Codex continues, "it is said that the medical profession in Europe considers it part of medical ethics to perform the operation [foetal extraction] if the family does not object and there is hope of extracting the foetus alive. In the US… men of high standing in the medical profession favour the operation after the death of the pregnant mother when there is no hope of extracting the foetus alive" (Woywod 1957, p.376).

[121] Canon 743 does point to baptismal training for midwives, doctors, and surgeons though.

[122] Canon 1209 also refers to the segregated burial of the clergy, as such separate burial is read as being respectful

enclosed and guarded" for those "whom ecclesiastical burial was denied" (Woywod 1917; 1957). In 1969, post-Vatican II, a new Catholic funeral rite was devised for children and specifically unbaptised infants (Sullivan 2011).[123] The Codex was revised in 1983, Canon 1239 was revoked, ecclesiastical burial (meaning burial with full rites) was granted to catechumens and the unbaptised, eliminating the perceived need for segregated burial on the basis of baptismal status.

Rules regarding baptism, also applied to Anglicanism. Due to Ireland's chequered colonial history, Anglicanism has a significant part to play in histories of death and burial as it was the official state religion linked to the ruling class from the Reformation to the mid-nineteenth century. The Anglican English *Book of Common Prayer* (BCP) was in use from 1549, however, under the Act of Uniformity 1662, the amended BCP was used in Ireland until 1878.[124] What the Act of Uniformity did was effectively bind the BCP rubrics to statutory authority, effectively linking Anglican liturgy to civil law (Anglican Church of Ireland 2021). Though belief in baptism was retained, the Reformation dispensed with the dual beliefs of limbo and purgatory from Anglican theology (Thomas 1991).[125] Coupled with the theological doubt over the fate of the unbaptised this meant individual Anglican clergy could not provide *Christian* burial, on the basis that the unbaptised were not Christians (Wall 1848) but retained discretion with regard to interment of the unbaptised infant in consecrated ground.[126] In practice this resulted, through the nineteenth century, in the refusals of burial to non-Anglicans (Dissenters) as they were not baptised in the Anglican faith, a fate extended to unbaptised infants, particularly to those of other Protestant faiths.[127] No refusals of burial for babies by Anglicans were found for Ireland, but there were many such instances documented in the UK *(Freeman's Journal* 1826*; Belfast Newsletter* 1840;

[123] Four years after Vatican II (1962-1965), Pope Paul VI approved new funeral rituals for children which were published in August 1969 (*Ordo exsequiarum*). Prior to this, Mass of the Angels was celebrated for baptised children (Sullivan 2011)

[124] In 1877, a bill to read the Order of Burial over unbaptised infants was proposed at the Anglican General Synod *(Nenagh Guardian*, 1877)

[125] Jupp (2006) found in relation to UK Anglicanism, by 1800 clerical stipends were greatly reliant on burial charges due largely to the Reformation removal of Purgatory from Anglicanism which removed the associated fees charged for plenary indulgences and masses for dead.

[126] By the 15th century there were some Catholic as well as Protestant scholars who believed that the personal desire of the parents to baptise their child would suffice for salvation of the soul if dying unbaptised. Some Christian sects delayed baptism until the 40th or 80th day, which falls in line with the Levitical Law for maternal purification (Wall, 1848), which is commonly known as 'churching'. In the medieval Church, a foetus was believed to gain a soul (ensoulment or quickening) from 40 days if a boy, 80 days if a girl but the unborn was not considered a child until birth (Orme 2001).

[127] Not all clergy were in agreement with these practices, with one Anglican cleric resigning his post as he believed there to be no difference between "baptized and unbaptized infants who die in infancy" and that considerate "church principles" had been set aside (*Kerry Evening Post* 1862)

Freeman's Journal 1840*; Irish Examiner* 1851). In 1960, the Anglican Church of Ireland introduced a modified Order of Burial for unbaptised infants (McKerr *et al.* 2009).

8.2.2.2 Securing the Sacraments

The effects of the penal laws meant that the home remained the focus for the expression of religious rites and sacraments and formal engagement with the clergy was limited for much of the population well into the nineteenth century. Though sacraments could be prohibitively expensive, accessibility was also restricted due to both the shortage of clergy and the distances necessary for travel to access services. This meant that people remained unmarried and children went unbaptised, often for years, as was the case in remote rural areas such as Rosmuc, Galway (*Irish Independent* 1914) and Claremorris, Mayo (NFC Claremorris 247, 1937).[128] Ó Súilleabháin (1967) notes the reform of wakes by successive Catholic synods and diocesan meetings. This shows that between 1614 and 1927 on 21 occasions the clergy attempted to regulate wake customs – many of which ridiculed religious sacraments, such as mock marriages (Westropp 1923). What this suggests is both ambivalence toward the clergy and a preference for tradition but more importantly it indicates that mock sacraments, such as marriages, at wakes may reflect exclusion from the actual ones – whether by virtue of prohibitive penal laws aimed at suppression of Catholicism by Anglicans, or the exercise of class snobbery by both Catholic and Protestant clergy directed at the peasantry, and/or the expense of participation in such rituals by this group.

Poverty was a factor in accessing sacraments (*Belfast Newsletter* 1834; *Nenagh Guardian* 1843; *Tuam Herald* 1841), consequently folk alternatives developed. Masses for the dead were a significant burden on bereaved families who were eager to ensure their loved ones ascended into heaven rather than suffer in purgatory. With no guarantee of when this could be achieved, this was a recurrent revenue stream for the clergy *(Belfast Newsletter* 1834; *Nenagh Guardian* 1843). Free alternatives to these plenary indulgences for the dead take the form of hollowed mortar-built pillars in which stones were dropped and a prayer of intercession offered; when the hole was filled the soul was released from purgatory (Westropp 1923), see Fig 6.[129] This had the added

[128] Children needed to be old enough to walk the twelve miles from Rosmuc, across the countryside, to the main road. Once a parish priest was appointed to this locality, it took a further seven years for the priest to visit each house to baptise those seeking the sacrament (*Irish Independent* 1914)
[129] Westropp (1923) notes these are in use from at least 1760 to the Famine era.

benefit of achieving a consistent measurable outcome, unlike masses which could offer no proof of safe passage to heaven. Similarly, there are several types of stone heaps or wayside *cairns* – these derive from passers-by tossing a stone (*leachta*) on to a heap with a prayer to remember the dead (Nic Néill 1946), e.g. see Fig 7. In Cork, it is noted that a funeral rarely went to a church instead going directly to the graveyard (NFC Knocknagree 423, 1937). This indicates that often no clergy were involved with death rituals for the peasantry at that time, only later becoming part of common mortuary ritual. Class based religious exclusion was perpetuated up through the twentieth century, as noted in the tenements in Dublin for the 1940s

> I'll tell you where the snobbery was - when you would go to mass. The people from the ordinary locality would stay at one side of the chapel, on the other side the people from Merrion Square[130] were in the grand sanctuary. It was called the grand sanctuary because the people were grand. Anyone from round here would be married in the little chapel at the side and if it was anyone from Merrion Square they would be married at the main altar (St Andrews Heritage Project 1992)

FIGURE 6: STONE HEAP MEMORIALS, GLENCOLUMBKILLE, CO CLARE

PHOTOGRAPHER (Ó'DANACHAIR, 1952)

[130] Merrion Square refers to an affluent area of Dublin city

FIGURE 7: STONE HEAP MEMORIALS, ROSSPORT, CO MAYO

PHOTOGRAPHER (Ó'DANACHAIR, 1946)

8.3 Institutional Death & Burial

Dublin was well serviced with dedicated maternity services via four maternity hospitals in the nineteenth century; outside of Dublin, there was a network of health care institutions.[131] Workhouses were the backbone of Irish medical provision in the mid-nineteenth century, many had basic lying-in (maternity) facilities for pregnant women (*Report from the Select Committee on Dublin Hospitals* 1854).[132] Where shame and stigma do occur relating to perinatal death, they show up in the workhouse, typically tied to Victorian concepts of morality and respectability. Stillbirths were attributed to the health and/or morality of the mother – this is overt in the case of the workhouses but less so in the specialist maternity hospitals, for example, the Rotunda did not enquire about maternal marital status whereas the workhouse did (*Report from the*

[131] Rotunda Lying-In Hospital est. 1745; Coombe lying-In Hospital est. 1826; Maison de Santé est. 1859 (*Census of Ireland 1861*, 1863, p.48); National Maternity Hospital, Holles St, est. 1894

[132] Writing in 1859 on behalf of the Irish Poor Law Commissioners, Chief Clerk Mr Banks records that every Irish workhouse combines the '"character of a lying-in-hospital, foundling hospital, hospital for acute and chronic disease, and hospital for incurables" (*Report from the Select Committee on Poor Relief (Ireland)*, 1861, p.439). Workhouses were in effect catch-all institutions for those in need – by 1906 reforms of workhouses sought to segregate based on perceived needs e.g. the insane to asylums (Poor Law Reform Commission (Ireland), 1906).

Select Committee on Dublin Hospitals 1854).[133] The workhouse took in all destitute persons, including those deemed to be immoral. The mixing of 'moral' married women and widows, with unmarried mothers (inferring immorality) was a source of considerable concern in the mid-nineteenth century (Parker 1869; *Poor Law Reform Commission (Ireland)* 1906).[134] This 'immorality' later came to be replicated in hospitals which referred to unmarried mothers as 'inupta' and determined whether women would be admitted to specified wards or could even be admitted to the hospital; this labelling lasted through to the late twentieth century (*Irish Times* 1949; *Clinical Report of the Rotunda Hospital 1981* 1982; HSE 1983).[135] This replication is directly linked to the conversion of workhouses into mainstream hospitals, for example, in Dublin, the North and South Dublin Unions were to merge and the South Dublin Union workhouse was repurposed as a hospital (currently St James Hospital, formerly St Kevin's Hospital) (*Poor Law Reform Commission (Ireland)* 1906; Coakley 2022).

In the North Dublin Union, where there were two specialist maternity hospitals, impoverished women opted for the workhouse.[136] The main reasons for choosing the workhouse for birth were the ability to stay for a long period of time whilst pregnant, fear of contracting puerperal fever in the maternity hospitals, and the provision of clothing for baby in the workhouse which was not provided by the hospitals (*Report from the Select Committee on Dublin Hospitals* 1854).[137]

Workhouses kept registers in which they recorded inmate details, including births and deaths. In 1861, 67 live births were recorded for the North Dublin Union (*Report from the Select Committee on Poor Relief (Ireland)* 1861). Though the workhouse Master

[133] The Rotunda admitted poor women who required a recommendation of respectability, from either the clergy or other respectable householder. Though this appears to apply to booked patients, the Rotunda Master, Dr Shekelton, insists they never turn away any woman in labour, casting doubt that the recommendation was always a prerequisite for admission. The committee members assertion that fecundity is associated with immorality was resisted by Shekelton, his contention was fecundity only reflected poverty (*Report from the Select Committee on Dublin Hospitals* (1854))

[134] In the Cork Union, to avoid their husbands being prosecuted for desertion, some married women misrepresented themselves as single to avail of the lying-in facilities without charge, meaning their children were purposely and erroneously recorded as illegitimate, up to the 1860s (*Report from the Select Committee on Poor Relief (Ireland)*, 1861).

[135] Inupta is a Latin term meaning 'not married', it was used up to the late twentieth. In 1949, Dora C, an unmarried mother died from sepsis (following a stillbirth at home), after refused entry to Gorey Hospital due to her marital status, instead being referred to Enniscorthy county home, the former workhouse hospital (*Irish Times* 1949).

[136] Mr Weddick, Master of North Dublin Union maintains that attendance is usually for first-time confinements (*Report from the Select Committee on Poor Relief (Ireland)*, 1861)

[137] The Rotunda notes that women are admitted once in labour, and stay on average for eight days (*Report from the Select Committee on Dublin Hospitals,* 1854)

confirmed that a large number of stillbirths also occurred, these however, were not recorded

> We do not keep a record of these cases; the doctor keeps a record. If a child were stillborn it would look awkward to put it on the workhouse register; but the doctor records it in his own sick and mortality book[138] (p.240)

The decision not to record perinatal death appears to be replicated in other workhouses, and thereby suggests this was a systemic practice. Ascertaining the discrepancies between actual confinements and recorded births is difficult but cross-referencing data from two later official sources enables a comparison for 1895 (see *Local Government Reports* and *Nursing and Administration of Irish Workhouses and Infirmaries* reports in Table 13 below).[139]

TABLE 13: DISCREPANCIES IN RECORDED BIRTH RATES IN WORKHOUSES 1895

Workhouse	Local Government Board Reports	Nursing and Administration of Irish Workhouses and Infirmaries Reports
	1895 (live births)	1895 (all births inc suspected stillbirths)
Bailieborough	2	10
Mullingar	11	50
South Dublin Union	127	100 *

**The day the investigative team visited the workhouse midwife was absent and an external midwife was on duty*

The disparity in recorded numbers of confinements indicates that four reproductive losses (miscarriages or stillbirths) occurred for each registered live birth in the workhouses. If this discrepancy is a 'true' measure of perinatal death, then it would

[138] The awkwardness in this instance relating to obscuring stillbirth records is interpreted as lack of due care towards inmates, as there had been a number of reports critical of the running of workhouses and the poor health of children and women (Arnott 1859; Parker 1869).

[139] *Local Government Report* (1896); see *Nursing and Administration of Irish Workhouses and Infirmaries* reports published in the *British Medical Journal* (1895; 1895a; 1895b; 1895c). Unfortunately, these three workhouses were the only ones in which the nursing investigation teams recorded confinements – the South Dublin Union figure provided by the external midwife, is not reliable given the numbers of recorded births for the 1890s are approx. 130. Consistently the nursing investigation team found the provision of care to be appalling in the workhouses with very poor sanitation in most instances. They noted there was no sanitary provision at all in the maternity block of the South Dublin Union.

indicate an extremely high level of reproductive loss not captured in official statistical reports.[140] Additional evidence exists to support this assertion.

In 1890, the Mullingar Cemetery Committee requested a portion of the new cemetery next to the workhouse wall be kept for the interment of stillborn children (*Westmeath Examiner* 1890). In 1895, Mullingar workhouse recorded only eleven births on its register. This figure differs from the *Nursing and Administration of Irish Workhouses and Infirmaries* record of 50 – the discrepancy indicating 39 births were either miscarriages or stillbirths. That a burial area was requested explicitly for stillbirths would suggest the higher *Nursing and Administration of Irish Workhouses and Infirmaries* figures are more accurate. St Joseph's Hospital, Clonmel (former Clonmel Workhouse) had an unconsecrated area for the burial of unbaptised children (NFC Clonmel 11_020, 1937). The Old Cemetery Castlebar 'Plot of the Angels' for perinatal deaths, is estimated to be in use since the early twentieth century due to its proximity to the maternity hospital (*Connaught Telegraph* 1999). A field adjacent to Donegal District Hospital was used for workhouse burials from 1842, and for the burial of stillborn babies until the 1930s (*Donegal Democrat* 1996). Navan Workhouse cemetery retained an unconsecrated burial area for unbaptised infants (*Drogheda Independent* 1921). The former Prospect Hill, Galway county infirmary (1802 – 1924) maintained a graveyard at its rear for the burial of stillborn infants *(Tuam Herald* 1992). That so many of these former workhouse institutions provided dedicated burial spaces for stillbirths is indicative of the use of workhouses for the provision of some semblance of perinatal maternity care and/or a higher frequency of reproductive loss beyond that reflected in official records of the time. This also confirms that institutional disposal of perinatal remains was occurring at workhouses through the nineteenth century, which continued on until the mid-twentieth century. This is significant as it demonstrates that the institutional response to perinatal death rested in poverty, rather than religion.

8.3.1 Consequences of Institutional Death

One of the most important and contentious pieces of legislation, related to institutional death, was the Anatomy Act of 1832. As the practice of medicine professionalised through the late eighteenth century, it required human cadavers for dissection; a black market trading in corpses resulted in widespread bodysnatching (robbing corpses from

[140] Official records only recorded live births and deaths over 28 weeks gestation. This means that official data excluded stillbirths, and deaths that were perceived to be under 28 weeks gestation. It may be that in the workhouse these records also included perinatal deaths under 28 weeks i.e. second trimester reproductive loss.

graves) which caused public alarm (Knott 1985).[141] Withycombe (2018) notes that the foetus was a convenient stand-in for full cadavers as they were easier to access and turn into scientific specimens.[142] The Anatomy Act 1832 endeavoured to regularise the trade of bodies, one aspect of which permitted the procurement of unclaimed bodies from workhouses and hospitals for dissection as legal cadavers (Knott 1985; Deblon & Wils 2017). The cost of burial of dissected remains was then passed from the taxpayer to the receiving institution; the law disproportionately affected the poor who availed of the workhouse and was viewed as a symbol of working class oppression (Knott 1985). The net effect of this policy was an omission of any rites or rituals at time of death. This was not uncommon for institutional deaths in general, for example, Mullingar Asylum had no clergy present for funeral ritual or graveside rites (*Westmeath Examiner* 1891).

Between 1940 and 1965, over 500 unclaimed infant bodies were donated from institutions to Irish universities for anatomical dissection (O'Regan 2014).[143] In 2000, the maternity hospitals of Holles St and St James' (formerly St Kevin's) received requests from bereaved mothers who wished for confirmation as to the burial of their infants decades before (Bowers 2000a; Bowers 2000b; O'Morain 2000). These reports confirm that burials did not take place for pregnancies under seven months gestation, i.e. 28 weeks (Bowers 2000a). Where the hospital had charge of burials, these were sent to Glasnevin Cemetery for burial (Bowers 2000b). Hospital burials were paid for by parents (Traynor 2011) or were taken care of by the maternity hospital (National Maternity Hospital 2012).[144] These examples confirm that in general hospitals, babies were baptised by midwives before being placed into adult coffins to ensure a "proper burial" thus sparing parents the "distress and expense" of a funeral, a practice which ceased in the 1980s (Bowers 2000b, p.4). In two examples for Dublin, the hospitals could not identify the pathway of the infant body and concluded that the remains were likely to have been incinerated which was the "clinically acceptable form of cremation

[141] Body-snatchers were colloquially referred to as 'Resurrectionists' and medical professionals dissecting bodies were referred to as anatomists. Bodysnatching resulted in watchmen and watchtowers at cemeteries. Dissection of the body was distressing as belief in the Resurrection (which required the body to be whole so it could rise again) was widespread, this belief though staunchly adhered to by Irish Catholics, also permeated nineteenth century Protestant working class Britain (Knott, 1985)

[142] This is exemplified in an early twentieth century account by Sacks (2001) whose obstetrician mother brought home malformed foetuses (sometimes quietly drowning them at birth) for them both to dissect.

[143] Such donations ended in the 1960s but other issues pertaining to retention of organs were highlighted in public enquiries in Ireland in the 1990s, see the 2005 *Report on Post Mortem Practice and Procedures* (Madden 2006).

[144] By the end of the twentieth century, Garattini (2007) maintains 90% of babies born in the Dublin maternity hospitals were still being buried in Glasnevin angel plot but this is anecdotal.

within the hospital" (Bowers 2000b, p.4). This they maintained was standard practice for foetal remains of under 28 weeks gestation, unless specifically requested for burial by their families. Gestational age thereby remained a factor in the hospital treatment of remains.

The practice of hospital disposals can be traced to the workhouses, as outlined above, but the earliest confirmation of maternity hospital burial is noted for the Rotunda in 1854. The Rotunda Master confirms that they did not arrange burial for maternal deaths but "the stillborn children we bury" (*Report from the Select Committee on Dublin Hospitals 1854*, p.42); these babies were sent for burial to Glasnevin Cemetery (*Freeman's Journal* 1859). Collectively, the above examples confirm that hospital disposals are rooted in long-standing responses to institutional management of death, preceding the move to mainstream hospital birth from the 1930s. Kearns (2001) provides more insight regarding institutional and hospital burial for the early twentieth century, through an interview with Tommy H, a former coffin maker, who says Dublin Council buried paupers in a "pit" at Glasnevin or Mt Jerome Cemetery. Maternity and homebirths were brought by an undertaker and the small coffins of children were put into the same "mass grave" or 'pit' (Kearns 2001).[145] Retired gravedigger Jack M, gives insight into shifting practices by the late twentieth century, noting that Glasnevin Cemetery angel plots are used for the burial of stillborn or perinatal infants (Kearns 2001):

> The 'little angels' are mostly stillborns or a day old or whatever… It's sad… it just hits you… it's something you have to live with…. Now thank God... the younger women and men are appearing with these little coffins. In my day they didn't… they'd just come up in a hearse and you'd be told, 'take that down and bury that in the angel's plot'. Nobody with it. The parents didn't come… they just didn't… I'd imagine the mother would be too distraught

8.3.2 Marginalising the Impoverished Dead

The institutional treatment of infant remains is noted in Dublin's eighteenth century Foundling Hospital, where babies were buried without ceremony (Roe 2022).[146] This reflects concerns later expressed by the workhouse guardians regarding adult burials

[145] Though the interviewee uses this term 'mass grave' this is more usually associated with contagion and/or violence (Rugg 2000). Further, pit graves or trench graves commonly used in England, did not appear to be in use in Ireland (*Reports from the Select Committee on Death Certification* 1893).
[146] In the UK, in 1912, a letter of complaint was published critical of Bletchingley workhouse who permitted the burial of an unbaptised infant without any church service. The reason given was that it was neither the custom nor the law of the Anglican church to do so, despite the fact that in "Christian England they liked a Christian burial" (*Leitrim Observer* 1912).

at Mullingar Asylum where the absence of graveside prayers for the dead was noted, to which the Catholic Bishop of Meath replies

> According to the existing discipline of our church the burial service at the grave forms no essential part in the interment of Catholics. Pauper lunatics are buried exactly in the same way as ordinary Catholics throughout the diocese (*Westmeath Examiner 1*891)

This example confirms that the presence of clergy at everyday funerals was limited, and their graveside absence for Catholic interments was normal. By 1926, institutional burials had been raised in Irish government debates for public services provision

> When an unfortunate person, who has no relatives outside, or who may have relatives outside who have no means, dies in a county home [former workhouse], he is treated as if he were nothing more than a beast… When a poor person dies the usual routine is carried out. The remains are removed to the mortuary—if you like to call it so—without any ceremony. They are afterwards placed in a coffin and conveyed for interment to the burial ground attached to the institution. The remains do not receive that Christian burial one would expect in a Christian country. There is not the usual Mass that is said for the dead in the case of Catholics…Ministers of religion undoubtedly attend and say… the usual prayers over remains at the interment. There is no proper funeral service, not that kind of funeral service which one would desire in a Christian country, or desire at the hands of a Christian people… The matter has, I think, been put up to the Ministry on several occasions… It would be well if the Minister looked into the matter to see that, at least, Christian burial is given to those who end their lives in such an undignified state (Hall 1926)

Hall's (1926) understanding of funerary ritual differs from those noted as normative in 1891 and confirms that impoverished death in institutions was treated minimally with no ceremony, rites, or mourners. These examples show comparable mortuary treatment for the institutional body, whether this was a perinatal infant or adult.

8.4 Irish Mortuary Traditions in the 19th & 20th Century

8.4.1 The Victorian Era

By the mid-1600s, Thomas (1991) notes the contrast between elaborate Catholic, and basic Protestant English funerals, Protestant funerals being simplified to the point that contemporaries likened them to burying a dog. This appears to have reversed by the Victorian era. Victorian middle and upper class funerals were often ostentatious, with the use of white silk winding sheets and other haberdashery, expensive coffins and headstones, funeral coachmen with plume feathered horse-drawn hearses, flower lined

graves and coffins, memorial cards and memento mori photographs[147] (see Fig 8) and jewellery, and the wearing of black mourning attire and armbands (Cassell 1869; Jalland 1996; Albano 2011). By the late nineteenth century, Victorian consumerism had infiltrated Irish middle class funerals and professional undertaking services were common (Albano 2011; Hepburn 2014). As evidenced from Fig 8, middle class parental responses to mortuary customs were comparable to those for adults; the use of flower lined coffins for children is found in later folk accounts (NFC Burren 167, 1937). Parents paid for white hearses to bring their children for burial to Glasnevin Cemetery (Hepburn 2014). Tandem burials (a child being interred in the same coffin as an adult), particularly of mother and child, were not uncommon (NFC Tiranascragh 269, 1937; *Reports from the Select Committee on Death Certification* 1893) and evidence of similar practices exists for Ireland in the twentieth century.[148] The extravagant mortuary customs of middle-class Victorian society, however, lie in sharp contrast to the reality of the lived experiences of the mainly impoverished population of Ireland, and overlook the role of poverty in the exercise of funerary ritual.

FIGURE 8: MEMENTO MORI PHOTOGRAPH OF BABY RAFAEL TONA (TONA, 1910)

[147] The example shown here is from Spain but is consistent with other infant burials for the time. There are many memento mori photographs of single and multiple births clearly showing premature infants available in photo archives at http://www.19thcenturyphotos.com/Twins-in-coffin-122577.htm and https://www.thanatos.net/, as these are subject to copyright, they could not be reproduced here

[148] [Name Redacted] Glasnevin Cemetery interment order for mother and child (Glasnevin Cemetery Trust 1916) confirms a tandem burial. Tandem burials of babies with strangers were recorded as common place in hospitals until the 1980s (Bowers 2000b, p.4).

In general, Victorian colonialism perceived Irishness as inferior. Murdoch's (2015) critique of impoverished Irish Catholic immigrants in nineteenth century England illustrates this point well. English Victorian mortuary reformers were repulsed by Irish Catholics with their "loud and copious" grieving being beyond the "rules of fashionable grief" and sought to erase wakes as "legitimate forms of mourning" (Murdoch 2015, pp.385, 388). The contrast between mid-nineteenth century Irish and Victorian custom is keenly noted by philanthropist tourist Nicholson (1847). Moved by the simplicity of the poor Irish funeral and the absence of "mock fashions" (i.e., professional undertakers, mourning horses and black hearses), Nicholson (1847, p.278) admired the natural "slow and solemn" step of Irish mourners in the funeral procession unlike her middle-class contemporaries' "unnatural" funeral walk. Most significantly, Nicholson (1847, p.278) devotes some passion to the presence of women in the funeral procession, asking why "woman, who loves to the last, and acts to the last" should not follow those she has loved and cherished to the graveside. This indicates that the presence of women was considered unusual by middle-class contemporaries. By the twentieth century, in Ulster, middle class women stayed in the house to commiserate, only working-class women followed the funeral to the graveyard (Lynd 1909). In early twentieth century Dublin, middle class women left the Church after the funeral mass, but working-class women attended the gravesite (Kearns 2001). This suggests that the Catholic middleclass, increasingly adapted to Victorian sensibilities as the nineteenth century progressed, and adopted similar class based mortuary customs.

8.4.2 Traditional Irish Mortuary Rituals

In the early nineteenth century, rural mourners were alerted to a death in the community through the lighting of *beal* fires (Maxwell 1843). Wakes were common at this time. As Maxwell (1843) notes the only difference between the wakes of the rich and the poor was the quantity of funeral refreshments. The impact of the Great Famine was devastating, affecting the conduct of mortuary rituals at, and since, that time (Nicholson 1847; Wilde 1850; Lawless 1912), as Lawless (1912) recounts:

> the permanent effects of the disaster differed in different places and with different people but in one respect it may be said to be the same everywhere. Between the Ireland of the past and the Ireland of the present the Famine lies like a black stream, all but entirely blotting out and effacing the past. Whole phases of life, whole types of character, whole modes of existence and ways of thought passed away then and have never been renewed. The entire fabric of

> the country was torn to pieces and has never reformed itself upon the same lines again.

Family and neighbours watched over the dying, reciting the rosary at the moment of death (Wood-Martin 1901).[149] After laying out the body, the neighbourhood was expected to attend a wake (Wood-Martin 1901).[150] Where wakes occurred, these took place over two days with the funeral occurring on the third morning (Wood-Martin 1901).[151] Financial contributions towards the cost of the funeral were known as 'altars', a collection plate being left by the coffin or at the door of the house during the wake (Lynd 1909).[152] The wake continued on in rural areas into the twentieth century, though these were simpler affairs lacking the ribaldry of pre-Famine traditional wakes (Westropp 1923).

Mooney (1888) provides the following insights into late nineteenth century mortuary ritual, indicating the distinctive Irish funeral lament known as the 'wild, wailing *caoine*' had long fallen out of use, though other authors of the time note its continued, if sporadic use.[153] The keen was raised at midnight or when the body was ready for the wake; though often viewed as a female activity, men also participated in keening (Mooney 1888; Lynd 1909).[154]

The keen was never raised for children or young unmarried persons in Roscommon, Meath and the north-east counties (Mooney 1888), including Mayo (NFC Eskeragh 117, 1937). The death of a young person was different, as "the sorrow is too great to allow of any such joviality or fun" (NFC Eskeragh 117, 1937). Instead, garlands of scalloped white paper were wound around sticks or hoops and carried in procession alongside the coffin, afterwards driven into the earth around the new grave to decorate it (Mooney 1888). A near universal theme in the folkloric record, is the custom

[149] Wood-Martin (1901, p.301) records wake behaviours at the turn of the twentieth century, writing when family and acquaintances enter the room, they stoop over the body and weep or lament, and those nearby join in. Strangers only kneel and say a prayer. Then the mourners take a seat and fill their pipes and glasses, in many places, smoking and chatting occur while the grave is dug.
[150] Ridge (2009) notes that by the 1950s, there was nobody left locally to perform the traditional rituals around death and the professional services of an undertaker were required
[151] Mooney (1888) had noted the decline in the Irish wake, which he attributed to education, the Famine, and associated politics, as well as the long-standing concerted efforts of the clergy.
[152] This caused considerable hardship in impoverished rural communities, with people sometimes selling possessions in order to contribute to a neighbour's wake 'for fear of a charge of meanness' (Lynd, 1909, p.116).
[153] The *caoin* (pronounced 'queen', anglicised as 'keen') was distinctive and noted as being something that once heard was hauntingly unmistakeable (Clarke, 1883; Lynd, 1909). The Irish funeral lament, the keen, is also known as the *ullagone* or 'morning cry' (*sgread na maidne*) (Mooney, 1888)
[154] Mooney (1888) illustrates the gendered elements of funeral ritual, as in Ballybunion, Kerry where it is men who take over the keening of the funeral for a man of good standing, as it passes through town.

discouraging mothers from attending the funeral of their first born child, regardless of the child's age (Bergen 1895; NFC Coshmore 44, 1937; NFC Creganbane 7 22, 1937; NFC Kealid 277, 1937).

The absence of clergy for sacraments was not unusual (Mooney 1888), even into the twentieth century this is noted (NFC Claremorris 247, 1937). Substitutes for formal rites included the rosary at time of death, and the De Profundis at time of burial (O'Hanlon 1870; NFC Dungourney 307, 1937). Mooney (1888) noted that priests rarely attended a funeral or were present at the burial, though this was increasingly common. It was customary in the nineteenth century to hold a requiem mass a month after the death (known as the 'month's mind') and sometimes another after the first anniversary (known as the 'year's mind') in the church (Mooney 1888). Lynd (1909) having attended the new custom of a 'removals' (bringing the body to the church overnight before burial) is struck by the solitary silence of the affair, it being devoid of any sense of ceremony or connection – and a sharp contrast to the typical Irish funeral. This again points to a disconnect between Victorian imbued customs which valued formality and Irish traditions regarding death, burial, and bereavement.

Between the 1930s and 1960s the social rites of death were replaced by religious ones (Ridge 2009). By the 1930s, it was still usual to wake for two nights at home except in "rare circumstances" where the body would be left overnight in the church (NFC Dunkineely 315, 1937). The rosary was still said at the wake and crying (rather than keening) was normal (NFC Tonatanvally 274, 1937). There was increased clerical and religious engagement but this was not the case everywhere; in many places the wake was reduced to one night, a formal funeral mass was more typical and the priest may have attended the graveside, but these practices remained variable (NFC Tonatanvally 274, 1937; NFC Cappamore 206, 1937; NFC Dunkineely 315, 1937). The changing social customs are clear in these accounts

> It is becoming customary to have the corpse removed to the church on the evening before the funeral (burial) though the older people have a great dislike for such a practice, and accordingly mostly all of the older people are buried from the house. (NFC Meelin 83, 1937)

> The beautiful custom of having the remains brought to the church is now common and it is not unusual to have a requiem mass on the following morning with the funeral to the adjoining cemetery. A few people who did not wish to make or break a custom still take their dead to the old burying ground but they have availed of the new idea of bringing the remains to the church (NFC Knocknagree 423, 1937)

The wake was not just an opportunity for commiseration, or social acknowledgement of death, but also part of the preparation for burial. As with other aspects of Irish life, the collective community response, the *meitheal*, remained instrumental. The grave was dug by male neighbours and friends, in the company of other men, as the wake continued (Wood-Martin 1901). The grave was also closed by them "the relatives hardly ever do this, it is usually friends or neighbours" (NFC Cappamore 206, 1937) and more usually, the young men (Lynd 1909). Comparable mortuary customs are recorded for the Dublin tenements in the 1940s. Neighbours offered support to the bereaved family, including the running of the wake and recording who attended and what material assistance they brought (Johnston 1985). By the 1960s, the wake had become unfashionable and professional funeral services were commonplace (Ridge 2009).

8.5 The Sacred & the Profane: Burial Grounds

8.5.1 Defining Place of Burial

Burial charges could be excessive, particularly affecting the poor (*Belfast Newsletter* 1834; Fitzpatrick 1900), and cost may have been a factor in choosing place of burial. Burial occurred in one of three places – churchyards, cemeteries, or folk burial grounds (*cillíní*). Rugg's (2000) framework attempts to make the distinction between churchyard and cemetery clear, and Henderson (2014) adapts this for Ireland, to include *cillíní*. The evidence here shows the terms graveyard, burial ground, cemetery, churchyard and *cillín* (and other Irish language terms used for them) are frequently used interchangeably, making these distinctions less certain. This nuanced understanding of burial grounds is widely reflected in the official and folkloric record.

Though churchyards and cemeteries were subject to legal precedents, as noted earlier, in 1893 the Registrar General for Ireland emphasised that there was a different class of burial ground unique to Ireland (*Reports from the Select Committee on Death Certification* 1893). These burial grounds had no formal or legal governance i.e. they are *cillíní*

> There are a number of burial-grounds in Ireland where there are no custodians and where the bodies are brought and buried some without funeral services at all, and where no one knows anything of them except the persons who bring the body to be buried. It is the practice for instance in many places to have the funeral service at the house of the deceased person, and then the body is brought to be buried and there is no service at the grave in a great

> many cases. Those bodies are quite unknown to anyone except the people who bring them there

This is significant for social histories of death and burial, and more specifically, cultural narratives regarding *cillíní* as places of segregated burial. This confirms that *cillíní* rather than being places of furtive burial, were widely used by the community, and that home based funerals were common. It confirms an absence of formal religion, and that no official record of burial existed, or appears to have been sought – and most importantly, authorities were aware of their existence.[155] In this example from Cork, the interchangeable use of graveyard terms is demonstrated, here *cillíní* are known as 'disused graveyards'.

> There are a couple of disused graveyards in the district.. called "cílls"… Unbaptised children were buried in "cílls". There is also a "cíll" in Coosheen in which there are head stones…The "cílls" are never interfered with… these "cílls" were the burial places of the people before the graveyard in Schull. (NFC Gloun Schull 88-89, 1937)

This account shows that *cillíní* were used by the parish and for the burial of unbaptised babies, and they also had grave markers. In Kerry, the change in use from a *cillín* to the parish graveyard, again renders these definitions as vague

> It was originally a burial ground for Infants, and was then known locally as *Cillúrach*, but this name fell into disuse when the churchyard became a common burial ground. (NFC Knocknagashel 79, 1937)

Similarly, the next example from Roscommon illustrates the complexity of these burial sites. Consecration was applied to what was perceived to be unconsecrated burial grounds, so that they could be adapted for regular use by communities

> About six or seven years ago there was a special unconsecrated place preserved for the burial of unbaptised infants, but as time went on the pastors were obligated to consecrate the place for the unbaptised children and make it a regular burial place for all (NFC Cartronavally 270-272, 1937)

[155] 40% of deaths were still medically uncertified in Co Mayo by 1937, compared to Dublin's 1.7% (CSO 1954). Connacht region overall had an uncertified death rate of 35.8% declining to 21.1% by 1954, compared to Dublin city which remained consistent at 1.7%. The high rate of uncertified deaths in remote parts of Ireland would suggest the widespread and continued use of *cillín* burials in these regions, as regulated burial grounds require medical certificates for burial. The higher rate of compliance in Dublin would similarly reflect the control of burial grounds, it was not possible to bury in Dublin without certificates for burial – this was an option in rural areas.

The changing use of burial grounds is noted further north in Cavan, the north-west in Mayo and the midlands, Offaly, in the examples below

> there is but one graveyard in this parish… beside the chapel… It was taken in and fixed as a graveyard by a priest called Father Hugh McGovern. (NFC Corratawy 151, 1937)

> There are two graveyards… Killeen is the nearer of the two to Attymass church and a good many people are buried in it on that account… When you go into this graveyard you can discern that about half the wall that encloses it is newer than the rest. This new piece was added at the time of the graveyards consecration in 1916 by our present bishop… It was first used as a burial place for unbaptized children as Killdermot is now. (NFC Corrower 477, 1937)

> I have seen it [cillín]. It is not fenced off from the field in which it is situated but as it has never been cultivated it is easily seen…There is a place in the monastery graveyard now for unbaptised babies. There was a graveyard [cillín] in Tommy Flattery's Garden. It "stopped" when Monastery opened… Father Cochran got 2 acres from Baggot for the Monastery Graveyard. (NFC Clara 446, 1937)

These accounts demonstrate that even if the same word is used, 'graveyard', the meaning can be different. The change in graveyard usage shows how *cillíní* were subject to a 'bureaucratic legitimisation' through expansion and consecration, expansion resulting in the enclosure of the burial ground. These stories illustrate the influence of local clergy in the acquisition, repurposing, and, as the example below shows, the maintenance of graveyards.

> The graves around here are kept very untidily. They are covered over with grass and weeds and are a disgrace to the people. Lately, Father Gilden and Canon Higgins have ordered the people to clean the graves and this is done by nearly most of the people around here. (NFC Cashel 294-295, 1937)

Though clergy did not necessarily have a formal obligation to assist local authorities in the establishment or maintenance of graveyards, the reliance on clerical assistance for the adoption of new cemetery usage and upkeep is later noted by Meghen (1952). Despite the assistance of local clergy, in general, burial grounds were often not well maintained (Norton 1934).

8.5.2 Ancestral Connections

In Irish culture, there is equally great fondness and great fear of the dead. The dead could appear during daylight or in darkness. The dead could punish or protect.

> The dead often mingle unseen with their former friends, watching over them and taking note of their actions. In general ghosts are regarded with dread, but when the spirit is supposed to be that of some dear friend… the feeling is one of love and pity (Mooney 1888)

> Visitors from the grave are, however, by no means always invisible, for instances are related of persons long dead appearing as if alive, in broad daylight. Then too it is implicitly believed that the dead often rise from their graves and amuse themselves during uncanny hours of the night at goaling [GAA] (Bergen 1895)

> People believed that the souls of the dead were buried in them [family graves], and that their souls were about them. That preserved them from attack of any kind. (NFC Killarga 402, 1937)

The eternal connection between mother and child was recognised within Irish tradition; when mothers died they still fulfilled their maternal duties from the afterlife

> A mother who dies in childbirth is believed by many to watch over and feed her child until it has grown up. (NFC Kilcommon 316, 1937)

> In olden times when young women died after birth of child it used be said that they… come back at night to nurse the little infant. (NFC Dunmore 86, 1937)

Ancestral burial was a feature of Irish mortuary customs. It was expected that people would return to their place of origin for burial, even if this separated families after death

> Many people bring their dead long journeys to bury them with their ancestors and many stories are told of the dead coming back to the earth and appearing to their relatives when buried in wrong graves. (NFC Moynalty 134-135, 1937)

This next example illustrates a change in the tradition of ancestral burial which did lead to separation of families in death

> The present parish priest Canon O'Sullivan had made a law that anybody outside the borders of his parish cannot be given graves in [this] parish… the old rules going to the family ground at Nohoval or elsewhere no longer obtain. As might be expected in the changeover… some members of the family are buried at Nohoval while others are interred at Knocknagree and

> in a few cases even husband and wife have been separated in death. (NFC Knocknagree 423, 1937)

Traditional burial practices extended to the burial of children in their father's ancestral burial ground, "a child [is always] buried in the father's family's ground" (NFC Knocknagree 423, 1937). In general, Irish people went to extensive trouble to ensure ancestral burial, and this included their children, as in the following example of a child death in the workhouse during the Famine.

> The child was buried without coffin or else, in the "Sand Bank" the burial place at Carrick workhouse. The poor man [father] went in at night, with a big *pardóg* [basket]… and he lifted the dead body out of the pauper's grave, and carried the body naked through Carrick, in the *pardóg* on his back…. He lowered the *pardóg*, took off his torn coat and shirt, and wrapped the dead child's body in the shirt and coat and buried his child among his kith and kin in Killukin graveyard. He could not rest, he said, day or night, dead or alive, as long as his child lay among the paupers (NFC Jamestown 491, 1937)

This example highlights how children's bodies were managed by institutions, in this case it appears the child was buried naked and without coffin, without any reference to the family. It further suggests that there was shame attached to institutional burial, the father's actions ensuring his child would lie among family.

8.5.3 Grave Marking & Visitation

Despite the cautionary warnings regarding interference with burial sites, widely noted in the NFC (Ó Súilleabháin 1939), a late twentieth century mapping study of disused burial grounds found the majority were under tillage and physical evidence of their existence had been destroyed (Donnelly *et al.* 1999). The survival of *cillíní* sometimes relied on the intervention of clergy to ensure they remained undisturbed or that they were even abandoned

> It is not right to interfere with the forts. John L's father ploughed the fort and he got suddenly ill. His wife sent for the priest and she told him about the ploughing of the fort. The priest was very displeased and said "In God's name leave the forts to the fairies". (NFC Ummeraboy East 327, 1937)

In other instances, the necessities of life dictated otherwise when resources were scant

Beside the graveyard lived an old man and his wife.. these were very poor and had no coal or turf to burn. The woman of the house used to go out… to gather sticks, bits of old coffins and old wooden crosses to burn (NFC Banagher 005, 1937)

A wall was built across the graveyard. This wall was built of headstones. (NFC Moylough 826-27, 1937)

FIGURE 10: STONE MARKER, VENTRY, CO KERRY (Ó'DANACHAIR, 1947)

FIGURE 9: VENTRY GRAVEYARD, KERRY (Ó'DANACHAIR, 1947)

The images above show grave markers in a Kerry graveyard in the mid-1940s – Fig 9 shows a rough stone used as a grave marker, Fig 10 shows a graveyard with few visible carved headstones, suggesting that this type of grave marker was less common at the time, in rural areas.

Graveyards, as the realm of the dead, were treated with suspicion and grave visitation was not a common practice in Ireland, though if attending a funeral, families did pay homage to their dead

It is not thought to be right to enter a churchyard save at the time of a funeral, therefore people do not walk there, or even go to visit the graves of their relatives. (Bergen 1895)

On reaching the burial place the mourners disperse, to pray at their own relatives' graves. (Westropp 1923)

It was not considered "lucky" to visit a grave except on occasions of funerals. A person visiting a grave with the sole intention of praying for the dead was not acting in accordance with the wisdom of the best authority and was believed to be inviting misfortune to himself. (NFC Dungourney 307, 1937)

In some places by 1937, grave visiting was becoming more common

> On Sundays and Holy Days the people flock to their friends graves and pray for their souls. (NFC Knocknagree 423, 1937)

In part, the reluctance to visit graves was consistent with a fear of the dead, but at a practical level, graveyards were dangerous, with uneven ground (see Fig 10 above). They were visually unappealing, with sometimes noxious odours; coffins were exposed, due to overcrowding, or the lack of earth deep enough for burial; and sometimes animals dug up human remains (NFC Faugher 110, 1937; *Drogheda Independent*, 1892). Nicholson (1847) notes the rocky ground in Connemara meant the graves of the respectable dead were barely put in the ground, instead rocks were built up around them and cemented into place. The graves of the poor however, lacked this permanency, a cluster of rocks and sods being barely placed over the body, this is reflected in the NFC:

> There is a graveyard… [where] infants buried in it long ago belonging to the Morgans. There are a lot of trees growing around it and there are a lot of heaps of stones in it where the infants are buried (NFC Inagh 112, 1937)

The photos below show this practice and changes in graveyard maintenance since. Fig 11 shows the original burial ground in Newport and the scattered stones making a visit precarious. The second photograph of Newport shows the subsequent modernisation of the graveyard (Fig 12).[156] Fig 13 of Louisburgh, shows the baby burial area to the right, with visible grave mounds and some grave markers. To the left, the graves are built up; this is the newer section. Fig 14 shows how the graves in Derrynane are stacked inside an abandoned church coming down a hill. The final images of Ventry graveyard, Fig 15 and Fig 16, date to 1947 and show visible grave mounds, heaped stones, barely discernible metal crosses jutting out of the ground, and uneven ground. There are also no paths in these graveyards. Though rural graveyards remained in a natural state of disarray, Mooney (1888) does note a change in custom between rural and urban areas, where new ideas about funerary customs are taking hold

[156] The possibility arises that additional headstones or grave markers were tossed into the raised area during the remodelling of the graveyard

It is accounted a sacrilege to disturb or pluck up any plants growing in a churchyard, and as a consequence the cemeteries are overgrown with grass and weeds, excepting in the cities, where modern ideas are bringing about a change. (p.290)

FIGURE 11: KILLEEN CEMETERY, NEAR CARROWSALLAGH BRIDGE, NEWPORT, CO MAYO (ASHBY 2014)

FIGURE 12: KILLEEN CEMETERY, NEAR CARROWSALLAGH BRIDGE, NEWPORT, CO MAYO (CASHMAN 2017)

FIGURE 13: KILLEEN CEMETERY, LOUISBURGH, CO MAYO © AUTHOR

FIGURE 14: ABBEY ISLAND, CAHERDANIEL, KERRY © AUTHOR

FIGURE 15: : VENTRY GRAVEYARD, CO KERRY (Ó'DANACHAIR, 1947)

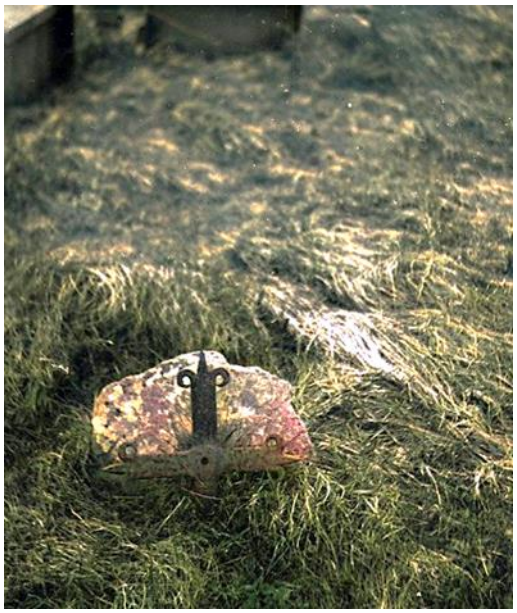


FIGURE 16: METAL CROSS, VENTRY, KERRY (Ó'DANACHAIR, 1947)

8.6 Chapter Discussion

This chapter briefly outlined the macro factors that influence the formation of two distinct forms of Irish mortuary ritual. This included a consumerist Victorian funeral, which required a certain income level, meaning these customs are linked to social class. Irish traditions, reflecting poverty, were far simpler, and according to Victorian contemporaries, more authentic in their expressive grief.

The prolonged failure to eliminate traditional mortuary customs points to the weak power of the clergy up to the mid-nineteenth century – it takes almost 300 years to alter wake customs – and this is suggestive of an ambivalent engagement with clerical authority, consistent with Kennedy's (2001, p.152) assertion that nineteenth century Irish Catholics were not "prisoners of their church". With a concerted effort to solve overcrowded burial grounds in the nineteenth and into the mid-twentieth century, and the expansion of Catholic church building, Catholicism strengthened, but its application to mortuary ritual remained second to tradition well into the twentieth century.

At the turn of the twentieth century, increased population surveillance also played a part in mortuary customs. This included notification of births legislation to control infanticide, changes to death certification, midwifery registration, and new canon laws which were more explicit and uniform. The high rate of mortality disproportionately affected those with the fewest resources, meaning the poor had the greater economic burden in ensuring an appropriate funeral. Impoverished families suffered frequent child and infant deaths, and in the context of burial this posed a significant financial burden, as noted by Murdoch (2015) amongst Irish immigrants in the UK. Consequently, this means impoverished funerals often lacked the material goods that make middle class funerals noticeable in the historic record. Given the volume and thus frequency of deaths in poor families, this also means that impoverished funerary ritual was by far the most common - just not the most visible.

Evaluating the historical evidence illustrates that the period from 1870 to 1920 is when social customs coalesce for the greater population. This is a result of increased population surveillance (through civil registration and death registration) and formalisation of death (reliance on medics to provide certificates for burial; clerical consolidation of rituals and fees; consolidated canon laws, expanded church building; laws pertaining to public health and cemetery management). Combined with the spending power of a new Catholic middle-class consumer, an intertwining of Victorian custom and Irish tradition occurred. This gives rise to the characteristics most Irish

people today would consider to be the ‘traditional’ Irish funeral – a wake, removals to the church, a funeral mass, procession to graveyard following mass accompanied by clergy, and a large group of mourners even at the graveside.

8.6.1 Socioreligious Dimensions of Ritual

Socioreligious elements of death are complex, with Anglicanism being as influential as Catholicism in Irish culture. Anglicans and Catholics held similar attitudes towards the burial of the unbaptised, despite different attitudes towards limbo. Nonetheless, the application of canon laws by both religions was variable and subject to local interpretation. The numerous nineteenth century refusals of infant burial by Anglicans contradicts McKerr *et al.’s* (2009) assertion that the absence of limbo resulted in an ambivalent response by the Anglican Church to baptism and those buried in the Protestant faith. In fact, baptism was equally if not more contentious for Anglicans, then for Catholics, at that time. The revisions in the Catholic Codex between 1926 and 1957, make clear that baptism was to be applied conditionally regardless of the condition of the foetus. This echoes Maltese clerics late nineteenth century baptismal policies (Savona-Ventura 1995). Further, such explicit instruction indicates an unbaptised child would be a rarity, as Cherryson *et al*. (2012) hypothesise. This analysis strongly suggests clerics interpreted the canon laws as fit within their own pastoral realm, and that individual clerics had discretionary powers, as noted in the 1917 Codex. This means there can be no certainty regarding perinatal baptism, or that clerics universally insisted on segregated or exclusionary burials for the unbaptised. This is strengthened by the evidence which shows unbaptised and stillborn infants are buried in family graves in consecrated burial grounds.

The introduction of a unified Codex for Catholicism at the start of the twentieth century brought theological arguments embedded in American cultural values to Ireland, alongside pre-existing Anglican policies rooted in Victorian England. Anglicanism as with Catholicism, had no funeral rites for babies, and canon law pertaining to baptism and burial was subject to individual clerical interpretation. Both Anglican and Catholic religions introduced special ceremonies for burial of babies in the latter decades of the twentieth century. This aligns with an increase in expressive grieving as a consequence of countercultural social change, as noted by Jalland (2013) and consequently, clinical recommendations for formal funerals for babies as advocated for from the 1960s.

8.6.2 Bureaucracy of Death

The evidence above supports the assertion that hospital disposals are rooted in long-standing bureaucratic responses to death, which reflect Victorian attitudes to poverty, immorality, and fiscal management. This permeated the hospital system, reflected in inupta patients either being refused entry to certain facilities, or being sent to county homes (former workhouses).

Institutional death and burial was a contrast to the consumerist rituals common to middle and upper classes. Institutional death meant institutional burial – if the body was not donated for dissection, it was brought for burial to an institutional plot without the benefit of religious rites, rituals, or mourners (though, as noted in the Famine era example above, a child was buried without clothing or coffin). Institutions had an ambiguous relationship with clergy. Though chaplains may have been assigned to institutions, the degree of their engagement was contingent on their contract. Clerical presence at the Catholic graveside was not typical at this time, especially for impoverished funerals, even if outside the institution. Hall's (1926) plea for religious rites implies that by the 1920s clerical presence became a criterion for an 'acceptable' funeral, even for the impoverished person. The most important aspect of this analysis is it confirms that it was the institution that set the policy for institutional disposal and this applied regardless of whether the deceased was an adult or a baby. This means that in the context of disenfranchisement, that such disenfranchisement occurred *because of the institution* – not the religion, age of the person, or their perceived legal personhood.

The data here does not permit dating of the practice but until the late-twentieth century, midwives in hospitals were still baptising babies and placing them in strangers coffins ostensibly to ensure a 'proper burial' and avoid the cost of a funeral. Unfortunately, Bowers (2000b) provides no additional data, however, these burials refer to Glasnevin Cemetery which was consecrated. Whilst this hospital practice may be indicative of a latent folk belief regarding the unbaptised, a concern regarding burial in unconsecrated ground, a compassion led intervention, or simply an excuse in the face of criticism, without additional investigation, all this is only speculation. However, it does suggest that whatever burial practices were occurring in hospitals, in general, were perceived to be inadequate by the social standards of the time, and this action would compensate in some way. From the examples above, it is confirmed that burial of babies did occur for babies over 28 weeks gestation, a continuation of a practice in place in Dublin

maternity hospitals from the early nineteenth century. The pathway for remains under 28 weeks is less certain.

8.6.3 The Decline of Tradition

Prior (1989, p.169) in studying Irish mortuary rituals is mistaken in saying nineteenth century Irish funerals were primarily religious and secondarily social. The evidence here reveals that religion is peripheral and social dimensions take precedence, though the balance alters as the twentieth century progresses.

Typically, home was the place of death, and home was where the body was cared for. The wake at the start of nineteenth century differed little among the social classes and formed the backbone of Irish mortuary ritual, consistent with Lysaght's (2009; 2003) research. Lysaght (2003) links the decline in wakes to the introduction of a new code of canon law in 1917. Writing 30 years prior to its introduction, however, Mooney (1888) had already written of the demise of the wake. Though the form of the wake altered over the course of the nineteenth and twentieth century, it still remained a key feature of mortuary custom. The wake afforded a collective response by the community, this had practical as well as social and emotional benefits. Wakes offered an opportunity for commiseration – men and women were both emotionally expressive but this alters with a move towards church based funerals.

Impoverished Irish Catholics developed alternative sacramental practices, substituting lay customs for formal religion – these included saying the rosary at the wake, and the De Profundis at the graveside. From the late nineteenth century, a change in traditional ritual is observed, with the new custom of bringing the dead to the church overnight prior to burial (the 'removal'). This custom is described as lacking emotional warmth by Lynd (1909), but by the 1930s is viewed more favourably, even if at this stage it is not universal. This suggests that the formality of church funerals resulted in repressive emotions and that the display of grief expected at traditional funerals was unwelcome. An important feature of church based funerals is that they rely on formal time – the funeral mass being at an appointed time, followed by burial. In traditional funerals, when the grave was ready, and the family was ready, the mourners set off for the graveyard, thus the bereaved families retained control over the body and time of burial.

Whilst socio-religious dimensions of mortuary ritual remain important, it is the contention in this thesis that poverty rather than religion was the defining aspect of mortuary ritual in general, and in perinatal mortuary ritual specifically. Due to the

absence of formal rites, folk alternatives included intercessionary activities and lay baptism. Babies could remain unbaptised through childhood, due to accessibility issues, either cost, distance, or social class. Mortuary rituals for the young differed from those for adults. This ceremonial difference reflected the deep sorrow at the deaths of young people and children – keening was absent, wakes were sombre, and a semblance of grave decoration was performed in some cases. Mothers did not attend the funerals of first-born children of any age, though in general, women did attend funerals and burials, however, this was contingent on social class.

With regard to baptism and burial, as noted above stillborn babies were recorded on burial registers, though bereft of a first name. Register entries are comparable to those for other deaths and not merely margin notations as has been suggested (Nuzum & O'Donoghue 2021). If baptism was the deciding criteria for burial, then Anglican and Catholic babies would have been buried together in unconsecrated plots, as neither of them had yet to join their faith based communities, but this is not reflected in cemeteries. Instead, babies are buried in family graves, or in graves shared with other adults, meaning they are buried according to their family's faith, and in consecrated ground. Thereby, the presence or absence of baptism does not appear to be a defining feature in the context of burial practices.

As with class based differences in funeral customs, burial practices differed between Dublin (urban) and rural areas, Dublin was more compliant with registration and legislative conditions for both birth and death. Rural areas offered more flexibility with regard to burial. Burial sites are complex and there is no clarity as to what actually constitutes a cillín. What can be confirmed is *cillíní* were central in communities and widely used for all forms of burial, their use and meaning changing over time. Their persistence has been attributed to socio-religious features but this belies a more complicated dynamic, outside scope for this thesis. *Cillín* use circumvented the bureaucracy of death, avoided fees connected with registration, charges for burial certificates, clerical fees, or burial charges, as Henderson (2014) posited. There was no requirement to use any specific type of coffin. Most importantly, continued use of *cillín* burials hid poverty under the guise of tradition, particularly, in an era where impoverishment was considered shameful.

8.6.4 Remembrance in Irish Traditions

Grave visitation was not a feature of traditional mortuary ritual due to both a fear of the dead (Bergen 1895), and the physical state of graveyards. The popularity of grave

visiting appears to have increased from the 1930s. Grave decorations for the youth included paper garlands. Grave marking is complex. In rural locations, grave markers which utilised natural materials, could be removed for firewood or building. This suggests that graves were not always unmarked, as Ó Súilleabháin (1939) identified. Further, the absence of registers and headstones for *cillín* burials does not mean anonymity, the people buried here were known to their communities. This knowledge is restricted to time and place, and means they remain unknowable in the context of contemporary records, and thereby scholars should exercise caution when making claims of anonymity. Alternatives to religious rites included the use of memorial stones and intercessionary prayers – these were visible in the landscape as cairns or stone heap memorials. Other forms of remembrance were religious, with remembrance masses one month and one year after death.

8.6.5 Influence of Rituals

The slow pace of change with regard to funeral rituals means they are threads to our cultural heritage (Irion 1991; Hoy 2021) offering us ways back into the past. Just as the living and the dead constitute the social world in Africa (Lee & Vaughan 2008), so too is this the case in Ireland meaning continuing bonds has long existed in Irish culture. A connection to the dead was culturally established, with a belief that the dead could offer protection to the living, and the facility to continue contact after death was accepted as normal. Continuing bonds are reflected both in the strong belief of the ability to commune with the dead, and familial burials.

Importantly, Irish culture is demonstratively different in its approach to death than other Anglophone cultures, maintaining a collectivist rather than individualist approach to funerals. This is perhaps nowhere more evident than the reliance on the Irish wake as the mainstay of Irish mortuary ritual, the funeral taking lesser precedence (Lysaght 2003; Lysaght 2009). Westropp (1923) surmises that attending a funeral is an act of civility and sympathy rather than intrusion – and this supposition fits well within traditional, collectivist responses to death – ‘mourners’ at Irish funerals are not always grievers, and are there to affirm a measure of respect.

Expressive grieving is recorded in formal funeral traditions, this occurs in the form of keening, typically conducted by women, but with examples of men also taking part in the lament and grief being expressed when viewing the body at the wake. Lynd (1909) describes rural Ulster funerals as having an air of stoic resignation, and grim fatalism. This appears to characterise the deaths of the young, mortuary traditions being more

subdued when a young person or child dies. This is qualified as being due to the great sorrow attached to the deaths of the young. As demonstrated above, with the move to church based funerals, public grief became more restrained, and social class dictated how people mourned. Overall, what this chapter shows is that disenfranchised grief did not occur within impoverished communities, it only became problematic when engaging with the bureaucracy of state. Middle class funeral customs followed bureaucracy more closely and gradual adoption of these customs displaced traditional beliefs and practices. Continuing bonds has a long cultural history in Ireland, communing with the dead was normative. Though certain rituals allowed for this bond to be expressed, whether formally through religious rites, or informally through folk alternatives, this social belief in Ireland remained consistent, predating the theorising of late twentieth century scholarship.

9 The Limbo of Forgotten Things: Perinatal Death

9.1 Introduction

As the social history of perinatal death and burial has made its way into a national dialogue regarding bereavement care, this chapter explores traditional Irish perinatal mortuary rituals for the early to mid-twentieth century, to determine what people did and what differences may exist between normative adult and perinatal funerals. In this chapter, everyday life sources were sought, resulting in a fragmented dataset. The primary data source sampled was the National Folklore Collection (NFC), chosen as it provides a rich source of sociological data on (mainly rural) Irish life from and before the late 1930s. This is invaluable as both a sociological and historical source of social practice relating to death and burial of the perinatal infant, being generated prior to the use of maternity hospitals as the dominant place of birth. This data is supplemented and triangulated with data drawn from newspapers, reports, and other eyewitness and/or biographical accounts. The NFC database is rudimentary, being a simple keyword search there are no Boolean operators, MeSH terms or simile functions (see Table 14).[157]

TABLE 14: SIMPLE KEYWORD SEARCH OF THE NFC DATABASE

Stillbirth	0	Stillborn	2	Unbaptised	651	Unbaptized	191

These search results reflect the data collection format, which asked the question "where were unbaptised children buried?" (*Irish Folklore Commission* 1937, p.35).[158] As detailed in Chapter 4, Hiberno-English presents a peculiar challenge for Irish studies of death and burial, as literal translations into English may affect meaning and interpretation.[159] Southern Hiberno-English relies exclusively on Irish, even where Irish is long extinct it exerts unconscious influence on Irish-English speakers, in grammar, syntax and idiom (Bliss (1979) as cited by Filppula 1993). This affects how to search the database but also the meaning of search results, e.g. the Irish word *poll* means

[157] MeSH (Medical Subject Headings) aid searches in health databases
[158] In Irish, *leanbh gan baiste* is used, translating as 'child without baptism', meaning unbaptised
[159] Irish influences Hiberno-English through pronunciation, vocabulary, and idiom. Idiom, the most interesting and important feature, means that literal word for word translations from Irish to English may be incorrect and so there is a degree of interpretation to make it intelligible in English (Joyce 1910).

hole but also refers to a specific type of field, and this can mislead interpretation of data, as in the following sample

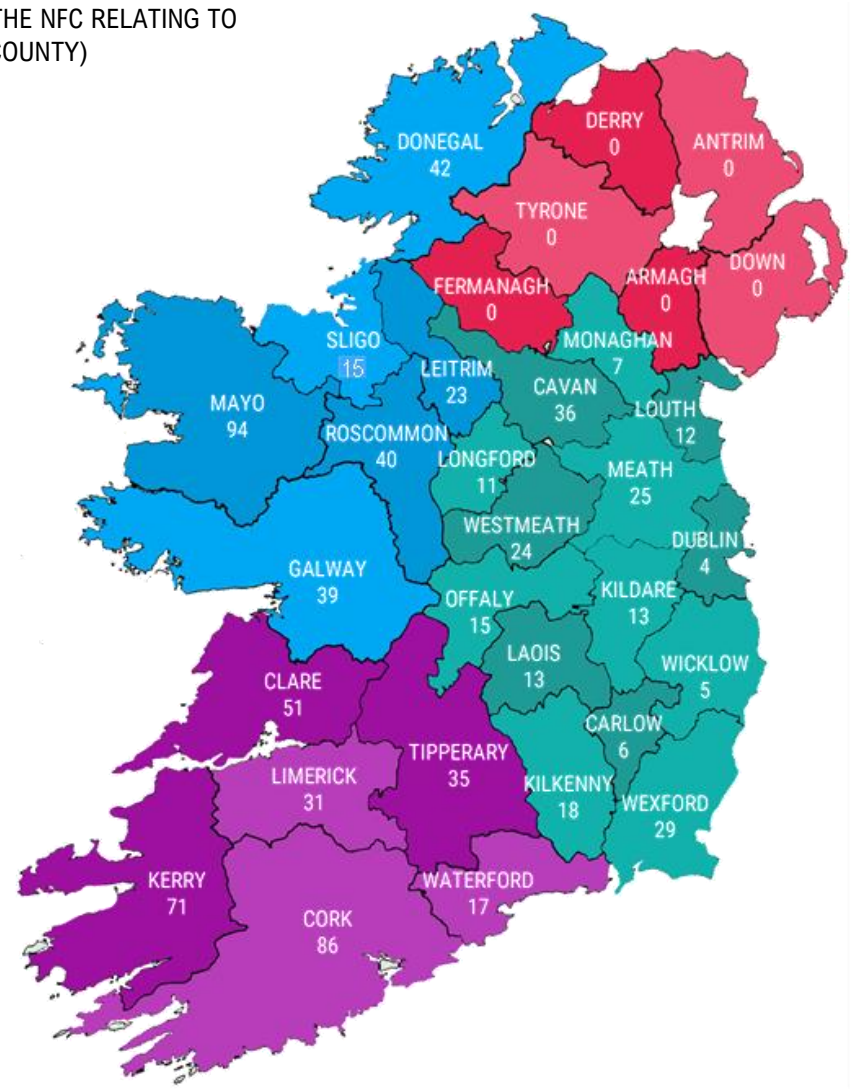
> There is a hole in the side of the road at the top of Bauravilla hill in the parish of Caheragh, Drimoleague, Co Cork where unbaptized people were buried. (NFC Drimoleague 196, 1937)

Replacing ‘hole’ with ‘field’, alters the meaning of this example, therefore, scholars using Irish sources, even if in English, should be aware that words can be mistranslated, and have literal as well as nuanced meaning. Through an iterative process of searching and analysing, over 1,200 entries were selected from the archive relating to birth and death. Entries referring to mythical tales were excluded, as were duplicates and Irish language entries. This left 762 entries relating to perinatal death, the geographic distribution of these entries is listed below for the Republic (Table 15 and graphically in Fig 17).

TABLE 15:
ENTRIES IN THE NFC RELATING TO PERINATAL DEATH (BY COUNTY)

						TOTAL	762
Antrim	*0*	*Down*	*0*	Leitrim	23	Roscommon	40
Armagh	*0*	Dublin	4	Limerick	31	Sligo	15
Carlow	6	*Fermanagh*	*0*	Longford	11	Tipperary	35
Cavan	36	Galway	39	Louth	12	*Tyrone*	*0*
Clare	51	Kerry	71	Mayo	94	Waterford	17
Cork	86	Kildare	13	Meath	25	Westmeath	24
Derry	*0*	Kilkenny	18	Monaghan	7	Wexford	29
Donegal	42	Laois	13	Offaly	15	Wicklow	5

FIGURE 17: ENTRIES IN THE NFC RELATING TO PERINATAL DEATH (BY COUNTY)



9.2 The Natural Place of Birth and Death

9.2.1 Birth at Home

Access to healthcare was curtailed by cost, and in rural areas, distance, weather, and lack of communication technology. On the Blasket Islands, for example, at the turn of the twentieth century, infant mortality was high, attributed to the inability of dispensary doctors to assist in difficult maternity cases due to bad weather (Matson 1996). Similar challenges regarding maternity care are noted for the nineteenth and twentieth century for remote parts of Ireland (Kuijt *et al.* 2021; Breathnach 2016; Breathnach 2018). Childbirth was precarious, and both qualified midwives and doctors were conspicuous by their absence

> the mother arrived and on her devolved all responsibility for her daughter's welfare. She had the ordering of the "Midwife". The midwife was an unqualified person but she was very 'Knowing'… There was no question of a doctor and when a doctor was summoned among

> the fairly well-to-do in those days people threw up their heads - there was no hope. Often, indeed, in serious cases the priest was summoned before the doctor. (NFC Knocknagree 396, 1937).

This meant a reliance on midwifery help that was locally available. Assistance during childbirth was constituted and rendered within communities through untrained midwives known as handywomen, and provided freely without "fee or reward by some kind neighbour" (NFC Dungourney 307, 1937). In part, the continued reliance on handywomen in rural communities is attributed to the fact that public health nurses, where available, were not indigenous to the communities in which they worked, despite the presence of trained midwives reducing maternal mortality (Breathnach 2018).

In urban communities, similar assistance is recorded for Westland Row tenements near Holles St maternity hospital, in the 1940s (St Andrews Heritage Project 1992) and in Belfast in the early twentieth century, "there was a handywoman in every area, most children were born at home" (Ferris *et al.* 1992, p.20).

> A lot of people had their babies at home, cheaper as far as I know. Midwives came to the house. Well I suppose it would cost ten bob for a midwife in hospital they had to pay her so much per day and they were kept a lot longer than now, they're out in two or three days now. One of mine was in hospital, nearly all gave birth at home, you might be lucky and have a neighbour who'd be a midwife. You don't necessarily have a midwife. I was at a few births, there was no need for a midwife, that's me neighbour that had ten kids. (St Andrews Heritage Project 1992)

> the district nurse had to be paid for, and the doctor as well…my mother said one birth she didn't think she'd get through it, and it was 7/6 for the doctor and she was thinking of the food for the next week, she kept saying to the nurse, don't get him yet because she didn't want to spend the food money… (Ferris *et al.* 1992)

These examples show a reliance on neighbours and friends who had already given birth, particularly in remote areas. More critically, it illustrates that despite the availability of clinical resources, decisions on seeking medical care were predicated on cost.

9.2.2 Death at Home

Though accessibility to medical services affected mortality so too did poverty, as detailed above. Poverty also affected mortuary rituals. Eyewitness accounts of mortuary rituals for perinatal deaths are rare, even for the twentieth century. One of

the most detailed accounts of traditional mortuary rituals for perinatal deaths in the late nineteenth century, is given in the infanticide trial of impoverished parents in Cavan (*Anglo Celt* 1894).[160] Following birth assisted by a midwife (meaning handywoman), the mother was "very weak", her baby son died two days later, surrounded by family. The grandmother cared for the baby as it was dying and administered lay baptism, then dressed the baby before coffining. It was considered "usual to have a wake on a child two days old" and the preparations were made of the "usual kind amongst the poor", and as was customary "all the neighbours came to sympathise with the family" (*Anglo Celt* 1894)

> … the child was waked in the ordinary way and on Tuesday morning a coffin was made and the child was put into it with care… [the men] left the house about nine or ten o'clock to bury it in Gubb graveyard, the family burying place', that is the ordinary time for infants' funerals

The baby was escorted by its father and a small group of men, to be buried in the consecrated part of the graveyard the day after its death. The coffin was made from a currant box,[161] was buried "four inches" deep, partly above ground and covered with sod, as close to the family plot as possible.[162]

This example illustrates that mortuary rituals for babies were social events, that lay baptism and baby wakes were still common by the end of the nineteenth century, that distance and impoverishment were factors in the context of material goods (in this case the coffin is made from a fruit box), and that there was a reliance on family at birth and death. This account details the normal time of burial as early morning, and that whilst neighbours gathered at the house to extend their condolences, the burial of babies was the realm of men – in this account, the father is accompanied by a small group of male relatives to the burial ground.

The wake continued to the be focus of perinatal mortuary ritual in the early twentieth century. This urban account provided by Bridie K living in the Dublin tenements at

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[160] The trial resulted in a not guilty verdict for the parents. It illustrates how suspicion was attached to the deaths of children, particularly those of impoverished parents, at this time. It is not clear in this account what prompted the investigation and arrest of the parents, though it is likely that the shallow burial of the fruit box coffin was a trigger. A similar makeshift coffin sparked a coroner inquiry in Donegal (*Donegal Democrat* 1927).

[161] In trial evidence, the distance to travel from the family home to town for supplies is given as the reason for the makeshift coffin. It is equally likely poverty was a factor and this reason is offered in order to add a layer of perceived respectability to the couple on trial. Additionally, the birth of the baby was not registered at the time of the death, as there had been no time to do so, the baby dying the morning of his formal baptism.

[162] The family refer to the overcrowding of the family burial ground and as a result the baby was buried in the "adjacent ground" (*Anglo Celt* 1894). This may also explain the shallow burial.

Foley St, in the 1930s and 1940s, demonstrates a comparable response between adult (as described in Chapter 8) and perinatal death, at this time.

> Now if a child died, ye know… you'd had to keep the child at home and the child would be reeked [laid] out on the table. There was a collection made then for to buy a little coffin, you wouldn't have the money yourself, the collection made to buy a coffin and the neighbours would do, they'd all help each other with a couple of coppers and the child then would be put into the coffin and it'd be there for two days and two nights but you never went to the church or anything, the priests wouldn't have young babies in the church. You weren't allowed into the church and whether they were baptised or not they weren't allowed in but the baby then had to be buried then after two days. And you'd be lucky if you got a relation belonging to you that you could bury the child in... my mother had a good bit of children that died, if she was alive today, she wouldn't know where they were buried. (Bridie K, 1990)

This example shows that babies were kept centrally in the home, being laid out on the kitchen table, for two days before burial, a practice consistent with rural customs recorded above, and by Ó Súilleabháin (1939). Financial contributions to the cost of burial were provided by neighbours, a confirmation of the 'altars' custom noted by Lynd (1909). This example verifies that baptism was not the defining feature in the exercise of religious mortuary rites, it was the young age of the child, rather than baptismal status that determined whether religious formality was applied in death. When considering this with the class based snobbery identified earlier, there remains the possibility that exclusion from formal religion reflects social class. A continued link with family represents both an emotional and practical element, reducing the cost of burial whilst retaining a familial connection in death. The last comment above, shows that women had recurrent child deaths, did not attend these burials, and the grave location remained unknown.

> Em well, there was fellas going round selling coal on horse and carts and if anyone wanted a little babbie buried there they'd take the longer way. They'd just put out the horse, the pony maybe, and they had the loan of a small yoke, ye know, a thing called a dray and he'd put cotton inside on the thing ye know and the little coffin up behind them… straight to the graveyard up to Glasnevin or wherever they were going, Mt Jerome but mostly Glasnevin and they'd be buried down in the paupers graves.[163]

> And they were brought at eight o'clock in the morning, you had to be buried before half past eight and sure it went on, or there was always someone, there was only a week that was

[163] Referring to Glasnevin Cemetery and Mt Jerome Cemetery in Dublin city

there, someone always died. There was often times there was two or three or four would be getting buried in the one week but no one went to the funerals because there was nothing, you just did a neighbour a good turn by bringing the child. And then you see it was arranged with Glasnevin that the people were very poor and they hadn't got the money to buy a grave or even a deposit so they knew the paupers grave was.[164] And they used to give them a little paper with the number of the grave they'd be going to because if they put them into a grave say that was two or three coffins, and maybe there wouldn't be no room, well they'd have to use the other side of it and that was brought down to the end of the cemetery to St Paul's ground and you'd have hundreds of children buried down there.[165] (Bridie K, 1990)

The final part of the story clearly outlines the mortuary ritual for impoverished families. It shows consistent and high levels of child mortality were a feature of everyday life at this time. The interaction in urban areas with civil and religious authorities to arrange burial reflected the realities and practicalities of impoverishment – there was a specified time and place of burial, there was no individual grave for the poor, there was no ceremonial farewell. In contrast, this story emphasises a reliance on, and responsiveness by, close community to ensure respectful burial - through the financial assistance of neighbours for a coffin, potentially through burial with family, and finally through the assistance of a kindly man with a cart who escorted the babies for burial at the start of his day's work. These are all non-verbal expressions of social solidarity.

9.3 Rural Burials

A rural *cillín* burial for a perinatal infant is recorded around the 1930s on the Blasket Islands, by visiting historian, Robin Flower (1945, p.85).

We were sitting in the King's kitchen one night… when the door opened and a man came rather wearily in.[166] At his entrance a complete silence fell on the company, and the King's son, getting up from the settle, went into the inner room and brought out a number of boxes of rough white deal. 'Will these do?' he asked. 'They will,' said the other, and taking the boxes turned on his heel and was gone without another word. For a few minutes a heavy silence hung over the company… It was not till the next morning that I understood the meaning of this scene. The day broke in rain… A little procession was coming from the top

[164] To secure a private or perpetuity grave, a deposit was paid, which would then continue to be paid off in instalments.
[165] St Paul's was an auxiliary cemetery for poor ground burials, opened in 1908 (Glasnevin Cemetery 2022), opposite the main Glasnevin Cemetery campus. It contains an estimated 3,900 burials, the majority of which are babies and toddlers from workhouses and asylums (Woods 2018)
[166] The king here referring to the Blasket Islands honorific title for the island community leader

> of the village, and from every house, as it passed, the men, women, and children came out to join it. The King's daughter… turning to me, said: 'It is the funeral. Will you come?
>
> A few words told me all. A new-born baby had died, and the father had come to us the night before for wood to make the coffin. He walked now at the head of the procession through the rain, with the little box that he had knocked together from that raw, unhallowed wood under his arm. We too went out and joined the company. It wound through the scattered houses of the village, always increasing; the men wearing their hats of felt, the women with their shawls drawn close about their heads, and all in a speechless trance of sorrow or respect.
>
> We turned into a little promontory of the cliff beyond the houses, and stopped in an unkempt space of dank, clinging grass, with stones scattered over it here and there. A man with a spade had dug a shallow grave, and there, amid the sobs of the women and the muttered prayers of the whole assembly, the father with a weary gesture laid away his child. The earth was shovelled back, closing with hardly a sound about the little box, a few prayers were said, and then we all turned listlessly away, leaving the lonely, unfledged soul to its eternity… It was now about eleven o'clock…

Though this account differs in the detail, it exhibits similar characteristics of those captured in the Dublin tenements. Birth and death occurred at home, the baby remaining with family till burial. Social solidarity manifests through the provision of wood for a coffin, an alternative to financial contributions for coffin purchase. This solidarity is expressed through the procession of the community to the graveside, whereas in Dublin, there was a wake. Finally, the *meitheal* assist in grave preparation, just as the coalman assisted his impoverished neighbours in Dublin – the details differ but the fundamentals are the same.

9.3.1 Baptism

9.3.1.1 Naming

In the NFC, baptism sometimes took place at home, where it was known as *baiste an úrlair* (baptism of the floor) (Kennedy 2021). Other times baptism took place in church with clergy.[167] The time between birth and baptism could be variable, sometimes the delay could be for years as in Rosmuc (*Irish Independent* 1914). Naming forms a feature of baptism (christening). In the account below, by simply speaking the name at home, the father christened his child. The second iteration offered shows lay baptism

[167] Clerical baptism could be solemn or conditional, if lay baptism had been applied at home, conditional baptism was performed otherwise solemn baptism was performed.

occurred at home, followed by conditional baptism a year later, again the name being uttered at home before going to the Church.

> Long ago when a child was going to be baptized the father used to say the name of the child in the house, and then the child would be Christened. Other people say that the child's foot used to be dipped in a bucket of water at home, and then the name was said. When the child was a year old they would bring him to the church and say the prayers over him. (NFC Clonmacnoise 138, 1937)

This account from Galway, indicates that lay baptism was well known and applied and, at least in this community, meant that it sufficed for burial in the ordinary graveyard.

> There is a burial place for unbaptised infants in a field called St. Patrick's well field. People living now have buried infants there but as explained to me the people are "better up" now and they all know how to give lay baptism so that every infant gets baptised and this graveyard was not used for about 50 years. (NFC Tiranascragh 269, 1937)

9.3.1.2 Soul Lights

Within Irish folklore, soul light legends are noted by O'Connor (2005).[168] These legends represent the spirits of dead children as lights, or soul lights, the brightness of which depends on their baptismal status (solemn, lay or unbaptised). Most often the unbaptised are faint lights, which upon baptism by a kindly young priest, get brighter and achieve eternal rest (O'Connor 2005). These legends differ slightly in their telling, in this example below, an ordinary person meets soul lights

> A man… saw three lights in front of him on the road… The first light was very bright and the second one not so bright and the third was like a little piece of a candle. Says the first light "I'm the soul of a child who got the baptism of the priest and I'm in heaven", Says the second one "I'm in heaven too but it was the nurse baptised me" Says the third light "I'm not baptised at all I'm wandering around because I didn't get baptism". The man went over to the other side of the road and took the full of his two hands of water and poured it on the light and he said the words. That light got as bright as the first one. (NFC Carrickbeg 52, 1937)

Through the nineteenth century, the concept of limbo was not widely believed, even by the most "unenlightened" peasants (O'Hanlon 1870, p.86). If the baptised (whether solemn or lay baptised) achieved entry to heaven and the unbaptised were condemned

[168] Visual representations of the unbaptised manifest as will-o-the-wisps, babies holding lighted candles, birds, angels, green grass, white flowers, flying creatures, fairies, pixies or other supernatural beings, falling stars or aerial lights and flames (O'Connor 2005)

to the perpetual darkness of limbo, then how and why were they appearing together in these legends? The general conclusion to be drawn is that these legends rather than implying the hopelessness of limbo, indicate a latent belief, that regardless of whether baptism was applied in life, there remained the possibility of reconciliation in the afterlife.

Soul light legends can further be read as reflecting the folk alternatives to formal sacraments identified earlier; the supernatural influence of a clerical sacrament is negated and substituted with the power of everyday life. The perceived hierarchy of baptism – the brightest soul baptised by clergy, the less bright by a nurse, and the faintest light of the unbaptised – is nullified by the stranger performing the baptismal ritual. In this example, when lay baptism is performed by the stranger, the unbaptised light gets as bright as the clerically baptised light, thus equating lay baptism with clerical baptism. This infers that lay baptism, even after death, was just as effective as solemn baptism in securing access to heaven. These soul light legends can thus be read as recognition of posthumous baptism i.e. baptism was possible after death. Though posthumous baptism for Catholics remains obscure, outside of these folk accounts there is one confirmed posthumous baptism registered for an Anglican baby in Wexford in 1885 (St Mary's Church 1885).

9.3.2 Preparing for Burial

9.3.2.1 Wake

Murdoch (2015) has confirmed that Irish immigrants in nineteenth century England waked their babies before burial, a practice that was ongoing in Ireland at the same time. Bridget M describes how when she was twelve years old, her first child was stillborn. Despite her young age and being unmarried, a wake and a funeral was held in her mother's house before the baby was buried in the local graveyard (*Leinster Express* 1846). Wakes for babies were still common by the end of the nineteenth century, as evidenced earlier (*Anglo Celt* 1894).

The amount of time between death and burial differs from place to place. In the Dublin tenements account above, there was a wake for two days and nights at home, and time of burial was restricted to morning (Bridie K 1990). In rural areas, by the 1930s babies were being buried either in the morning or evening, before or after the day's work.

> The unbaptized children were buried in the graveyard where the people were buried, they were brought in a box in the evening the time that the sun is setting. (NFC Rosmead & Cavestown 164, 1937)

> Long ago… those [unbaptised] babies were buried at day break before the sun rose. (NFC Kiltormer 332, 1937)

The account below differs little from the depictions of the Blasket Islands or Dublin tenements earlier, or what was typical for an adult funeral described by Mooney (1888). The baby was waked among its family, before being escorted for burial, accompanied by a large group of mourners.

> Recently a young baby died in the camp near Rathangan. The friends and relations came from far and near. The corpse was "waked" in the tent, candles were lit, and mourners sat around. Next day the remains were carried on a cart to Rathangan graveyard, the little coffin covered with blue cloth and all the camp men, women and children numbering about fifty marched two deep behind. It was an edifying sight. (NFC Bostoncommon 138, 1937)

9.3.2.2 Care of the Body

Though the preceding example notes the coffin being wrapped in blue, in general babies were wrapped in a white linen shroud, or as noted below, a christening robe (NFC Kilcommon 316, 1937; NFC Kiltormer 332, 1937) before burial.

> When a baby dies it is usual to wake it in its christening robe. (NFC Kilcullen 326, 1937)

Babies were not always coffined as the "*pistheorogues* [fairies] forbid the coffining of unbaptised children", for example, in Mayo (Rambler 1919). Even when coffined, a distinction was noted between 'makeshift' and 'proper' coffins

> They were not put in a coffin; but in a little box which was made for the purpose. (NFC Kiltormer 332, 1937)

> The people used to make a coffin of a box for them and bury them in the hagart (NFC Knockjames 13-14, 1937)

The use of fruit boxes as makeshift coffins was so common in impoverished Dublin that they were referred to as the 'parochial mahogany' (*Freeman's Journal* 1859); similar repurposing of boxes is noted elsewhere (*Anglo-Celt* 1894; *Donegal Democrat* 1927).

9.3.3 Infant burial in the NFC

Though *cillíní* are dated to the post-medieval period (Murphy 2011) given the difficulty in determining what exactly is meant by a *cillín* creates some ambiguity with regard to understanding the time period of their use. At the time of NFC data collection, *cillín* use for infant burials was still active in some localities in the 1930s, but this was a declining practice. Approximately two-thirds of the entries that refer to usage, confirm *cillín* burials had already ended, attributing the cessation of *cillín* use to the famine era (mid-nineteenth century). Some contributors identify precise dates when burials cease, others simply say 'long ago'

> There used to be children buried in the fort, this being the burial-place for Cloonfinish children up to about thirty-eight years ago, when it was arranged by the village people, to bury them in future in the graveyard (NFC Tumgesh 113, 1937)

Though a common belief is that clergy forbid the burial of unbaptised babies, there are many entries in the NFC that indicate clergy were instrumental in the abandonment of *cillíní* used for this practice, and encouraged the use of consecrated graveyards instead

> About forty years ago unbaptized children were buried there in a place called the "Cillíns" but the priests ordered the unbaptised children should be buried in consecrated ground. (NFC Athea 108, 1937)

> A fort is a place where young babies were buried long ago. The priests don't like to bury children there. They bring them to the graveyard. (NFC Rathcarran 350, 1937)

> Those graveyards are forbidden by the Priests in some parishes. The other graveyards were called "Lisheens". There were usually one or two in each parish. (NFC Kiltormer 332, 1937)

These, and the following accounts, also demonstrate that babies were buried in consecrated ground, and often with family, as customary for other deaths.

> There is not that I know of any special burial ground for unbaptised babies. They are, as a rule, buried in the ordinary graveyard. (NFC Kilcommon 316, 1937)

> Unbaptised children are buried in consecrated ground usually in the family graves. (NFC Glounthane 132, 1937)

> Unbaptised children were and are buried in the family plot. (NFC Curreeny 36, 1937)

> The children, who were not baptised were buried in the churchyard where their friends were buried before them. I never heard of them having any special graveyards. (NFC Tullaghanstown 242, 1937)

Cillín burials were not furtive and *cillíní* were not peripheral to communities, on the contrary, there was considerable knowledge about who owned the land they were on, where they were located, and who was buried in them. These accounts also emphasise that older children were buried in *cillíní*, the practice was not just restricted to babies.

> That field is still called the *Lisin*… Two infant brothers of John R, *Carnarlár* and one infant brother of Godfrey G, *Carnarlár* were buried there. There are stones over the graves. The field round it was ploughed but the *lisin* was never interfered with (NFC Ballindine 767, 1937)

> Long ago, the people used to bury baptised children up to two years or three years of age in a Kyle. The Hogans buried two in Vaughan's Kyle and the Shea's buried one in it and the Carthy's buried one also…. (NFC Knockjames 13-14, 1937)

Though parental perspectives are hard to capture in the NFC, this final example from Clare, indicates parental decision making regarding place of burial.

> They used to have very large families and when an infant would die without baptism the parents used to bury it in that dry spot [under hawthorn]. Father could hear for his memory the old men of the place talking about babies having been buried there and nobody could see the two little patches which are plainly graves. (NFC Knockerra 339, 1937)

9.4 Remembrance

9.4.1 Grave Markings & Decoration

Given that grave markers may have been removed due to other practicalities (e.g. for firewood) as noted in the previous chapter, this means that grave marking has some ambiguity attached to it, both in general, and more specifically for infants. In some instances, it appears that no grave markers were used, and in others, it is very clear that graves were marked

> There are no head-stones or crosses over the unbaptized children. (NFC Raphoe 184, 1937)

> There are no headstones in the children's burial grounds except crosses made of iron (NFC Moylough 826-27, 1937)

Grave marking appears in many forms, however, traditionally including the use of spikes, stones, and trees. Whitethorn are the most common grave trees and are known by a variety of names in Ireland.[169]

> In Rathronchion in our own parish there is also a rath and a little graveyard called the Dula bush where dead born children were buried. For each child buried a spike would be driven into the tree which was in it and that is how it got its name Duala (NFC Monastervin 53, 1937)[170]

> Unbaptised children were buried in "Kyles" with small stones marking the graves (NFC Lakyle 215, 1937)

> The graves are small mounds and are easily discernible, there are also stones on the graves… there are blackthorn bushes growing on the graves (NFC Ballindine 768, 1937)

> The graveyard is now all overgrown with bushes and was used for the burial place for unbaptised children. This is called *sgeach na nGearrlach* [whitethorn] (NFC Conahy 385, 1937)

> Children unbaptised are not buried in graveyards, they are buried under a lone tree [whitethorn] (NFC Dring 217, 1937)

These alternate forms of grave marking are indicative of a practical and economic way to mark graves, utilising materials that were freely available.

9.4.2 Commemoration

Whitethorn marked the place of burial but also fulfilled a memorial function, giving rise to the term monument bush. Monument bushes were, according to O'Hanlon (1870, pp.86–88), the burial place for "unbaptized children and abortions" and held in great veneration. The burial sites of unbaptised infants, rather than being hidden or shameful places, remained central in local communities and were incorporated into commemorative practices.

> Whenever a funeral cortege passed by these monument bushes it was customary for all the attendants to uncover their heads, while the De Profundis had been recited. Then the

[169] Whitethorns are also referred to as lone trees or lone bushes (if they appear as a singular tree), hawthorn, blackthorn, fairy trees or fairy bushes (Wood-Martin 1902), raggedy bushes, or wishing trees (Wilde & Wilde 1887), monument bushes (O'Hanlon 1870) as well as derivatives of *sgeach*

[170] This is an anglicised form of *dolaí báis* (dollabushes), translated as 'tributes to the dead' (Ó'Súilleabháin 1939)

> processionists continued their way with the corpse towards that graveyard chosen for interment (O'Hanlon 1870, p.87)

> At the top of the hill there is a place called "*Sceac na Croise*". Here unbaptized babies were buried and here when there used to be a funeral going to the old church in Ullard long ago, the people used to stop to rest and say the "De Profundis". (NFC Ullard 215, 1937)

In the above examples, the saying of the De Profundis was part of normative mortuary ritual that was adapted for child remembrance. As described, in the accounts below, the burial places of babies were considered sacred, and a slightly different practice emerged in other localities

> On the cross of Clongeen at a place known as Foley's pond, unbaptised children were buried and it is still regarded as a sacred spot, at local funerals the corpse is carried round this (NFC Clongeen 258, 1937)

In this final example, the very ancient practice of cairn memorials still lingered, with the throwing of a *leachta* or memorial stone as an intercession for the dead

> Unbaptised children were buried near crossroads, these graveyards were called "*Crisín na Leanbh*". There was one at the forge cross quite close to our school. Con B… told me that he remembers quite well throwing a stone on a little cairn there as he was going by. These graveyards are never used nowadays. (NFC Sillahertane 100, 1937)

9.4.3 Symbolic Communications

Returning to the soul light legends, these comprise after death communication between parent and child, not just between the living who can offer spiritual salvation to the dead infant through posthumous baptism. Some soul light legends link parents to their dead children, with the children returning to safeguard their parents eternal salvation, either by ensuring they receive last rites from a priest, are forgiven for transgressions, or to guide their parent to the afterlife. Most of these legends refer to mothers

> A woman was dying once, and they sent for the priest. As the priest was coming along, he met lights. One was behind and not as bright as the others It was said these were her dead children coming to meet her (NFC Curragh 363, 1937)

> There lived a man and a woman.. who had three sons when the boys were big they died. Their parents were very grieved after them. Later on the man was dying… the priest [following three lights] then told the woman it was her three children that brought him to the house. In this strange way the children's father was anointed (NFC Tawnaghmore 423, 1937)

> …the woman was anointed and the Priest stayed with her until morning but it was thought that the three lights were her three children who had come to bring her the Priest and to save her soul (NFC Coornagillah 268, 1937)

> a voice answered saying "I'm the soul of a child that died belonging to the woman that is dying tonight without being baptised and the three lights are the souls of children that died but they were baptised and we are coming tonight to see our mother"… the four lights went before the priest all the way to the house. The woman died that night also. (NFC Kilbride 12a, 1937)

This more unusual account of a soul light refers to a seven year old child and can equally be viewed as after death communication. In this version, the boy appears after his death to comfort his grieving mother. The child persuades his mother to stop crying, he appeals to her to show courage, and his gentle reproach works.[171]

> The boy was seven years old… very good and nice… and the mother loved him very much. One day he got sick and died. The mother used to be crying day and night after the little boy. Not long after his death he appeared one night in the place where he always used to be playing and while his mother wept he wept too… He appeared again one other night. He said he felt he was going to be laid in his coffin and a lot of flowers were to be put round his head. He sat down at the foot of his mother on the bed and he said to her "mother don't be crying." The mother got courage and dried her tears. The child appeared once again and he was holding a light in his hand. (NFC Burren 167, 1937)

9.5 Representations of Parental Grief

The first account of parent grief is provided in an autobiographical account of Blasket Island life, by Peig Sayers (1873 – 1958), who describes both her own and her mother's perinatal deaths.

> They [her parents] had three.. the sum total of the family that lived. After that, one after another, the children died, until in all, nine children were buried. My poor mother was troubled and distracted as a result of the death of her children. Day after day, her health and courage ebbed away until in the heel of the hunt the poor woman hadn't even the desire to live (Sayers 1974, p.14)

[171] Courage in Irish is from the word *misneach*, which embodies fortitude, encouragement, empathy, faith and hope (Dhuinn 2020)

Sayers (1974) also gives some insight into her own reproductive losses, she records how she had three babies die, followed by the death of her eight year old daughter

> I had buried my fourth child, and it was no wonder that I was troubled in my mind. I sat on the bank above the beach… dead indeed is the heart from which the balmy air of the sea cannot banish sorrow and grief. A sigh welled up from my heart and I said aloud… 'who could be troubled with so much beauty around'… a voice came from behind me… 'Isn't it time you were going home' [said Seán Eoghain].. I told him… to tell the truth I've no mind to do so. 'That's no wonder my poor woman, everyone feels lonely after a death of a child'. Not child Seán, I said, but children. (p.176)

Despite the common belief that grief was not spoken about, it is clear from the above account, this was not accurate – here, a neighbour acknowledges Sayers' grief and commiserates over the loneliness that parents feel when their children die, thus showing a familiarity with child death.

The Cavan trial described earlier, provides insights into parental distress following the death of a baby. Family members described to the court how "all appeared to be in grief when the child was dead, James [the father] was crying and trying to console his wife who had fainted" (*Anglo Celt* 1894). In this account, grandparents played a key role, the grandmother had attempted to revive the dying baby but when the child died, she tells the court his father

> appeared to be most anxious about it and lamented its death; I told him that many fathers lost their children before, we had not time to get the child baptised and I gave it a private baptism

A reflection on parental grief is detailed in a 1905 magazine (Oakleaf 1905), describing the grief of bereaved parents and illustrating the social recognition of loss which included silence and space to grieve.

> Those little graves spoke eloquently of the parents' love and grief. Very pitiful is, especially, the sorrow of a mother for her dead child. Her tears flow without measure, and it is well that she weeps. Tears relieve the burdened spirit, and after the first vehement burst of sorrow, they will flow with a quieter tide. It is scarcely a kindly act, though it may be done from kindly motives, to check a mother's tears with the plea that it is vain to weep. She knows well that tears cannot restore to her arms the little one she has lost, and that conviction is a chief cause of her sorrow. Let her weep on. Silence and sympathy are the best consolation one can give

There are fewer detailed accounts in the NFC but there are some examples of parental grief

> Mothers sometimes sleep on their son's grave (NFC Ballindine 766, 1937)

> Children who were unbaptized were buried only in lonely places. There is one story connected with it. It is said that a man had only one daughter and she died. This man was very heart-broken and he used to go to the graveyard every night to cry for his daughter to come back. (NFC Carrickard 376, 1937)

> There is a *Cillíneac* in Clonee, Tuosist, which is called "*Doirín a Cléibh*" where a certain *cailleach* [old woman] used *caoin* her eighteen stillborn babes. No babies are buried there for the last fifty years. (NFC Coornagillah 255, 1937)

The NFC records a public yet private space where parental grief is expressed, in the form of a dedicated 'weeping stone' in the section of graveyard assigned to child burials.

> In Chapelfinerty graveyard there is a weeping stone, which is in the cave. Long ago the unbaptised children were buried in a corner of the "Stone Park" [meaning the graveyard]. It is called the "Lisheen". There is a small stone placed over each grace. (NFC Fohanagh 137, 1937)

Collectively, these accounts demonstrate the prevalence of child loss, the depth of grief bereaved parents felt for their children and babies and the loneliness, sorrow and stoicism attached to parental grief, in the past.

9.6 Chapter Discussion

This chapter relied on data drawn from the NFC, supplemented with alternative sources, to determine what traditional mortuary rituals, if any, were used in Ireland prior to hospital as the primary place of birth.

9.6.1 Evidence of Social ritual

The accounts here illustrate that mortuary rituals for babies were similar to those for other deaths, even if the details differ slightly from place to place. This means that mortuary ritual for impoverished families of infants constituted lay baptism, a subdued wake, social acknowledgement either at the wake or funeral procession, material contributions, assistance with burial, and an absence of formal religious rites. This was considered the 'usual' or 'ordinary' funeral response for children. The biggest

discrepancy between impoverished urban and rural accounts here, is the urban necessity for formal documentation to enable burial – in rural communities this could be avoided by choosing *cillín* burial.

The baby was kept centrally in the home until burial. The interval between death and burial differs from one to two days. This time referred to as the wake, allowed for the making or purchase of a coffin and arranging for burial. There is some evidence that coffining in rural areas was not always practised, and makeshift coffins were common. In urban communities by the 1930s, two days was necessary in order to gather funds for the coffin, and then to arrange for burial in the cemetery, which required a certificate from a qualified informant to confirm birth, death, or stillbirth. Burial times differ in the accounts presented here – though evening burial is confirmed in the NFC, the eyewitness accounts all indicate morning burials as normal.

Regarding religious rites, it is clear that social class precluded impoverished families from formal sacraments, as discussed in the preceding chapter, and the same issues of class, cost and accessibility arise in this chapter. Formal baptism may not have been applied until children were much older, contingent on the distance from a church in rural areas. Baptism most frequently appears as lay baptism. This may have been given posthumously, according to folk accounts, with one clerical baptism appearing on an Anglican parish register.

Children whether baptised or unbaptised did not go to the Church for death rites. Whether baptism was performed, and regardless of who it was performed by, this does not appear to be the defining factor in burial practices. Given the prevalence of lay baptism, and when considering O'Hanlon's (1870) assertions that there was no widespread belief in limbo, as well as the prolific volume of soul light legends which speak to posthumous baptism, this casts significant doubt on the scholarship which maintains that baptismal status was the distinguishing feature in burial practices. The evidence here strongly indicates that this is not the case.

Though the NFC indicates segregated burial of the unbaptised in *cillíní* was still practised in certain localities, for the most part the use of these is attributed to the mid-nineteenth century or earlier, and the reasons offered for such practices remain vague. Segregated burials are not recorded as universal, and it is likely that there is some loss of traditional knowledge regarding their usage, wrought by the Famine – this is underscored by the conceptual ambiguity attached to the term *cillín* itself, as discussed in the preceding chapter. Further, as evidenced here, Catholic clergy intervened to

stop *cillín* burials, and this strengthens the supposition that neither the theology of limbo, nor baptismal status were determining factors in their use. Rather, clerical intervention to prevent burials in *cillín* would suggest an association with older, pagan practices as opined by early scholars recorded by Ó Súilleabháin (1939).

9.6.2 Significance of Social Ritual

The evidence here illustrates that the wake for babies amongst the poor was an opportunity for commiseration and that it differed little from that of an adult. The wake remains the primary mechanism for both social recognition of loss and a collective response to cost of burial. The procession from home to burial showed more variability and this appears to be due to distance to graveyard. Burial was, with or without procession, the realm of men. In Dublin, the baby was escorted to Glasnevin Cemetery by the coalman and parents were not at the burial, nor did they know specifically where their baby was buried. In the other examples here, fathers coffined their baby, then escorted their baby for burial in the company of other men, usually close friends, and family. It was these other men who dug the grave and buried the baby, rather than the father directly. As discussed in the preceding chapter, the digging of graves was a social activity, around which male camaraderie developed. Grave digging had two further effects. First, it was part of the socialisation of men into bereaved fatherhood. Digging the grave of someone else's child was preparation for the death of your own. Second, it lessened the direct impact on the bereaved father by insulating him from the finality and isolation of digging the grave and burying his child. This exchange of emotional labour had a bonding effect, that lasted a lifetime, as indicated by the recollections of old men. Mothers did not attend burials in either urban or rural settings. This reflects, as indicated above, the physical fragility of women after birth. It may also suggest that place of burial was not so important at this time – grave visiting in general was not commonplace until the mid-twentieth century.

9.6.3 Place of Birth Effect

In the accounts presented here, women's birth choices were affected by cost of, or distance to, professional services. Impoverishment affected women's decision-making regarding their care during birth, economic necessity taking precedence over a mother's own health needs. Even when clinical services were available, women opted for caregivers who were familiar to them, from within their own social networks, as Breathnach (2016) asserts.

Birth at home facilitated contact with the infant body. In the examples here, either the father or grandmother cared for the infant body, dressing, and then gently coffining the baby. The baby was kept centrally in the home until burial, which proceeded at a time that suited the family in rural areas. In urban areas, the cemetery dictated the time of burial. Whilst mothers were highly distressed at the deaths of their babies, there is no evidence that prolonged access to the infant body at home was detrimental to the mother – if this had been the case, it is likely a different social practice would have evolved.

Birth at home maintained social connections between parents and their extended social networks. Mothers were assisted during and after birth by family and caregivers known to them, and both parents were cared for similarly when tragedy occurred. In one example here, the reliance on the grandmother to provide practical and emotional support at time of birth and death was described – the grandmother caring for the baby until its death as the baby's mother was too weak following birth. When the baby died, the parents were distraught and the grandmother stepped into to comfort them – they did not bear their losses with stoic silence, rather there were intense emotions, and this was true for other parents.

9.6.4 Remembering

Grave decoration at time of death was not observed in the accounts presented in this chapter. Grave marking was noted and these were pragmatic based on the available resources, often gathered from the natural environment. Frequently simple stones were used to mark a grave though traditionally whitethorn was more common, particularly for children.

Normative mortuary ritual was adapted for child remembrance. Burial places of children remained central in local communities and were the focus of commemorative practice, through their incorporation into adult mortuary rituals. Thus, the burial sites of children take on a sacred role within communities. The use of *leachta* memorial stones was another mechanism for remembering child deaths, as was the weeping stone in the graveyard.

9.6.5 Connecting Grief and Ritual

Despite the common belief that grief was not spoken about, it is clear from the above accounts, this assertion is incorrect. As per the previous chapter, Irish mortuary traditions included a formal lament which were absent for young people and children.

In this chapter, informal expressions of grief were explored, with evidence that parents, even when experiencing high levels of reproductive loss, openly mourned, and grieved for their children.

At time of death, strong parental emotions are recorded, including anger and loneliness, similar to those found in contemporary parent accounts. What Sayers' (1974) account shows, like others presented here, is the frequent recurrence of perinatal deaths in the nineteenth and twentieth century, and how parents carried this grief through their lives. This is reflected in the Cavan trial, when the grandmother attempting to console the father, tells him many fathers grieve for their babies. It is also evident in the old woman keening her eighteen stillborn infants. Sayers notes how her mother never really 'got over' the deaths of her six babies. Sayers, too, is troubled by grief. These stories are clear about the lifelong emotional impact of reproductive loss.

When these accounts are considered against soul light legends, the lifelong bond is only strengthened. There are many such accounts that link parents to their dead children eternally, with children acting as spiritual guardians and ensuring that they join their parent in the afterlife. These legends constitute after death communication, and more specifically, reflect end of life visions. One such account was depicted in Chapter 6, and recorded in end of life care (Kerr *et al.* 2014; Kerr & Mardorossian 2020).

There was clear social acknowledgement of loss and parental distress by others. The reliance on grandparents to provide practical and emotional support at time of birth and death is noted, and this too is consistent with contemporary records. In her conversation with her neighbour, Sayers ensures her babies are included in the tally of child deaths and that they are not forgotten. Sayers' neighbour acknowledged her grief and commiserated over the loneliness that parents feel when their children die, thus showing a familiarity with child death.

In general, parental bereavement was not silenced, instead silence was offered as a space for expression of grief, and sympathy was tenderly extended, recognising that words offered little comfort. Moderation of parental grief is gently administered by the grandmother to the young, bereaved father, as she repeats how child death is frequent and so many others experience it. The only other example of admonishment comes from the soul light legend where the young boy chides his mother for crying, he is crying because she is. Instead he tries to describe a peaceful death and shows himself to be happy if only his mother would be, encouraging her to stop. Though there are

many examples of parental grief and distress, and parents maintain the memories of their children, what is historically observed is expressive grief, but one that is tempered. Given the prevalence of child and infant death, this makes sense, recurrent child loss and continuous expressive grief would overwhelm the social structures upon which communities relied.

The evidence as presented here, given the social advice, strong support, social and familial acknowledgement, normative mortuary ritual, and home based care, strongly indicates that disenfranchised grief, was not a factor for bereaved parents, in general at this time. *Social* disenfranchisement, however, is a clear product of poverty. Parents were unable to afford medical or religious services, or very frequently, material goods associated with death, which may have ultimately influenced decisions to prosecute parents for infanticide, as noted above.

Continuing bonds was a strong feature of bereaved parenthood. This is most visible in soul light legends which represent after death communications and a continued bond between parent and child which survives a lifetime. Continuing bonds are also reflected in the use of memorial stones and memorial practices for adult mortuary rituals. Therefore, continuing bonds are evident in both non-ritualised and ritualised ways in Irish traditions.

10 Integrated Discussion & Conclusions

10.1 Introduction

The present does not occur in a vacuum, it is a culmination of what went before. This study demonstrates how parents coped with what is popularly considered a 'hidden' grief in the past and generates new insights regarding mortuary rituals. The overall aim of the study was to understand more about the significance of Irish mortuary rituals in the context of perinatal deaths, and whether ritual had any discernible effect on two grief theories, disenfranchised grief, and continuing bonds. As Gerson (2017) reminds us, history is about 'getting the story straight', therefore the preceding chapters;

1. Presented data to establish what is meant by a normal Irish funeral
    a. Described Irish mortuary rituals for the nineteenth and twentieth century, to enable a comparison with perinatal deaths
    b. Discovered three dominant forms of mortuary ritual existed in Ireland through the nineteenth century
    c. Traced how these progressed and eventually intertwine in the early twentieth century
2. Examined the macro environment relating to Irish deaths
    a. Briefly illustrated how civil registration, church regulations, and hospital acknowledgment came to be understood as the barometers for social recognition of perinatal loss by the mid-twentieth century
    b. Established that religion had a peripheral, not a dominant role, in mortuary rituals
    c. Confirmed Irish mortuary traditions differed from those of other cultures, e.g. grave visitation was uncommon in Ireland to the mid-twentieth century
    d. Verified that the Irish social world was comprised of the living and the dead, and a strong cultural belief persists relating to after death communications
3. Provided evidence for perinatal mortuary rituals and
    a. Established that perinatal deaths did have mortuary rituals that persisted from the nineteenth and into the twentieth century
    b. Described these ritual responses according to place of birth (urban/rural location, social class, home/hospital)

c. Proposed baptism had multiple meanings and that lay baptism and posthumous baptism were widely practised
d. Established baptism did not determine place of burial, in general
e. Demonstrated that high and recurrent rates of reproductive loss were experienced by many families and that social class had an effect on mortality
f. Illustrated that impoverishment enabled the persistence of traditions which gradually diminish in the mid-twentieth century as overall poverty declined
g. Verified that parents, regardless of the time period or social class, felt intense distress when their babies died
h. Confirmed that parents felt ongoing sadness and sorrow over the deaths of their children and babies, even when they experienced numerous losses
i. Showed parents had a strong sense of after death communication with their babies. These are also represented in soul light legends which confirm parental preferences at end of life and reunite parents with their dead children in the afterlife

4. Compared adult and perinatal mortuary rituals and determined that
    a. Irish responses to death were collective and primarily social and these were broadly comparable for both adults and children
    b. Home birth and home death responded to adult and child deaths similarly though some differences were observed. The muted traditions relating to children are due to overwhelming sorrow
    c. Social class and urban location had an impact on mortuary customs but the basic framework was comparable
    d. Death and burial relied on the support of others, this social exchange of labour is known as the *meitheal*
    e. There was no difference in the institutional treatment of the dead body, whether adult or child, both were devoid of rituals and this practice persisted up until the 1980s for babies
    f. By the mid-twentieth century, remnants of tradition are still present as place of birth moves from home to hospital, confirmed in parent accounts provided. This manifests as fathers collecting their baby directly from hospitals, coffining and then burying their babies themselves without the assistance of professional undertakers

5. Outlined the development of psychological theories and how these culminated in the introduction of funeral as an intervention
    a. Emphasised that this intervention was introduced without any supporting evidence
    b. Showed the basis of this psychotherapeutic intervention rested on the concept of confronting the reality of death
    c. Revealed the intervention was rooted in white, English, Protestant middleclass interpretations of funeral convention
    d. Recognised the intervention conflated rituals for adults with rituals for children on the basis that social recognition would alleviate parental distress, which was believed to be short lived
    e. Demonstrated that psychological models and grief theories originate in Anglo-American cultures, are perpetuated in scholarship, and do not consider individual cultures
6. Illustrated the importance of sociocultural responses to death by examining a selection of cross-cultural responses to perinatal death and
    a. Demonstrated that regardless of religion or culture, in the sampled studies, the mortuary treatment of perinatal infants differed to those for adults
    b. Illustrated altered mortuary rituals applied to children under the age of eight which is relatively consistent in all places meaning religion is not the primary driver in perinatal mortuary customs
    c. Revealed parallels to Irish perinatal responses to perinatal death
    d. Identified global trends suggesting demographic changes influence mortuary customs

10.2 Reviewing the Findings

10.2.1 Institutional Death & Burial

In this study, adult and perinatal mortuary rituals were compared to identify areas of overlap. Three primary forms of mortuary ritual were identified in this historical analysis; hospital disposal, middle class consumerism, and Irish traditions (see Chapter 8 for details). The biggest difference in mortuary rituals was not between adult and child, or social class, but between hospital and non-hospital death. Institutional death meant institutional disposal, whether adult or infant it was devoid of all semblances of

social ritual.[172] The hospital pathway for the treatment of the perinatal infant body originated in nineteenth century institutional responses to poverty and was maintained through the twentieth century until the funeral reforms of the 1980s. This is a notable finding.

Hospital death and disposal contrasted strongly to deaths at home, with less disparity between social classes, than between institutions and home. Nineteenth century (predominantly Victorian) middle class mortuary trends were elaborate but for most Irish people, such luxuries were financially unattainable. Towards the end of the nineteenth century, a Catholic middle class developed and with it an increase in Victorian funeral consumerism. The reliance on consumerism means that middle class deaths remain more visible in the historical record; bereaved parents could afford newspaper birth announcements, memento mori photographs, the services of clergy if desired, headstones, and more elaborate funeral goods. Despite these additional trappings of wealth, the use of material goods should not be confused with depth of emotion. Regardless of social class, Irish mortuary traditions were similar until the mid-nineteenth century. Despite changes in the macro environment which influenced mortuary rituals, the Irish wake remained pivotal in mortuary customs (Lysaght 2009), preserving the collective orientation of Irish death customs. As the century progressed, changes in mortuary custom were more pronounced in urban areas which were subject to increased bureaucracy. Around the turn of the twentieth century, middle class Victorian era fashions mingle with Irish traditions, giving rise to what most Irish people today consider a normative or 'traditional' funeral – a wake, removals to the church, a funeral mass, procession to graveyard following mass accompanied by clergy, and a large group of mourners at the graveside. In rural areas these changes were slower to occur and even up to the late 1930s there is evidence of the continued use of the 'old ways' for old people. Ridge's (2009) analysis of death customs in Roscommon found that by the 1950s, there was nobody left to perform the old ways, and hence a reliance on professional services became part of normative practice by the mid-twentieth century. This coincides with place of birth moving to hospital.

10.2.2 Socio-Religious Dimensions

As discussed in Chapter 8, the role of religion is complicated in histories of death and burial. The civil laws in Ireland until the mid-nineteenth century meant that control of

[172] Institutional death in this context refers only to the evidence presented here, which relates to nineteenth century workhouses and asylums, and nineteenth and twentieth century hospitals - but not other residential institutions

churchyard burials fell under the authority of the Anglican church, and Catholics were not permitted to perform funeral rites for anyone. Sectarian influences continued to have an impact through the nineteenth century. As the century progressed, municipal cemeteries were opened which diluted the religious power over churchyard burials. The Catholic church was weak in Ireland until the mid-nineteenth century and the application of its canon laws were variable. It was uncommon to have a priest at funerals for ordinary Catholics, in many places this remained the case until the 1930s at least. The detailed evidence presented in Chapter 8 disputes Prior's (1989) argument that religion was the focal point of Irish funerals. On the contrary, Irish mortuary rituals were predominantly social and remained so. This finding is consistent with a cross cultural study of mourning by Rosenblatt *et al.* (1976) which argues Christianity had little effect on traditional death ceremonies and customs.

In the context of perinatal death and burial, the evidence presented here dispenses with the 'myths' regarding the socioreligious term of 'unbaptised'.

1. The term unbaptised has multiple meanings. It may refer to the unquickened soul, i.e. a foetus of less than five months gestation; stillborn infants of any gestation; babies, toddlers, or older children in receipt of lay baptism but not solemn baptism (due to accessibility issues); or those of an opposing faith. This may, in part, explain the differences observed in mortuary traditions.
2. Due to issues of accessibility, children could remain formally unbaptised for years and consequently, lay baptism was commonly practised.
3. Despite contemporary scholarship's obsession with the theology of limbo (Garattini 2007; Kennedy 2021), nineteenth century contemporaries confirm the concept was not widely believed in Ireland at the time.
4. Canon law of the twentieth century encompassed baptism of all forms of reproductive loss, whether miscarriage, stillborn or liveborn infant, meaning it allowed for posthumous baptism. These findings are consistent with the evidence of posthumous clerical baptisms of the stillborn in nineteenth century Malta (Savona-Ventura 1995), also noted here in Irish Anglican registers, and reflected in folk stories (see Chapter 9).
5. Soul light folk legends confirm that both lay and posthumous baptism could be applied. If lay baptism could be performed by anyone for anyone, then the likelihood of 'truly' unbaptised infants is very low. This supports a theory posited by Cherryson *et al.* (2012) based on their observation of few infant burials outside designated cemeteries in Britain, in the postmedieval period.

Collectively, baptismal status did not appear to influence the exercise of Irish mortuary rituals. Nor did baptismal status appear to determine place of burial, in general, though there are some examples of segregated burial which require further investigation. This finding strongly contradicts the scholarship in other Catholic countries which claims that baptism dictates place of burial (Peelen 2009; Bleyen 2010; Charrier & Clavandier 2019; Faro 2021).

10.2.3 Infant Burial

Walter (1996, p.21) refers to the "clinical lore of bereavement", i.e. the trickle-down effect from scholarship which has permeated everyday life . To borrow from Walter, there is also a 'cultural lore of burial', permeating Irish death and burial scholarship, specifically for infant burials, aided by media portrayals and incomplete scholarly exploration. As evidenced in Chapter 8, for example, stillborn infants were recorded in burial registers in a manner consistent with other deaths, they were not just 'margin notations' as suggested by Nuzum & O'Donoghue (2021). Babies may have had grave markers, often these were drawn from the natural environment e.g. whitethorn bushes, or grave markers may have been removed for alternative uses e.g. reusing headstones for buildings. In conjunction with the three forms of mortuary ritual identified for the nineteenth and twentieth century, three categories of burial grounds were also identified - churchyard, cemetery, and folk burial grounds (*cillíní*). This classification is an important one. Churchyards and cemeteries were subject to more bureaucracy and thus scrutiny. *Cillíní* as unregulated and unmonitored burial grounds, enabled the evasion of bureaucracy, omitting the need for registration or burial certificate. The authorities were well aware of the use of these burial grounds to circumvent bureaucracy through the nineteenth and into the twentieth century. By the early twentieth century, clergy were actively dissuading their use for the burial of babies. This contradicts the scholarship (Garattini 2007; Donnelly & Murphy 2008) and the popular belief about the clerical denial of burial in consecrated grounds.

The use of *cillíní* is attributed to socioreligious beliefs, predominantly as the term unbaptised is associated with their use. Attached to this is the belief that such burial grounds were unconsecrated (Dennehy 2016). The evidence here indicates this is inaccurate. As revealed here and confirmed by Ó Súilleabháin (1939), *cillín* usage was not restricted solely to the burial of the unbaptised, other parishioners were buried in them. For the most part, a *cillín* is simply a burial ground. These burial grounds may originate in formal graveyards (either churchyard or cemetery) or evolve into one. In either case, this casts doubt over the idea of these being unconsecrated. Further,

when considering that lay baptism was so common, and that limbo was not widely believed, the idea of *cillíní* as marginal sites reflecting a marginal afterlife (Finlay 2000; Dennehy 2016) is debatable. Second to this, is the issue of distance to burial site, in rural communities *cillín* were focal points in townlands and more easily accessible, whereas churchyards or cemeteries tended to be located in population centres.

Cillín use circumvented the bureaucracy of death, avoiding fees connected with registration, charges for medical certificates for burial, clerical fees, or burial charges. There was no requirement to use any specific type of coffin. This means that *cillíní* burials were more cost effective options for impoverished families, and this may explain their persistent use, in times of costly burial fees, high poverty, and high child mortality. Most importantly, continued use of *cillín* burials hid poverty under the guise of tradition, particularly, in an era where impoverishment was considered shameful. Considering the shame attached to pauper burial, as noted in Chapter 8, only reinforces this. Further, the continued used of *cillín* burials sites as a continuation of ancestral burial practices, or tradition, disguised impoverishment and allowed a sense of honour to remain intact. These findings have important implications for the scholarship and Irish cultural knowledge.

10.2.4 Irish Death Traditions

With regard to perinatal deaths, there were some differences between mortuary rituals for adults and children, though these retained the same basic structure i.e. a reliance on others (see Chapter 8 and 9). The persistence of Irish mortuary traditions can be attributed to poverty. Impoverished families suffered much higher rates of perinatal and child loss, and thus it is the funerals of the impoverished that create normative responses, hence the focus on poverty in this thesis. Unlike the scholarship which attributes absent or nominal rituals to the concept of incremental or non-personhood (Hertz 1960; Jolly 1976; Jackson 1977; Cecil 1996; Scheper-Hughes 1992; Peelen 2009; Shaw 2014), in Irish mortuary traditions, the reduced performance of rituals is attributed to the deep sorrow attached to child deaths. This is a major finding both for anthropological and psychological studies and strongly disputes the common belief that babies were considered non-persons.

Though commemorative activities including grave visiting and decorating were noted in this study, as the twentieth century progressed these have become more elaborate, a practice Flohr Sorensen (2011) has also noted. Graveyards were the place of the dead, they were dangerous and haphazard, and it was traditionally considered bad luck

to interfere with them. Therefore, grave visitation was not part of normal mortuary ritual in Ireland but increased as the twentieth century progressed. Grave marking and decoration were minimal and relied predominantly on the natural environment, and despite warnings against interference, grave markers such as headstones could be reused to fulfil other pragmatic functions e.g. wall building. What is observed in the contemporary data presented here is that parental responses to graves are variable. Not all parents decorated or visited graves, sometimes visiting graves was too painful and the responsibility for grave tending fell to grandparents. This is comparable to the psychological benefit observed in Irish burial traditions, where it is others – not the bereaved family – who dig the grave and perform the burial.

Other commemorative practices observed in Irish traditions included intercessions for the dead in the form of prayers, masses, the use of *leachta* memorial stones and monument bushes for babies. Not only did the use of monument bushes work as a grave marker which remained a visible reminder in the natural landscape, it also worked to preserve the memory of children through its central use in adult mortuary rituals. This is a unique perspective which has not been found in other contemporary rituals and forms a significant finding.

Adult mortuary rituals thus fulfilled several functions. Through the reliance on others for the disposal of the body, social bonds were reinforced, similar to Shimane's (2018) analysis of funerals. Additionally, they served as focal points for community commemoration of dead children, and thus there is a component of 'private visibility' enmeshed into the practice – these monument bushes thereby become shrines known only to the communities in which they exist. In this way, Irish traditions recognised the lifelong continuing bond of parent and child and presented a mechanism for this parental grief to be expressed in a communal way. This aspect of 'private visibility' is similar to the Mizuko-Kuyō rituals seen in Japan, where parents prefer anonymity and silent grieving in public, using *Jizō* statues as public markers of private grief (Smith 2013).

10.2.5 After Death Communications

Continuing Bonds recognises an ongoing relationship with the dead, however, this behaviour was once considered abnormal (Howarth 2007a). In the twentieth century, for example, though sensory experiences of the dead (with variable degrees of intensity) were noted in medical, counselling and psychological texts, the assumption

by psychologists had been that these experiences were imaginary (Bennett & Bennett 2000).

After Death Communication (ADC) includes sensory experiences of death. Sense of presence is the most commonly recorded ADC, and for those encountering them are associated with reduced adverse consequences common in the bereaved e.g. loneliness, sleep problems etc (Elsaesser *et al.* 2021). Over half the contributors in this study referenced sensory experiences of death, a figure consistent with Rees' (1971) study of ADC.

An unanticipated finding was that of end of life visions (ELVs).[173] For the dying, ELVs were also once written off as drug-induced hallucinations, but more recent research shows that ELVs are both very common and deeply meaningful to the dying (Barrett 1926; Kessler 2010; Kerr *et al.* 2014; Kerr & Mardorossian 2020). In this study, one contributor witnessed her mother's ELV (see Chapter 6). ELVs are very common in the folklore record, best represented in soul light tales, and thus the contemporary and folkloric accounts align.

That both the dying and the bereaved experience communication with the dead is now only forming the basis of scientific interest, but this is something that Irish culture has long recognised. In Ireland, a belief in ghosts was and is common, a feature shared in many other cultures as noted by Rosenblatt *et al.* (1976). Little attention has been given to this concept in psychological models, despite the near universality of this belief in other cultures which suggests this aspect of the grieving process is significant (Rosenblatt 2017). In Irish culture, the manifestation of ghosts occurs in ongoing contact with dead relatives and a belief in fairies. These beliefs are connected to social rituals, both in the reluctance to visit graveyards, the language used to describe death (Donnelly 1999; Magan 2020), and end of life visions. These can all be read as part of a continuum of continuing bonds which long pre-dates the development of the theory in the 1990s. The retelling of soul light legends depicts end of life visions observed in this study, and those noted by Kerr & Mardorossian (2020) in hospice care. The depictions confirm a lifelong connection between parent and child, one that sees them reunited in the afterlife. Whilst intense sorrow was recorded at time of death in the past, it may be that parental grief was assuaged with the belief that they would be reunited in the afterlife with their children. This cultural belief is a contrast to the finality of death

[173] End of life visions are also referred to as near-death awareness, deathbed phenomena, and death-related sensory experiences (Kessler 2010), death-bed visions (Barrett 1926), end of life experiences (ELEs) (Kerr *et al.* 2014) or pre-death experiences (Kerr & Mardorossian 2020)

expressed in other cultures, reflected in the dominant paradigm of early twentieth century scholarship.

10.3 The Relevance of Funerals

Hospitals disrupted mortuary rituals. Care pathways in hospitals were embedded in bureaucratic responses to death originating in nineteenth century institutions. By the mid-twentieth century, when hospitals become the primary place of birth and perinatal death, these pathways were deemed deficient and funerals as a psychotherapeutic intervention were introduced. This is particularly significant as Glaser & Strauss (1965, p.33) discovered that in hospitals where psychotherapy is practiced, patients collectively develop a "philosophy" of faith in the doctor. This means that what doctors say takes on additional importance.

Despite the expressed concerns of peers, who felt these recommendations were populist and lacked evidentiary rigour, these compassion led interventions (Harvey *et al.* 2008) were introduced without supporting evidence of their benefit. This reform occurs in tandem with the uncritical adoption of the activism of the burgeoning foetal personhood movement of the 1970s (Reagan 2003), and a return to Anglo-American expressive grieving (Jalland 2013; Walter 2000). Psychotherapeutic suggestions to confront reality through the use of funerals for babies of 28 weeks gestation or over, were eventually cemented into clinical guidelines in 1985 (RCOG 1985). These best practice guidelines were adopted in Ireland through the use of professional memberships and clinical textbooks.

The issue with the theory and recommendation of funeral as an intervention is that it oversteps from clinical biomedical practice into psychological 'treatment' and 'prescribes' private rites (Sanger 2012) and thus creates the *expectation* of universal rituals and universal emotional responses (Reagan 2003). Given at the time of introduction, it was assumed that grief lasted only a few weeks and could in essence be 'cured' through funeral rites, the zeal for this new approach may have seemed appropriate in the 1970s, and it was well intended. Yet there were clear and unintended consequences, which are evident today. In essence, it created a one size fits all biomedical policy which as argued here, and supported by Rosenblatt (2017), assumes culture has no significance. This means that the intervention treats funeral ritual as clinically 'agnostic' and easily deployed from hospital to hospital but it misses the diversity of experience and displaces culturally bound death 'ecosystems', which may offer protective benefits. Though there is a long standing policy of hospital

disposal, which removed all rituals dimensions of death, by implementing models which required adult like funerals, the policy sustained the creation of disenfranchised grief. It created a barometer for comparison, and it completely missed the impact of birth trauma which had been identified as problematic by 1980. As Cooper (1980) found, the legacy of birth experience far outlasted the grief attached to the deaths of babies. This is poorly reflected in the scholarship presently.

Families, as primary social support systems, may be left not just supporting someone who is bereaved but someone who is traumatised. Additionally, as perinatal death has declined, mothers and fathers may be left without any kinship or support system experience of perinatal death. In the past, when perinatal, infant and child deaths were high, most older people would have direct personal experience of loss and perhaps be in a position to better comfort the younger bereaved parents in their familial circles. This absence now results in higher and longer reliance on healthcare professionals to provide support once provided within communities and closer attention should be paid to macro demographic factors as Yamazaki (2010) has articulated.

Culturally, Ireland retained a collectivist response to death and as presented here, this is a contrast to the individualist approaches more common in Anglo-American cultures. Anglo-American influences have populated the psychological scholarship and clinical practice via published works, textbooks, and professional bodies, all of which overlook the cultural situatedness of mortuary ritual and bereavement – despite the recurrent observation that such cultural awareness is integral to scholarship and practice (Silverman *et al.* 2021; Rosenblatt 2017). The recommendation of funeral as an intervention was rooted in a specific social class and culture which came to define the appropriate standard of mortuary care in hospitals. This has persisted to the present day. Most perinatal deaths today occur in communities with high levels of mortality, and low resources. Psychological studies of these communities need to engage deeply with localised practices regarding death and the degree to which death traditions persist.

McCreight (2004) asserts that in Ireland, communities failed to develop and pass along appropriate rituals from generation to generation, which would validate perinatal death and provide coping strategies for bereaved parents. The evidence here proves this assertion is unfounded, and that rituals did exist though these are gradually displaced as birth moves to hospital in the mid-twentieth century. It is not clear why hospital disposals persisted for some families, nonetheless, the trend towards adult like funerals resurged following new clinical guidelines *(Royal College of Obstetricians and*

Gynaecologists 1985). These funerals lacked the same embedded social responses observed in early twentieth century rituals and differed in their expectation of religious rites. Despite parents in the 1990s rejecting religion, the data here shows that parents relied on church ceremonies for ritual power and there was an expectation for some that both rites and traditions were necessary for a 'proper' funeral. This may reflect secularisation in Irish society but it also demonstrates how, over the course of the twentieth century, Irish mortuary rituals evolved. Conducting funeral rituals did not appear to offer any significant emotional benefit, in general, for this group of 1990s parents, and in fact there appeared to be a higher rate of distress associated with the exercise of this newer form of ritual.

Parents exhibited emotional distress when their babies died – this is irrespective of place of birth, time period, or social class. Parental distress at time of birth can thus be considered a relatively standard response. Birth at home meant mothers retained more control over their birth experience, including choice of birth attendant, and control of their baby's body. Death proceeded at a pace that suited the family, this is also noted in contemporary accounts of home death (Murphy-Lawless 1998; Dybisz 2016). Home was also seen as preferable for stillbirth by Lewis (1979b) who believed that hospitals impeded healing after death. As presented in Chapter 7, the issue of control rather than ritual was more important in the context of disenfranchisement.

Whether present or absent at birth, men took on both a physical and emotional burden. This was not without distress. Fathers were eyewitnesses to death and burial, as with birth, they were the link between mother and child. Men were relied upon to take care of the baby in death, taking responsibility for the infant body post-birth. This responsibility differs a little in the detail. Up to the 1940s, birth occurred mainly at home and a description of mortuary response is detailed in Chapter 9. This is consistent with parent accounts describing perinatal death between the 1940s and 1960s, as birth moves to hospital. In these accounts, hospital disposal did not occur and remnants of tradition are observed. Fathers did not use professional undertakers but instead purchased a coffin, went to the hospital, collected their baby, dressed, and coffined it, and brought it home before burial. These fathers escorted their baby for burial, assisted by their own fathers, brothers and friends. It is these other men who dug the grave and buried the baby, in this way the same social bonds were reinforced. It may be, that men's reluctance to visit graves stems from this aspect of post death ritual. When fathers have to also provide emotional support to postnatally bereaved mothers, who may have been deeply traumatised by birth, quite apart from death, the

emotional toll for men could be substantial. Research focus tends to be on women's birth experiences but little research, if any, has focused on death ritual as a dimension of parent, or specifically paternal, experience.

From the above, it is inaccurate to say that early twentieth century perinatal death had no funerary ritual, or that parents were forbidden from mourning (Lang *et al.* 2011; Markin & Zilcha-Mano 2018). As found here, it is a hospital rather than cultural response which results in absent rituals. Disenfranchisement was more likely to occur within the hospital as hospital disposals limit social ritual and acknowledgement; it may be that in these author's cultures the research has not yet been conducted that shows rituals once existed, or which is more likely, there is reliance on ethnocentric scholarship. Charrier & Clavandier (2019), for example, surmised that Anglophone culture has shaped French mortuary traditions. Further, as the evidence here found, the absence of ritual did not prevent continuing bonds. Equally, clear is that mode of burial did not reflect the depth of parental emotion, a theme also noted in the scholarship (Orme 2001; Strange 2002; Howarth 2007b; Cannon & Cook 2015). This contradicts Prior's (1989) assertion that the cursory manner in which (unbaptised) stillborn infants are buried reflects the social antipathy towards them. Additionally, there is a distinction between what is parentally *expressed* versus what is *felt* and this may be culturally bound (e.g. within Muslim traditions (Shaw 2014)) – for some, feelings are simply private, there is no social coercion *to be* silent (Rosenblatt & Burns 1986). In Irish traditions, parental grief at time of death was observed and silence was seen as respectful not punitive. Reduced rituals reflected the sorrow attached to repeat perinatal mortality, and in communities where most people had this experience, it appears there was little to be gained from discussing it. This does not mean parental grief went unacknowledged or was of no consequence.

10.3.1 Protocols and Rituals

Outlining the historic development of perinatal death interventions, and the psych literature that informed midwifery practice, this thesis illustrates the convergence of a specific way of thinking about death which ignored culture. These findings illustrate that with high levels of reproductive mortality, parental distress remains constant across time, social class, and frequency of death. It is acknowledged that the grief attached to these losses was often described as lonely, inferring that this is an individual grief that only bereaved parents undertake. In a society, in which most if not all parents experienced reproductive loss, the features of this grieving experience were understood. In societies which now have lower incidences of perinatal loss, parents

may feel misunderstood and alienated. This in turn, as Yamazaki (2010) found, may increase the burden on healthcare professionals to provide emotional supports.

Over the twentieth century, an expectation of universal rituals and emotional responses emerged, creating a pregnancy loss or perinatal bereavement 'movement' (Reagan 2003; Kobler & Kavanaugh 2007). This social movement resulted in a reimagining of practice and a belief that rituals and memory making activities centred around death would enable parents move forward with their grief, transform their relationship with their baby and create new connections (Kobler & Kavanaugh 2007; Davidson 2020). This thesis traces how these idea translated into practice and how they impacted on parents.

Whilst this study looked at a broader interpretation of mortuary ritual, aligned around four categories (see Chapter 4), Steen (2015) examined 30 bereavement interventions used by Spanish and American midwives. Of these, baptism and funeral planning were favoured by American midwives e.g. 93% engaged with funeral planning in contrast to only 20% of Spanish midwives. This illustrates sociocultural interdependencies may determine the interventions favoured by midwives in any given country. It underscores why context and nuance are important and why midwives must engage deeply with the scholarship.

Though Steen (2015) is suggesting that midwives strive for better standards of care, it seems she favours aligning to American interventions and standards, which as discussed in this thesis, reflect a specific, individuated culture of death. Ritual, in the context of death, is a socially recognised set of behaviours imbued with ceremonial value and meaning, this is what gives ritual its' power (Cook & Walter 2005). Individualisation however, renders ritual power ineffective (Cook & Walter 2005) which is unfortunate in the context of tailoring midwifery practice to individual families. Kobler & Kavanaugh (2007), for example, maintain caregivers can transform hospital procedures into specific rituals. This adaptation should instead be read as part of the aesthetic value of nursing (Carper 1978), and person centred care (see further below), rather than ritual.

In the context of the findings here, it is important not to confuse ritual with protocols. Funerals are complicated, and funeral rituals do not possess magical healing qualities, despite the extensive reliance on them in the psychological and midwifery scholarship. For example, Tseng *et al.* (2018) assert that rituals after stillbirth allow women to recover from grief and hope for a subsequent pregnancy, though no evidence for this

conclusion was found in the data here. Additionally, whilst Kobler & Kavanaugh (2007) maintain rituals allow for the healthy expression of grief, often the presence of others may inhibit it (Goodall 2000). The 'failure of society' to recognise parental grief is attributed to the absence of funeral rituals (Cecil 1996; Kobler & Kavanaugh 2007; McCreight 2008; Markin & Zilcha-Mano 2018). Historical analysis here illustrates however, that social rituals existed and social solidarity was exhibited to bereaved parents. It was not 'society' that failed but hospital protocols rooted in institutional responses to poverty originating in the Victorian era. It is clear in this study that parents had strong emotional responses regardless of whether they had funerals or not. It is also clear that funerals took on different levels of meaning for parents – for some, it was a source of contention, leaving them feeling further isolated and excluded. Further, the 1990s parents who had the benefit of new hospital protocols, modern grief theory, normative type funeral rituals, parent supports and social solidarity collectively exhibited ongoing emotional distress, consistent with Hoy's (2021) assertions that neither ritual nor social acknowledgement necessarily relate to low levels of distress. As no long term study has been conducted on the impact of funeral as intervention and few studies exist that incorporate parents lifetime experiences, this would seem to be an imperative area of further interest for midwifery research as it constitutes such a large part of current practice.

In summary, the above illustrates that psychological models continue to overlook nuance and the many ways in which emotions may be expressed. It assumes that verbal expressions and ritual expression are vital to 'prove' mourning, a stance rejected here, and by Smørholm (2016) in Zambian studies of perinatal death. The study of perinatal grief and ritual has not attended well to the plasticity of grief, or the cultural expression of emotions which may vary greatly and are not necessarily indicative of failure to mourn or grieve. Further, as society has increasingly moved away from collectivist responses to death, people must seek help elsewhere. The consequence of this is an increased reliance on medical models of care, as O'Sullivan (2021) opines

> When societies lose a shared spirituality and a sense of community and family, people have to find new avenues of support. If a person lives in a community where the only caring institutions are medical ones, then medicalizing social and psychological distress makes perfect sense p.326

Whilst historically, given the high and recurrent mortality rates, this meant that parents were rarely alone in experiencing bereaved parenthood, as mortality rates have declined this means fewer people have this experience. Bereaved parents inhabit

another world and feel only other bereaved parents can truly understand them (Klass 2013). If this is true, then regardless of how perfect care pathways become, or how receptive or responsive society is towards baby loss, there will always remain a sense of parental disenfranchisement and it is this question that should lead researchers to reconsider current approaches to death – it may be that scholarship will find the answer in other cultures than the dominant Anglophone one.

10.4 Reflections on Methodology

10.4.1 Finding Meaning in Culture

Social constructionist research is interpretive and culturally situated, and this contrasts with much of the scholarship which is psychological and considers grief to be an inner and private process (Neimeyer *et al.* 2014). Other scholars have called for broadening interdisciplinary perspectives on death and grief by leaning into cultural heritage (Vidor 2015; Silverman *et al.* 2021; Littlemore & Turner 2019). This study showed how three different cultural responses to death emerged in the late nineteenth century (see above).

The primary driver in Irish death and burial customs is assumed to be Catholicism and a socioreligious lens has coloured the scholarship in this regard – omitting the larger impact of poverty. Connected to and influencing all of this is the Great Famine (1845-1852). Unlike the two world wars, which defined mortuary and mourning customs in Britain and America (Cannadine 1981; Jalland 2006), the Great Famine was Ireland's defining mass death event, displacing normative responses to death (Lawless 1912).[174] This mass death event washed away the richness of accumulated knowledge and custom leaving only remnants of our cultural past, and thus as Lawless (1912) surmises any Irish history of death, burial and bereavement must leave room for the possibility of what has been lost, survived or misremembered and direct comparisons with Western Europe or Anglophone cultures must attend to differences in the micro and macro environment. Taking up Ó Súilleabháin's (1939) appeal to explore child burial utilising the wealth of information within the National Folklore Collection, this thesis attempts to redress this imbalance.

In Ireland, nineteenth century expressive grieving was constrained through the adoption of Victorian fashions and a move to church based funerals in the early

[174] Ireland remained a neutral country during World War II and was somewhat insulated from the devastation of war in Europe

twentieth century. Expressive grieving emerges in the 1970s after a hiatus following the mass death events of two world wars and aligns with other significant macro changes which work together to create new ways of thinking and being in the world. Historical comparisons in the twentieth century thus require careful analysis and consideration. This is also true sociologically. The dominant framework of modernity is individualism versus the traditional model of collectivism. Grief is both an emotional and intellectual experience, the emphasis in scholarship since the 1970s has been on emotional dimensions of loss. Contemporary hospital protocols focus on *individual* emotions whereas traditional mortuary rituals and social attitudes benefit the collective – this leads to a form of 'culture clash'. Sociological studies of grief therefore must first consider the degree to which any society maintains modern or traditional approaches to death and bereavement. Consequently, it is important to bear in mind that burial practices do not always reflect the depth of parental emotion and that maternal resources and cultural stoicism shaped personal and social responses to burial and bereavement in the past, as noted in Chapters 6, 8 and 9.

Though Irish is not widely spoken in Ireland, as explained in Chapter 9 Hiberno-English expresses the idiom of our native language. This cultural nuance and expression of language can impact the analysis process and how knowledge is produced, yet it is "glossed over" in research (Borgstrom & Ellis 2017). Culture is important in the context of bereavement and trauma, as native language shapes the metaphors used to express and frame these concepts (Littlemore & Turner 2019). How words translate between languages are not minor matters as language is integral to sociocultural norms which literally make experiences (Hamilton et al. 2022). For example, Ó'Tuama (2021) reminds us that in the Irish language emotions are transient. In Irish, you do not say 'I am sad', instead you say 'sadness is on me' *(tá brón orm)* – the emotion does not define you but reflects a temporary state. Equally, Donnelly (1999) found in a study of home based end of life care, death was seen as sacred and natural, represented in the term *nadúrtha*, an Irish word encompassing holistic communion, empathy, and balance between creation and the Creator. Death was seen and accepted as a natural continuation of Irish life, it was simply a step into the spirit world; death was only a "slight movement" from one existence to another (Donnelly 1999, p.61). *Púcín*, is an Irish word meaning a supernatural cover that allows those from the spirit world appear unseen in this reality (Magan 2020). That these beliefs and words exist suggests a different way of thinking about death, and an afterlife, and by extension must influence the ways in which Irish people grieved. These latter concepts combined are an archaic cultural embrace of the scientific concepts of ELVs and ADCs described above.

Further, the folklore data analysed in this study drew from the category of 'true experience' rather than 'legends' (Degh 1972). Initially, I had relegated soul light stories to the category of interesting but irrelevant legends. On receipt of a contribution describing an ELV (Sibling, Monica, SB, 1945), the story was so familiar that I returned to examine soul light legends – and moved them to the category of true experience. This illustrates the benefit of using an iterative or constant comparative method, moving back and forth between data sources. It highlights how easy it is to discount data at face value, particularly remnants of the past as having no value to contemporary society or social research. The commonality of this story in the folkloric record, suggests that there is a higher frequency of ELVs than is currently recorded in contemporary research. This is the kind of detail, that biomedical and psych disciplines miss through the artificial separation of "mind and body, reason and emotion, nature and culture" (Mamo 1999, p.34) and hence our own cultural understanding of death and perinatal death.

10.4.2 Crossing the Chasm: Interdisciplinarity

At the start of this thesis, I referred to the enmeshed webs of meaning that the study of death presents, and hence why it is challenging to research. Most studies in health and social research tend to evaluate a fixed group of participants, against specified measures at specific points in time (see Chapter 2). The few bereavement studies that examine longer term impact of bereavement do not focus on ritual. The task was further complicated by the absence of work examining how normative responses to death change over time – this is history. As a novice historian, I was unprepared for the complicated, complex history of normative death. In fact, Cannadine (1981) in his study of British war mourning, emphasises that the history of death, grief, mourning, bereavement, funerals, and cemeteries are all distinct subjects, "at best complex, at worst obscure". And Cannadine did not even consider the politics and emotions of birth, or healthcare or how these topics whilst categorically separate are also inextricably linked. To ask what is or was the context of perinatal death or how did it impact on parents, is to leap into a vortex of ambiguity. To answer this means to know what the normative context of death is – a history that is curiously absent, particularly for Ireland. Does the wisdom for dealing with death lie in Victorian ritual as Gorer (1965) believed? Does the past offer any value or insight into death, grief, and mourning? These are not easy questions to answer, and so the learning curve was steep, and the research design was difficult because these are difficult questions. The difficulties are not limited to understanding, or creating a research design, or

negotiating disciplinary boundaries but extend to how we construct and present our work.

Interdisciplinary research can be defined in different ways as detailed in Chapter 3, often construed as disciplines working in parallel silos before integrating separate findings at the end of the project (Woodworth *et al.* 2022). Despite the theoretical benefits of interdisciplinary approaches which are viewed as transformational (Nissani 1997; Cann & Troyer 2017), in practice this is far more difficult to achieve in the context of doctoral research, for the following reasons.

- First, unlike in project teams, a single person i.e. the doctoral candidate, is responsible for executing the research process. This means in conducting interdisciplinary doctoral research, the workload is cumulative as each disciplinary strand must follow its distinct end to end process. Interdisciplinarity thus results in at least a doubling of work. For this reason, interdisciplinary research within the context of doctoral programmes should be carefully considered as it demands considerable investment of energy and time.
- Second, professional socialisation occurs in the context of disciplinary training, which trains researchers to speak a specific language, select analytical models, and specify methodologies which have developed within that discipline; these can be obstacles in interdisciplinary research (Pellmar & Eisenberg 2000). In this research as a social scientist, with both a supervisory and examining team comprised of historians and midwives, I often felt as if I spoke a language nobody understood. In part, this reflects the process of learning how other disciplines do the things they do, and the language they use to describe it, e.g. the constant comparative method is an iterative process used in history, though the term itself is not used. The flip side of this equation is it also makes it a difficult project to supervise and examine, for the same reasons. Therefore, for interdisciplinary research, it would be beneficial to have the doctoral candidate's discipline represented in either the supervisory and/or examining team. This should help to balance and integrate the various disciplinary skills and expectations e.g. assessing the degree to which faculty will accept deviation from its normal research frameworks or determining the best way to present specific data.
- The third difficulty is one of philosophy (see Chapter 3), which links to the above point regarding professional socialisation. Professional socialisation in the clinical arena means positivism and post-positivism are unavoidable, being the

bedrock of science. This meant that sometimes the demands of what or how to analyse and write, created conflict as this philosophy is incongruent with history (see Chapter 3). Practically, this manifested in the format of the thesis following a standard social sciences structure which was very challenging for the data being analysed, resulting in a slightly awkward thesis structure - such issues represent the 'structural hindrances' that Woodworth *et al.* (2022) refer to.

Newnham & Rothman (2022) suggest that midwifery research should recognise the origins of patriarchal and colonial knowledge. Decolonising knowledge means recognition that all knowledge is shaped by its political, social, and cultural contexts, which includes attending to the history of marginalisation and how inequality may be deeply ingrained over centuries as well as a lifetime (Hamilton et al. 2022) – in this study, this is where history shines. This thesis showed how hospital procedures were rooted in nineteenth century responses to systemic poverty and institutional deaths. By the mid-twentieth century, social class, and the 'psych' disciplines (psychotherapy, psychology and psychiatry) had redefined hospital protocols. This reflects an "individualised, medicalised, interventionist" perspective on bereavement, defined by the psych disciplines ('the psychs') dominant in affluent societies, and thereby this knowledge raises "uncomfortable" questions about its universality, and how pain and suffering are understood and shared (Hamilton *et al.* 2022, p.1). This is why it is important for midwives, and midwife researchers to understand the foundation of their practice – in the context of this study, it was the psychs who decided on the nature of perinatal grief; that grief should be confronted by seeing, holding, and naming the baby; that grief was short-lived; and that it was curable with funeral ritual. It is midwives who were/are left to implement these theoretical positions, now defined in hospital protocols and care pathways, and midwives who must deal with the bereaved mothers and fathers. Midwives did not define these new protocols, yet they were the ones literally left holding the baby.

Patriarchal knowledge is explored in the historical analysis of psychological theory, and the way in which mortuary rituals were socially constructed towards the latter part of the nineteenth century. This includes the way in which official records were compiled, for example, often omitting data pertinent to perinatal deaths (Woods 2008). In Chapter 2, various authors indicated that perinatal death was virtually invisible in the historic record and thus it was not possible to gauge parental responses to perinatal death in the past (Cecil 1996; Hart 1998; Smart 2003). From a historical perspective, this is inaccurate and suggests a disciplinary perspective regarding what constitutes data and meaning. Though official records may omit relevant data, as this thesis

confirms, historical data does exist, albeit in a format less familiar to social researchers. By looking in the unexpected places, by tracing back through footnotes of prior scholarly works, through close examination of older studies, there emerges a whole range of possibilities with regard to data.

One aspect of the data examined here is the homogeneity of the population. Ireland had relatively stable population characteristics – white, Irish and Catholic for the twentieth century; even up to the early 2000s, about 88% of the population described themselves as Catholic and there was little inward migration (O'Mahony 2006). The National Folklore Collection represents a breadth of rural Irish life that comes from this same homogenous society but which extends back to the early nineteenth century – an equivalent rich resource may not be available in other countries. In social research, homogenous convenience sampling is preferred as it reduces variability and strengthens generalisability (Jager *et al.* 2017) i.e. it means that the findings are more likely to reflect the broader population and thereby improves validity. This study relied on the concepts of information power (Malterud et al. 2016) and data adequacy (Vasileiou et al. 2018) rather than sample size and saturation, in turn these rely on data quality rather than data quantity (see Chapter 4) (Liamputtong 2019b). Exploratory studies offer new insights and aims to provide contextual understanding of a specific aspect of human experience (Polit & Beck 2010; Smith 2018), and the analysis offered here meets this criteria, drawn sometimes from isolated or fragmented examples. The point of this study is not to offer statistical generalisability but plausibility i.e. theoretical sufficiency and soundness (see Chapter 4) so whilst positivist researchers may be seeking comfort in positivist concepts such as saturation or sampling, this is incongruent with the stated aims of this study and its humanist social research approach (see Chapter 3 and 4). Meaning and understanding are the domain of humanities who embrace outliers, purpose, morality and connection (Bullough 2006; Sarnecky 1990). Thus, individual experiences have validity within exploratory studies, and sole examples are not a limitation. It is up to midwife researchers, and historians to take the issues framed in this research and develop further detailed studies.

As a dataset, the various data sources analysed here were predominantly naturally occurring – only the personal accounts from living participants were purposely sought by the researcher. This patchwork of data sources complemented each other. Analysis of the folklore records reinforced trends in newspaper reports. Newspapers, official reports, texts, and biographies were broadly aligned, though some details differed. The bridge between the two datasets rested on personal testimony from three

contributors pre-1960. The later contributions remained consistent with twentieth and twenty-first scholarship pertaining to hospital based care. This triangulation of data improves the soundness i.e. trustworthiness or validity, of the study. There was more data to be gleaned from all the sources presented than was possible to include.

Interdisciplinarity, despite its benefits, cannot be all things to all people. For historians familiar with monograph structures, this study may feel that further discussion is required. It was not feasible to consider the multiplicity of meaning and relevance to histories of death and burial in this particular thesis. For social scientists and clinicians, the historical perspectives may be less relevant. However, the historical basis for clinical practice does form part of the lexicon of clinical knowledge (Sibley 2019). This aligns with the concept of theoretical sufficiency which maintains that exploratory studies offer new insights which challenge dominant views in the scholarship rather than being exhaustive interrogations (Malterud *et al.* 2016).

Perinatal bereavement interventions present a specific ethical challenge, particularly with regard to randomised control trials (Koopmans *et al.* 2013), requiring alternate methods to evaluate the effectiveness or absence of interventions. Retrospective data collection may be considered a limitation of research, however, in this study it was considered an asset. It enabled people to reflect and consider how their views or feelings may have changed over their lifetime. Given people remember what is important to them (Yow 2005), the data gathered here from living contributors suggests their accounts were meaningful to them. Further, the methods used here were less intrusive than interviewing and the topic guide could be easily adapted to collect data from a larger population to investigate the myriad ways in which people experience lifetime bereavement.

Despite the complexity that comes with interdisciplinary work, the benefit is that it can draw together disparate areas of academic and clinical research (Silverman *et al.* 2021). This is where the three disciplines of contemporary History, Midwifery and Sociology align. All three seek to advance the humanistic imperative and to reach a deeper understanding of what it means to be human. What can be determined from this thesis is that interdisciplinary approaches to perinatal death are necessary, bridge gaps in knowledge and provide a more holistic understanding of a complex area. The findings here tackle some of the ‘myths’ regarding perinatal death, burial and bereavement that persist in the scholarship, and further scholarly scrutiny is welcome, as it will advance knowledge of an under researched area.

10.4.3 What Lies Beneath: Emotions & Reflexivity in Research

Prior to starting this research, I had little appreciation of the development of Midwifery research or practice. I had not considered the dilemmas of midwife researchers and midwife practitioners as they alternate between medical and aesthetic knowledge, the science and art of being 'with woman'. The dominant masculine, scientific way of knowing subjugated centuries of feminine, intuitive ways of knowing. Compassionate yet rigorous research models are needed but it is not clear how we achieve this, despite calls by authors to move forward with sensitive RCTs. Indeed, the holistic approach of Death Studies scholarship refers explicitly to the lack of textbooks that deal with the methodological and practical dimensions of researching death, dying and bereavement (Borgstrom & Ellis 2017).

For midwife and nurse researchers, this methodology charts the development of practice and interventions. It shows how the close reading of texts can illustrate bias arising from social class and politics, and how this may inform the origins of interventions. It demonstrates how certain narratives become dominant, how the gendered aspects of scholarship can overlook critical information, and how culture may be ignored in health research. And most importantly, it emphasises how what we take as 'fact' may be anachronistic i.e. judging the past by today's standards, without understanding its context.

Whether midwifery or nurse researchers would choose a research design that looks at all the variables this study does, or consider interdisciplinarity useful, is a matter for each researcher to consider. One thing I believe is relevant for all researchers, however, is to ensure they lead their research with evidence rather than emotion, even when the topic is particularly emotive. Not doing so can obscure relevant ideas, narrow the field, or create a politicised agenda. This is evident in the history of the scholarship pertaining to the use of funeral as an intervention (see Chapter 5).

Emotive language can also colour an experience in a specific way – this may reflect an individual researcher's own journey or life experience relating to death, grief, or loss, as Borgstrom & Ellis (2017) suggest. Whilst constructivist research values reflexivity, this takes on additional significance for sensitive issues, as researchers own emotions become part of the analytic process and thereby knowledge production (Borgstrom & Ellis 2017). For this reason, Rowling (1999) maintains reflexivity is vital for qualitative researchers dealing with loss and grief. Hence, though this is an interpretive rather

than constructivist thesis, the dimension of emotions is assessed here, and arises in different ways.

Hamilton *et al.'s* (2022) decolonisation of research asks researchers to recognise the complexity of people's lives, focus on listening respectfully and with humility, to be open to learning, and to walk alongside those we research and be their ally. This aligns with the concept of *yindyamarra* (see Chapter 1) which guided this research, and which in biomedical terms might be represented as the principle of 'do no harm'. This took on additional significance for me, as though I am not a midwife, I am based in the School of Nursing and Midwifery, and I wanted to ensure I honoured those professional standards (see Chapter 3 and 4). The contention regarding infant death and burial in Ireland, influenced my research. I was reticent to present or publish my doctoral work without it being complete. The fragmented nature of the data also meant that I did not, or rather could not, produce 'neat blocks' of research to present, right to the end it was a dynamic, iterative endeavour.

Epistemologically, Social Constructionism is about migrating between subjective experiences and objective analysis. This balance between "objective detachment and empathic understanding" is both critical for historians and difficult to achieve for historians, according to Robins (2021). The danger for social researchers is that objectification can diminish personal experience, this is discussed in Chapter 4. To avoid this, I worked hard to reflect the stories that were shared with me, as fully and accurately, as I could. I believe, as De Chesnay (2015) does, that telling someone else's story is a privilege. This takes on extra significance when so few exist in the historical record, and the data is fragmented.

Risk assessments in research usually refer to research participants, and more recent methodological papers point to the need to include the researcher, particularly in dealing with sensitive issues (Dickson-Swift *et al*. 2008), which death and dying are (Borgstrom & Ellis 2017). Other research has flagged that postgraduates working on sensitive issues or with vulnerable populations should receive adequate training and support (Dickson-Swift *et al.* 2008). The sociologists in Dickson-Swift *et al.'s* (2008) analysis recognised their own professional limitations and felt out of their depth not being counsellors or therapists. This is relevant for nurse and midwife researchers, who similarly to sociologists or historians, may lack adequate training for sensitive research (see further below).

Researching death is difficult but during a mass death event can feel overwhelming – this is not a topic addressed in the literature because it is over a hundred years since the last pandemic. As I live near a hospital, my doctoral journey was set to the soundtrack of non-stop ambulance sirens; when Covid faded from the news cycle, I could still tell how bad it was based on this cacophony. Death felt omnipresent. This sometimes meant decision making and analysis felt heavy. I offer this example which has stayed with me over the last three years. When I was still deliberating whether to conduct interviews, after the first lockdown ended (June 2020), I was surveying a graveyard in the West of Ireland where I got to talking with an elderly man. As we chatted, he broke down crying. I had been the first person he had spoken to since his wife died almost six months earlier, he had been isolated away with nobody to speak with, when he needed it most. This encounter illustrated to me the distress that many were feeling at this time, cut off from their normal daily lives and social networks and how bringing up long distant memories may be antithetical. This ultimately influenced my decision not to progress to video or phone interviews (see Chapter 4).

In health research, there is a perception that to feel emotion is to be weak or a poor researcher (Howarth 1998). As a humanist researcher, I believe this to be untrue, qualitative researchers are often more explicit in their endeavours than positivist researchers. Nonetheless, less experienced early career researchers, postgraduate students or non-clinical researchers may experience negative or challenging feelings (Borgstrom & Ellis, 2017; Mallon *et al.* 2021), and one solution offered is to ensure they are equipped with counselling skills (Dickson-Swift et al. 2008). I did undertake formal training in counselling skills, completing a certificate in counselling during lockdown but I did not find, in the context of this study, that such skills were useful. Rather, I found enormous benefit in my peer groups.

Debriefing and support networks can take several forms, including the supervisory relationship, experienced colleagues, research teams, academic mentors, peer groups and professional counselling or supervisory sessions (Howarth 1998; Dickson-Swift *et al*. 2000; Mallon *et al.* 2021). Several of these options were limited during the pandemic. Borgstrom & Ellis (2017) refer to cultivation of a community of support and in this study, I sought this community in death research networks. This made sense as these researchers were spanning a vast range of topics and were presented with unusual and unique situations which we were able to share. Fortunately, as a consequence of the pandemic creating a new digital world, these networks became available to me, whereas pre-pandemic this would not have been the case.

Meeting this group online provided me with the space to share but also proved valuable, particularly when it came to analysis. Though I had anticipated interviews being emotionally challenging, I was unprepared for this in the context of documentary and historical analysis. Death research can be arduous at the best of times and whilst vicarious trauma can occur for historians the emotional challenges are not well documented (Robins, 2021). Whilst I often found this research very sad, I did not find it traumatic. Rather, I felt that I had been entrusted with a legacy and perhaps this role of guardian, offered a protective benefit. I did however equate the idea of legacy to a strong sense of responsibility. This sense of responsibility to participants can manifest as anger, which is connected to frustration at being unable to change the situation for interviewees (Mallon & Elliott 2021). Though I was doing online data collection anonymously, I was not immune to emotion. The living contributors wanted someone to be a witness. I could not reach out and say 'I am that witness' or acknowledge the past and present failure of professionals to help them, nor was I able to acknowledge their pain, or help them find burial sites. This is an aspect of online methods that does not address the practical dimensions of using the internet for death research (Borgstrom & Ellis 2017). Nor was my engagement with historic data emotion neutral – the same sense of frustration arose in reviewing these records, as there was nothing I could do about this either, being so far in the past. Discussing these issues with my death studies peer group gave me a solution which may be of benefit to other death, nurse, or midwife researchers. A colleague working in postmortem practice suggested creating a ritual around analysis, which I did. The ritual was simple. Choose a story and fix a period of time to analyse it. Light a candle and analyse the story for the prescribed time. At the end of the analysis period, close the file, and thank the contributor for their courage in sharing their story. Take a moment to honour the baby's memory and then blow the candle gently out, acknowledging that their brief life has contributed something to the world. It may not be a ritual that suits all researchers, some may even find it peculiar, but for me it aligns with the principles of humanistic research and the concept of *yindyamarra* or the Irish *nadúrtha*. It offered a way to honour the contributions that people made and it gave a focus to the analytic process.

There is always more that can be said, but I end here with saying, as Cannadine (1981) mused, I did not find some magical answer in the past. What I found instead was a profound respect for our ancestral knowledge, how it embodies such complexity and with it a deep simplicity, the *yindyamarra* or *nadúrtha* of Irish life. What I come away with is deep appreciation for the midwives who hold space for bereaved parents, and who advocate for better care.

10.5 Limitations of the Study

Due to the expansive nature of the topic, a single doctoral thesis cannot incorporate all there is to know regarding death and perinatal deaths. This thesis thus represents only a fraction of a very rich and complicated topic. A potential limitation of this study is that it relies on sociological rather than psychological analysis and for clinicians this means that the findings may not be directly applicable. However, the thesis does present key findings which challenge some dominant perspectives in psychological models, queries the development of funeral as an intervention, and raises questions regarding clinical pathways. All require additional investigation.

The use of historical records in this study was limited to those that were accessible via digital searches, due to closure of archives. Hard copy searches may yield different results. The useable records in this study were restricted to those already translated into English. This means some localised differences in mortuary ritual were not captured in this study, for example, not all the details in Ó Súilleabháin's (1939) paper were confirmed.

This study on Irish death traditions recognises an ongoing cultural belief in the dead, a characteristic common to many cultures (Lee & Vaughan 2008). This cultural belief may not be present, or have the same interpretation, in all cultures (Rosenblatt *et al.* 1976). Therefore symbolic communication after death may take on greater significance in specific cultures. Equally, without further investigation, it is unclear as to the extent which these long held cultural beliefs persist, even in Ireland. Thus these findings may not be generalisable across all cultures, however, it should prompt other scholars to investigate cultural traditions within their own communities more fully and reflect on the dominant forces which have shaped clinical practice in their own hospitals.

This study relied on personal accounts and official records to retrospectively investigate perinatal mortuary rituals. The reliance on convenience sampling from living participants meant that there was a disproportionate representation of dates, with a chronological gap for the 1980s. Additionally, the examples gathered here may reflect extreme parental experiences or emotional responses. Though gathering personal accounts from living participants provided some key insights, this data did not always possess the richness present in qualitative interviews, resulting in 'dense data' (Elliott & Timulak 2021). Whilst 'dense data' can be succinct, the downside is it can be difficult to understand or contextualise. This meant there were some gaps in particular parts of the family experiences gathered.

Finally, as there is no agreed definition as to what constitutes a funeral, Howarth's (2007a) work was adapted to create a mortuary framework for analysis. This included pre and post death activities encompassing different perceptions of funeral. As discussed in Chapter 7, even when people participated in the same mortuary activities they understood these differently. This makes for a broader investigation which is more culturally situated, and other cultures may differ in their definition of what constitutes funeral.

10.6 Implications for Scholarship

The scholarship of the nineteenth and twentieth century had disproportionate male authorship, this is also reflected in the folklore records which relied predominantly on male collectors. This indicates the spiritual and emotional significance of birth for women, and often men, is largely overlooked and presupposes, as Hertz ([1907] 1960) does, that neonatal deaths were of no social consequence. This is a repeated theme in the scholarship, both in antiquarian and clinical scholarship of the late nineteenth and mid-twentieth century. Only one study conducted by a female social worker in 1980 (Cooper 1980) described the issue of birth related trauma in the context of perinatal deaths. The evidence presented here confirms that perinatal deaths were deeply distressing to both parents, and further historical and clinical scholarship may wish to consider gender bias in the authorship relating to birth topics.

Historical demographers have paid scant attention to stillbirth independent of infant mortality, attributed to unclear definitions and lack of civil registration data (Woods 2008). This means that in historical research, the use of reproductive terminologies is not always clear and like comparisons are not always made, 28 weeks gestation being the most common medicolegal definition that persisted through the twentieth century. In this study, this issue of unclear definition was raised, in particular with regard to the term unbaptised, which has multiple meanings as detailed above. Therefore, the scholarship, in assessing historic burial practices or demographic research may reconsider this terminology.

The historical evidence presented here challenges many aspects of scholarship and disputes the socioreligious focus of what has been written to date. For example, McCreight (2008) suggests that folklore and religious belief informed the "restrictive funeral practices that prohibited burial for stillborn babies". This is not to say religion is not important but by focusing only on religion or taking a socioreligious stance, it obscures other relevant aspects of Irish responses to death. Undoubtedly, as Lawless

(1912) has confirmed, swathes of our cultural history and heritage have been lost due to the effects of famine. Some of the findings presented here are signposts to this lost heritage and will be subject to contestation, as is the nature of research. The findings and references provided here should enhance current investigations into historic burial practices in Ireland, particularly those regarding institutional burials.

Sociological studies of perinatal death may take on additional significance as the role of death rituals has been impacted by Covid19. Being able to say goodbye; missing social supports, including wakes and funeral masses; lack of physical contact with other mourners and the deceased; and absent post-death rituals, were some of the features causing disrupted bereavement found by Selman et al (2021). These qualities are common to many parents of perinatal infants who have died. Thus the cultural situatedness of perinatal death provides, quite coincidentally, a pre-existing framework for society as it struggles to make sense of disrupted bereavement due to Covid19. This study thus may offer insights for contemporary grief researchers.

10.7 Implications for Policy

Though there are many important findings in this thesis, the most significant one, is that parental bonds last a lifetime, with variable emotional responses, including grief. This key finding is not reflected in current policies relating to bereavement care, nor the scholarship. If parent grief lasts a lifetime, then this should also inform healthcare processes, care pathways and interventions at birth and death.

This thesis is one of the few to examine funeral ritual, and the context of life long grief. Despite the extensive research conducted on the emotional impact of perinatal death, this has been restricted to the immediate time after death, little long term analysis has been conducted. This means that the current policies and practices, derived from Anglo American cultural interpretations of birth, death, and grief, have not been evaluated for efficacy over the life span. What this tells us, is that perinatal death and its lifetime effect has not been studied, the impact of funeral ritual on grief has not been well researched, and the potential benefit of mid-twentieth hospital protocols have not been evaluated within time based models that mimic lived experience, as Saltzman (2019) suggests. This seems a shocking omission in the scholarship and this thesis is a foundation for all these issues.

This study demonstrates how the dual cultures of America and Britain influenced the development of grief theory, maternity care (Loudon 1992), canon law, and civil

registration.[175] Thus, Irish responses to birth, death, grief and health have been cultivated between these two cultures, which represent a different understanding of death and grief. With regard to perinatal death and bereavement, cultural bias in the psychological and midwifery fields is dominated by American cultural values (Cann & Troyer 2017).

This project shows the cultural expression of ritual and grief differed to that in America and England. Ireland retained a collective response to death, a strong belief in after death communications, maintained relationships with the dead, and adult mortuary rituals traditionally incorporated remembrance rituals for babies. This historic perspective is relevant for today, particularly in LMICs (Low to Middle Income Countries) who may still retain similar traditions, and collective responses to death. In essence, a culture clash takes place between contemporary hospital practice and traditional mortuary rituals and social attitudes.

Given that Goldenberg et al., (2011) noted that 98% of third trimester stillbirths occur in low to middle income countries, mainly sub-Saharan Africa, closer attention should be paid to importation of American centric psychological bereavement practice. Though it is noted that cultural beliefs around death vary enormously and impact on grief, recent research in Africa has identified comparable themes to those outlined earlier in this thesis: illicitness, stigma, silence, rapid disposal, absence of funerary ritual and hospital burials, among others (Kiguli *et al.*, 2015; Kiguli *et al.*, 2016; Heazell *et al.*, 2016; Ayebare *et al.*, 2021). A question mark remains over the efficacy of deploying American or Anglo centric policies into other cultures, displacing death traditions, without an adequate evaluation of the effectiveness of such policies in their own home cultures. Such displacement of tradition is evident in an Irish context, as this thesis demonstrates.

10.7.1 Culture and Care

Culturally appropriate healthcare is defined as cultural competence i.e. the dynamic ability to provide safe, quality care to patients attuning to their individual cultural beliefs and practices (Capitulo 2005; Cai 2016; Louw 2016). Culturally competent care improves patient and family outcomes, and is seen as essential for appropriate care

[175] For a comprehensive review of the development of maternity hospitals and maternity care through the 19th and 20th centuries, including the cross Atlantic relationship between the US and UK maternity systems, see Rogers, (1889); Wertz and Wertz, (1979); Loudon, (1992); Richardson, (2013) and for the parallels in the development of healthcare in Britain and Ireland in the 19th and 20th century see Stewart (2014)

and interventions, particularly with regard to grief (Capitulo 2005; Louw 2016). In the context of bereavement care, the concept of cultural competency is challenging, as Giblin & Hug (2006) assert there are no guidelines for what constitutes normal as opposed to deviant mourning, no definitions for proper grieving and normal grief responses are still to be fully realised. This raises the question as to the extent in which cultural responses to death and grief are homogenous, in any given culture. Even within this thesis, in a relatively homogenous society, there was wide variability in emotional responses and funeral rituals. Therefore, midwife and nurse researchers should recognise the strengths and limitations of their *own* cultures. As women deserve culturally relevant research (McCarthy 2003), scholarly findings should be evaluated for cultural bias which may be incongruent with any given country's responses regarding death and grief – interventions may not be interchangeable among cultures.

Whether we attend to our own culture, or attune care for patients from other cultures, the ability of healthcare professionals to become culturally competent comes through continuing education, training, and clinical experience (Louw, 2016), see further below. It may be that in increasingly diverse communities, midwives and researchers look cross-culturally to determine what aspects of death, grief and ritual are comparable and aim to develop a global standard based on a cross-cultural analysis, rather than relying specifically on Anglo-American cultures. This is reflected in Steen's (2015) recommendation to improve global consistency and standards in perinatal bereavement care, whilst ensuring midwifery practice retains cultural sensitivity.

10.7.2 Implementation & Maternity Care

As evidenced here, parents were previously not encouraged to see their baby or have a funeral, and by the early 21st century, as noted by McCreight (2008), bereavement care still depended on individual hospital practices, staff awareness and sensitivity, with haphazard burial arrangements. The National Bereavement Standards (NBS) are therefore welcome. Though the NBS outline extensively the responsibilities and actions taken to underwrite good bereavement practices, the report uses permissive language, for example, "resources permitting; where feasible; within the capacity of local resources" (O'Donoghue 2022, pp.18, 21, 32), which implies that implementation of the standards is optional rather than mandatory. The report does not confirm ring fenced funding for midwifery ratios, bereavement care, or public health programmes for community based supports. Therefore, though the NBS outlines an extensive protocol

for perinatal death in Irish hospitals, it remains to be seen whether this can realistically be implemented.

Staff ratios are very important in the context of delivering safe nursing care (Aiken *et al.* 2014), this study illustrates how staffing shortages contributed to the introduction of AML (see Chapter 5), for example. By 2020, the European Commission had estimated a potential European shortfall of 600,000 nurses and midwives (INMO, 2019). In Ireland, nursing and midwifery shortages are deemed to be a threat to the delivery of safe and effective care (INMO, 2019). By 2014, a critical shortage of midwives had been identified in Ireland's nineteen maternity units. The midwife to birth ratio nationally was 1:40 (range 1:32 to 1:55), compared to the international recommendation of a ratio of 1:29.5 (INMO 2014; Ball *et al.* 2018). The National Maternity Strategy determined the health service required a minimum addition of 200 WTE (whole time equivalent) midwives by 2018, in order to achieve the recommended international midwife to birth ratio. This was not achieved and as of 2019, 262 WTE were determined necessary (INMO, 2019).

In the context of bereavement care and staffing, the impact on underfunded maternity care is noted in UK reporting (Hunt *et al.* 2022):

- Staffing shortages mean individualised or woman centred care is absent, with an associated return to 'conveyor belt' labour and birth
- Staff are tired and switching off
- Staff are too stretched and over worked to provide quality bereavement care
- Staff may have to choose between assisting women in labour with a living baby over offering bereavement care
- Families are not referred for psychological supports as midwives have no time to make referrals
- Few (often only one per unit) specialist bereavement midwives, means mistakes are made due to inadequate staffing
- Increased pressure on trained specialists who absorb additional work on their days off
- There may be no debriefing or staff support for the midwives who have to attend to bereaved families

The role of Clinical Midwife Specialist (CMS) in Bereavement is recognised by the NMBI as a specialist role (O'Donoghue & Cotter 2021), however, most Irish maternity units have one WTE midwife, which means that no CMS may available on some shifts.

With no ring fenced funding to increase standard midwifery care, specialist training, and specialist midwifes, it is hard to see how the NBS can be successfully deployed. The danger without this funding for staff, means the checklist remains an ideal guideline rather than an active protocol, and the same issues that arise in UK bereavement care, arise in Ireland.

10.8 Implications for Practice

10.8.1 Implications for Education

In this study, parents did not feel a one size fits all approach to their care was adequate and believed that clinicians would benefit from additional skills training. Parents felt that hospitals should do follow up surveys, and this specific engagement with parents is reflected in the NBS (O'Donoghue 2022).

Midwives, and other health professionals, exhibited discomfort meeting parental needs, in this study (see Chapter 6 and 7). This indicates that all staff working in units with bereaved parents should have some basic skills in how to respond to perinatal death. Many clinicians struggle with bereavement care, and bereavement training should comprise specialist skills taught via balanced curricula and clinical practice (Steen 2015; Louw, 2016; O'Donoghue 2022), though this is a formidable task in educating healthcare professionals due to an ever expanding field of knowledge (Louw, 2016). This may in part explain the desire to move towards standardised training for those involved in direct patient care (O'Donoghue 2022). The NBS recognise skills and specialist training in bereavement are required to improve quality of patient care (O'Donoghue 2022, p.14). Currently, six Irish universities offer medical and midwifery education, with highly variable curriculums and time allocations for perinatal death (O'Donoghue 2022). This matters in the context of equitable and quality care – it means the standard of patient care may rely on the quality of education at undergraduate level. Midwife educators and policy makers may need to evaluate clinical training programmes to find compatible areas of instruction that means all healthcare professionals will receive a similar basic 'emotional toolkit', with tailored midwifery skills offered on midwifery curriculums.

Shock, numbness, and disbelief were the top three parental emotions at time of death and within the immediate months following perinatal, reflecting symptoms of birth related trauma and PTSD, as noted by Ayers *et al.* (2008). This suggests that parents are not in a position to 'face reality' at birth, as Lewis (1979) believed. As this study

shows, parents may exhibit symptoms of birth trauma rather than grief, and it would be extremely difficult for midwives to be able to distinguish between them due to the overlap in the presentation of symptoms. Therefore, midwives would benefit from trauma informed education which would incorporate both dimensions of care.

10.8.2 Implications for Midwifery

Scholarship informs best practice guidelines, from which birth interventions are derived. The emergence of a universal expectation of ritual and grief for pregnancy grew from developments in healthcare, over the twentieth century (Reagan 2003; Kobler & Kavanaugh 2007). As Rosenblatt (2017) has identified in his extensive cross-cultural bereavement research, the field of grief studies has limitations, adopting one size fits all models, and treating grief as if culture is immaterial. This according to Rosenblatt (2017) is no longer tenable, yet practice has not caught up to this recommendation.

Parents will forever remember what midwives do and say (Capitulo 2005) which places an enormous burden on midwives dealing with perinatal deaths. This is demonstrated in the evidence presented here, with parents recalling that midwives, doctors and allied health staff could invalidate their experiences. Parents insist there is no 'one size fits all' model of care, in this study. This contrasts with the way in which hospitals do seek models of universal care and follow systematic processes, protocols, and best practice guidelines. The desire for standardisation is honourable but Howarth (2007a) believes that health professionals need flexible, responsive models and frameworks that adapt to individual, social, and cultural context. This creates a dilemma for caregivers caught between following a standard and deviating from it.

Though quality standards, such as the NBS, provide a checklist of things *to do*, they may not show midwives *how to* (Kobler & Kavanaugh 2007). In Spanish midwifery care, though clinicians were sensitive to perinatal loss and families received quality bereavement care, this was not necessarily based on protocols or standards drawn from the literature (Gálvez Toro (2006) as cited by Steen 2015). This reflects Harvey's (2008) concept of compassion led interventions. However, it exhibits the conflict clinicians have as they follow a standard process/protocol which may not give them practical skills, and thus suggests:

- that adapting from a guideline based on a specific unit's resourcing, means they are not 'standard'

- that a checklist is ‘things to do’ but misses the aesthetic component of nursing (Carper 1978)
- that conflict arises in creating a universal system in which parents do not see themselves as having universal responses, despite commonalities in their behaviours

To improve quality of care means there needs to be an objective with clear steps to achieve this. Whilst midwives need to follow discrete guidelines, the more extensive these are, the harder it is for midwives ‘in the moment’ and it may be that a simpler framework yields more consistency. This requires further evaluation.

10.8.2.1 Respectful Care

Woman-centred care (linked with patient, client and person centred care) has no universally accepted definition within the midwifery literature (Crepinsek et al. 2022). It is broadly understood as focusing on meeting the social, emotional, physical, psychological, spiritual, and cultural needs of women (Moridi et al. 2020; Crepinsek et al. 2022). Respectful midwifery care, which incorporates woman-centred care, is seen as a universal human right that encompasses respect for women’s feelings, dignity, and preferences (Moridi et al. 2020), and is thereby inclusive of cultural sensitivity (Crepinsek et al. 2022).

The displacement of birth from home to hospital may alienate and distress parents, disrupting their emotional ecosystem and creating ‘root shock’ (Hynan 2021), a feature observed in this study. Woman-centred care is an attempt to mitigate this, however, care pathways are always going to be a substitute for an organic process that once occurred at home. The NBS identify that continuity of care is “paramount” both for in and out patient care but policy changes have not been implemented to support this endeavour (O’Donoghue 2022, p.18). In hospitals, with underfunded maternity systems (see above), continuity of care and/or relational care is infrequent. None of the contributors to this study identified continuity of care meaning all these birth and death experiences occurred among strangers with whom parents had no prior engagement. As discussed in Chapter 6 and 7, mothers having hospital births are physically and emotionally vulnerable relying on midwives who are strangers, and hence continuity of care takes on additional significance, if we are to avoid root shock.

The need to retreat from others is a core element of dealing with shock and trauma, necessary for reshaping traumatic experiences (Van der Kolk 2014). Birth in hospital means mothers are removed from home when death occurs and then must return

home, disrupting this process and the normal community responses to death. Dybisz (2016) recorded both a feeling of empowerment and peace regarding the home birth of her stillborn child. This suggests that her emotional ecosystem was protected by continuity of care with a known midwife, minimal procedures and people, and a home environment in which she retained control over her birth and her child's body. One way to potentially avoid root shock, and the hospital failures identified by earlier scholars (Lewis & Page 1978; Lovell 1983) is to consider a paradigm shift in home births. This may be more achievable than the current NBS recommendations for dedicated accommodation for bereaved parents (O'Donoghue 2022), which are contingent on capital expenditure and funding for training skilled staff.

Tied to this idea is the issue of birth trauma, which was clearly present in the data gathered here (see above). Birth trauma is another term that lacks agreement in the scholarship, however, Leinweber *et al.,* (2022) offer a definition to guide research, practice and education.[176] Today, up to 50% of women may describe some aspect of their birth as traumatic (O'Donovan *et al.*, 2014) thereby, what midwives do matters. Respectful care of the body, both infant and maternal, was perhaps the most important intervention expressed by parents, in this study. Parents reported feeling shock, numbness, and anger at the time of birth and in the immediate weeks afterwards. This thesis illustrates how mothers relied on fathers as conduits for information, and as witnesses to their birth experience. For this reason, when feasible, midwives should give information to both parents, and recognise that they both may be in shock and unable to process what is happening, for months afterwards. Further, midwives should recognise that due to shock, women may not be able to truly consent and time should be given to allow parents decide what to do together.

Modern grief theory has tended to validate 'talk therapy' over silence (Howarth 2007) yet emotions may be linked to cultural expressions, sometimes reflecting religious beliefs (Shaw 2014). Steen (2015) found Spanish midwives preferred talking as a primary intervention which contrasts with American midwives preference for creating mementoes, for example. Historically, when mortality rates were high, silence created space for grief rather than being punitive, the futility of discouraging maternal grief was respected. In this study, and reflected in the literature, bereaved parents experience a unique individual grief but one which happens thousands of times for caregivers.

[176] The definition offered by Leinweber *et al.,* (2022) is "a traumatic childbirth experience refers to a woman's experience of interactions and/or events directly related to childbirth that caused overwhelming distressing emotions and reactions; leading to short and/ or long-term negative impacts on a woman's health and wellbeing"

Parents wanted someone to acknowledge their distress and offer respectful care to them and their babies. The desire to talk to midwives was not evidenced in the data here, this may reflect the fact that no preexisting relationship existed between parents and carers. If parents choose to talk, however, it is important for clinicians to listen, as this may provide consolation (Kobler & Kavanaugh 2007). Midwives need to be comfortable with the concept of 'watchful waiting' (Scheper-Hughes 1985; 1992), learning to just be 'with woman' at one of the worst times of their lives. This may be the hardest intervention for midwives to master as the natural inclination is to 'do' something.

Memory making interventions (i.e. mementoes or keepsakes e.g. footprints, photos) were used by 93% of American midwives compared to 67% of Spanish midwives in Steen's (2015) intervention study. This suggests a cultural distinction in the reliance on material goods between cultures. Increasing the material reliance on 'things' may be a distraction from 'feeling' for both midwife and parent and alleviate distress at a specific point of time. Midwives should be careful that the creation of 'things' is not a substitute for care.

Parents in this study either had none or few birth mementoes and attached various levels of meaning to them. The significance of birth mementoes decreased over time, most parents preferred their own ways of memorialising and these took on an equal or greater value than the birth mementoes. Parents make their own meaning and this occurs over time regardless of ritual or keepsakes. Traditionally the material culture of death relied more on the natural environment, which was also reflected in contemporary accounts gathered here. A reliance on grave visiting and tending also reduced over time. Parents appear to seek a degree of permanence in their memorials, therefore, midwives may wish to evaluate the possibility of a natural memento e.g. tree or plant as an alternative to physical objects or keepsakes.

This study demonstrates that hospital policies can disenfranchise parents, and parents remember their caregiver interactions at time of birth. These memories stand out strongly for them even today, almost 65 years later. This supports Capitulo's (2005) assertion that what midwives do and say matters. Though care pathways now differ to those of the past, the impact of birth experience is clear. Parents and their babies should continue to receive respectful care. This includes listening to mothers concerns; informing parents together; and where possible providing choices, particularly with regard to the control of the infant body. This aspect of control

remained significant for parents, more than the desire for rituals, as discussed in Chapter 7. Caregivers are there to support not control.

10.8.2.2 Religious Rites

As part of cultural competencies in nursing and midwifery, clinicians are encouraged to respect religious rituals (Steen 2015). Baptism forms part of midwifery practice where required by parents (Cameron *et al.* 2008; Steen 2015). In this thesis, baptism was perceived as a cultural as well as religious practice, for both Anglicans and Catholics. Historically, lay baptism was acceptable, whether performed by midwives or parents. The canon laws of the early twentieth century confirm posthumous baptism of the baby is acceptable, regardless of gestational age or signs of life at birth. This means that for parents who prefer religious practices, midwives can provide assurance that lay baptism, even if posthumously given, is and has been accepted by the Catholic church, since the late nineteenth/early twentieth century.

Religion remained important even for non-practising Catholics – becoming part of the social lexicon for acceptable or normative ritual, in this study. This intertwining of tradition with religion is examined in Chapters 6, 7 and 8. Steen (2015) found a difference in the interventions used by American and Spanish midwives, noting that religious rituals of baptism, clerical referrals, and funeral planning were most used by American midwives. This suggests a cultural preference for religion. As such, it may be that midwives need additional supports or training to perform these rituals and this should be included in continuing professional development and/or hospital practices. Equally, consideration should be given to baptism equivalents from other religions, particularly with an increase in population diversity and religious expression in Ireland.

10.8.2.3 Beyond Birth

Parents sometimes sought emotional assistance much later in life, through parent advocacy/support groups or professional counselling services. As evidenced here, parents who attended parent bereavement groups found these initially supportive, whilst over time, they could also anchor parents to a negative emotion or memory that they want to move on from.

There is a distinction between birth trauma and the tragedy or trauma of death, this is a feature not well explored in the scholarship. Birth and death trauma may exist independently of each other and may share similar characteristics. Further, parent advocacy groups may provide sufficient support for death but may not include trauma

informed capabilities. Parent supports for older parents may need to include therapeutic models that consider legacies of birth trauma, and/or the absence of compassionate care many years ago. These are all dimensions of bereavement not addressed in the current national bereavement standards. As healthcare professionals provide care to men and women through all phases of life, it would seem prudent to address this clearly unmet need.

Parents bonds to their children last a lifetime. This raises important discussions for midwifery practice, for example, is the maternity hospital the appropriate place for ongoing or long term bereavement care? Should this be integrated into public health nursing, or fall under the realm of general mental health services? How can these longer term needs be assessed and met? Is there a requirement for a national support service? These are all necessary questions, though the response will lie with future midwife researchers.

10.8.2.4 The Landscape of Death

Midwifery practice, along with hospital based birth has shaped the physical landscape of burial and the mortuary rituals regarding perinatal death and remembrance, as also noted in France (Charrier & Clavandier 2019). This illustrates how compassion-led interventions (Harvey *et al.* 2008) can have a lasting effect outside of the domain they were introduced for. Similar observations are recorded for Ireland, originating first in the nineteenth century in defining institutional death, and the late twentieth century by introducing the same clinical policies expressed in the literature, practice, and professional guidelines. This means that what midwives do can impact the entire death ecosystem, shaping grief responses and how societies define their cultural responses to death. It is wise therefore for clinical researchers to recognise that personal or individual interventions can impact entire societies and may shape public perception and memory.

10.8.3 Implications for Palliative Care

Regardless of rituals, all parents expressed a continuing bond with their babies. This lifelong continuing bond has received little attention to date and is most evident in after death communications. End of life visions (ELVs) are a very under researched aspect of death and dying. In the context of palliative and end of life care, clinicians should be aware that end of life visions pertaining to babies were once common in historic records, though only one contemporary account was recorded here. This study shows that witnessing ELVs may be distressing to families who observe the phenomenon.

However, this study also shows that ELVs may be read as part of a continuum of continuing bonds which can be comforting to the dying. Thereby, it would be useful for clinicians, particularly end of life nursing teams, to try and learn more about this unique phenomenon in order to explain what is happening to both the dying, and their family members.

10.8.4 Recommendations for Further Research

This thesis has traced the emergence of funeral as an intervention, and the psychological theories that shape clinical practice and parental responses. This topic has many ambiguities and thus three key concept analyses would be beneficial.

- One difficulty in analysing reproductive histories is the terms attached to different experiences. A concept analysis of reproductive loss terminologies would benefit historic works. Though Donaghy (2021) has attempted to create clarity regarding reproductive terms for the eighteenth century, this could be extended for the nineteenth and twentieth century to enable like with like comparisons, as recorded above, this should include the term unbaptised.
- In the context of funerals, confirming a definition of funeral is crucial in determining whether rites or rituals have been denied or altered, this enables proper comparisons to be made. As was demonstrated in this study, a funeral can be understood differently even when people perform the same mortuary tasks.
- The final concept analysis is one which has caused significant distress in Irish mortuary studies. *Cillín* burial grounds are poorly defined in Irish scholarship. As presented here, these are complex sites which extend beyond the socioreligious characteristics currently attributed to them. Being able to confirm their usage, physical attributes, and import in communities would be beneficial for understanding these places as sites of cultural significance, spiritual influence, and remembrance.

Other areas that would benefit from additional research are:

- The death literature for Ireland is not as well developed as it is for other countries. This research suggests that the role of poverty may inform both future Irish Victorian death studies, and twentieth century social histories of death. This would complement studies of nineteenth and twentieth century death in England and Australia (Jalland 1996; Strange 2005; Jalland 2006; Howarth 2007b; Rugg 2013). Additionally, this research demonstrates the

social complexity regarding perinatal death and burial. The findings and references provided here may enhance current investigations into historic burial practices in Ireland, particularly those regarding institutional burials.

- Anglicanism being linked to state authority exercised considerable control over burial practices in Ireland, this has received little attention in the scholarship. As this study illustrates, religion has an important part to play in the context of macro studies of death, the political influence of religion on the development of mortuary rituals in Ireland is worth further interrogation. Given the global nature of religion, such analysis may extend beyond studies of Irish Catholicism. The socioreligious dimensions of death as illustrated here are secondary to the social rituals regarding death, nonetheless, religion retains importance, and how this may influence repressive or expressive grief in Irish studies of emotions would be worthwhile.
- Traditional Irish responses to perinatal death share some characteristics with other cultures, particularly with regard to burial customs. Deeper examination of cross cultural responses to perinatal death may yield more insights into the degree to which these are shared and by which cultures, and offer ways back into the past as, Irion (1991) suggests. This may enhance not just death specific studies but also by tracking the similarities in belief systems, offer insights into global migration patterns e.g.
- Compassion-led interventions whilst well intentioned (Harvey *et al.* 2008) can have a lasting effect outside of the domain they were introduced for. Funerals as interventions have affected mortuary customs all around the world. These changes are embedded in the physical landscape of cemeteries (Charrier & Clavandier 2019). More importantly, psychotherapeutic models of the 1970s which insisted on creating a person to be mourned, and the American rituals attached to foetal personhood were adopted uncritically by clinicians (Reagan 2003). These have perpetuated a belief that these babies are 'real' (Charrier & Clavandier 2019) and continuing bonds theory has remained consistent with this. This is not innocuous, and though there is only a glimpse here, there is a difference between honouring the memory of the dead baby, versus behaving as if the baby is still alive. Whilst the accounts here may be outliers, this would seem to be a very important feature to consider and further research on this specific topic is recommended.

Finally, this topic would benefit from further qualitative research studies which embrace psychosocial factors. There are five areas which stand out in this research.

1. As this study confirms, continuing bonds occurs regardless of ritual. This lifelong continuing bond has received little attention to date and is worthy of further study to evaluate the pattern that long term bereavement may take. This was an original objective in this study.
2. After death communications offers a rich field of exploration, particularly in the context of end of life visions, as Kerr & Mardorossian (2020) note. As found here, caregivers at time of death may not recognise these end of life visions as significant. This ongoing connection is poorly understood and appears to be significant for the dying and their families.
3. The value of funeral rituals is subject to further investigation, particularly the role of men in the performance of mortuary ritual. Though in Ireland, there are increasingly fewer older fathers who would have had a hands on traditional approach to the burial of their babies, this may not be the case in other cultures. What is demonstrated here is that the act of burial has a significant effect on fathers who may often be the last person to touch the baby's body or coffin and the lasting effects of these practices have been largely overlooked in the scholarship.
4. Thorough intergenerational dimensions of perinatal loss offer other avenues of inquiry. In this study, though briefly mentioned, generational loss prompted new conversations within families and great-grandparents, grandparents and grandchildren all played significant roles in assuaging the grief of bereaved parents.
5. The issue of routing women for home birth rather than hospital, when stillbirth has been identified, needs further evaluation and risk assessments. To do so, also requires a reconsideration of public health homebirth policies which should include relational care.

10.9 Conclusions

This thesis demonstrates that interdisciplinary approaches to perinatal death research offer new insights. By taking a social constructionist perspective this study illustrated how death customs are shaped by external and economic forces, which in turn influence the expression of mourning.

Though cultural dimensions of grief and mourning are affirmed in the scholarship, in practice the grief scholarship largely behaves in a way that ignores culture, and thus social context. This study shows that context is important. It reveals that death rituals form part of a complex ecosystem that develops and evolves in response to external

influences. Interference can have unintended consequences, as for example, by changing place of death, grief can be disenfranchised. Disenfranchisement was not observed in home births and thereby the conclusion to be drawn is hospitals may be responsible for the creation of disenfranchised grief.

Moving beyond Anglo American interpretations of mortuary ritual, this thesis explored Irish mortuary traditions which differ to those of England and America. Irish culture was demonstratively different in the way in which it expressed grief and performed rituals, maintaining a collectivist rather than individualist approach to funerals. Mortuary traditions in Ireland relied on material assistance from others for the disposal of the body, thereby rituals were both collective and social. Their primary purpose was to reinforce social bonds amongst the living. Thus Irish mortuary rituals are firstly sociological, though they may incorporate psychological benefits. This conclusion suggests that when scholarship limits itself to disciplinary silos or ingrained perspective, it can miss important context.

Rituals for perinatal infants were found in Irish history. Rituals for children were comparable to those of adults but differed slightly, being more subdued. The rationale for this was attached to the deep sorrow felt at the deaths of children. The evidence here confirms that despite high rates of poverty and recurrent reproductive loss, Irish parents grieved for their children. This is true across all time periods under exploration. Babies and children were not considered non-persons. Silence was not punitive, it represented deep and shared sorrow. Further, adult mortuary rituals incorporated commemoration of dead children, this suggests that the experience was common, deeply felt and regretted. Over the course of the twentieth century, this knowledge was lost.

In the context of bereavement, this thesis concludes that parents continue to have a relationship with their babies for their whole lives, regardless of whether they met their baby or had any mortuary rituals. This study provides a counterpoint to the assumptions in the psychological literature which assume verbal expressions of grief and the exercise of normative adult funeral rituals are vital to parents mourning. This thesis concludes that much of the western psychological literature regarding perinatal death fails to consider the individualistic origin of these theories and overlooks the potential benefits of traditional rituals in collective societies. Traditions may embody far more meaning and nuance than is immediately apparent. Psychologists should tread carefully, particularly in low income countries which retain collectivist cultures, and

recognise that what they do may have negative consequences both for bereaved parents and cultural understandings of death.

Regarding midwifery practice and research, this study concludes that midwives face a dilemma between following universal standards and woman-centred care. Without adequate funding for maternity care it is difficult to see how ideal standards can be implemented and maintained. There is no doubt that standardisation should be an aspiration for quality care, however, this may be better served through university programmes which offer a coherent 'emotional toolkit' to trainees so that they are more comfortable providing direct patient care. Trauma informed care should be integrated into midwifery programmes, as well as additional specialist training for trainee and qualified midwives. Bereavement awareness training should be provided to all hospital staff, and not restricted to midwives. This should be extended to palliative care units. Culture can influence midwives preferences for interventions, culture can also influence the expression of emotions. Midwives thus should be aware of both, and how these relate to their practice. Further, midwives must consider advocating for renewed home birth schemes which, as illustrated here, suggest the potential for reduction in parental trauma regarding perinatal deaths. Finally, as parents continue to negotiate perinatal death over their lifetimes, often with unmet needs and birth trauma, midwives may need to consider engaging with public health programmes to better support these parents in the community.

There is much left to explore in both social histories of death and perinatal death, and the emotions and practices attached to both. Folklore and native language both have an important role to play, though barely featured in this study. Much is lost to us, especially regarding Irish rituals, but there is also much to be found when we look in the spaces between.

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Appendix 1 Topic Guide for Parents

TOPIC GUIDE FOR PARENTS

Please include your age now and the year your baby was born

There are 9 Sections

These questions are designed as prompts so you understand the kind of information we are looking to gather. Answer in your own words or choose the survey if you prefer.

ABOUT YOU AND YOUR FAMILY

Could you tell us a little about yourself and your family?

Did you live in rural area or an urban centre at the time your baby died?

What county did you live in?

What was your relationship with the mother/father of the baby who died, at the time? Has this relationship changed?

If you had other children at the time or since that time, did you tell them about this baby?

If you had other children at the time your baby died, how did this affect your family?

If you had other children after your baby died, how did this affect your family?

When thinking about your baby who died, what name would you like to use?

Does this name have some special meaning for you?

Is this name recorded in any official way - birth registration, christening or some other way?

Is this the name you decided to give your baby because there was no official recording of their name?

Was your baby's birth, death or stillbirth officially registered? If so, was this important to you?

If your baby was stillborn, did you retrospectively register their birth after the Stillbirth Registration Act 1995? If so, how did you feel about this?

Is the story you are telling us about one or more babies?

If you had more than one baby who died, would you like to share their first names and the years they were born?

ABOUT THE BIRTH

Could you tell us about the birth of your baby?

Where did this birth occur? (Hospital, home, private nursing home, etc)

Were you attended by a midwife, GP or obstetrician?

How long did labour last for this birth?

How would you describe your overall birth experience?

If a homebirth, who delivered the baby?

If in hospital, could you tell us a little about the birth?

How would you describe the care you received?

If you are the mother, was your partner present in the delivery room with you?

How did you think the healthcare professionals responded to you when your baby died?

Did you get to meet your baby?

What was this like for you?

If you did not get to meet your baby, could you tell us why?

Did you get to make a decision about whether to see, hold, care for or name your baby?

Did you decide to have a hospital baptism for your baby?

If you are the mother, were you well enough to make these decisions?

If you did not make these decisions, who did?

When you think back, was it a good decision to see, hold or care for your baby?

Is there anything you regret about your decisions relating to your baby's birth?

EMOTIONS

What is the strongest emotion you felt at the time your baby died?

When you think of your experience, what is the feeling that stands out the most for you at the time your baby died?

How long do you think you felt this?

Did you have other strong emotions at that time?

Did you ever feel stigma or shame about your baby's death?

If so, what caused you to feel this?

Did you ever feel silenced or that you couldn't talk about your baby?

If so, who did you feel did not want to listen and why?

As you consider all the time that has passed since your baby died, do you think your feelings have changed?

If so, can you attribute this to any specific time, stage or reason in your life?

When you think about your family now, what impact did this baby have?

Did you ever use social media to express your sadness about your baby?

Was there a reason why you chose to do this?

YOUR PARTNER

Can you tell us if your partner responded differently to you, if so, how?

When you think back to the time of your baby's death, do you think your partner felt the same way as you?

If it was different, how was it different?

Was your partner supportive during and after this time?

Would you talk with your partner about your baby more, less or just differently?

Does your partner remember their experience differently now to when you were younger?

Did your partner make the decisions relating to the funeral and burial of your baby?

If your partner made these decisions, how did this make you feel?

SAYING GOODBYE

Could you share with us how you said goodbye to your baby?

Did you feel you had enough time with your baby to say goodbye?

Were you or your partner present when your baby died?

Were you holding your baby when this happened?

Did you ever receive an explanation for why your baby died?

If you were not present at the death of your baby, how was this communicated to you?

Did you get to bring your baby home before burial?

Did you have a wake for your baby?

When your baby died, do you recall being asked about a funeral or burial service?

Who made the decisions regarding the funeral and/or burial of your baby?

Were you asked what funeral arrangements you would like to make for your baby?

Did you feel pressured to make decisions?

Was financial cost a consideration in your decision making?

Did you participate in decisions about the funeral arrangements for your baby (songs, prayers, coffin, etc)?

If not, could you explain why?

Did you put any personal items into the coffin with your baby?

What was the thing you felt you had most and/or least control over relating to your baby's death and burial?

If you chose Cremation for your baby:

Cremation was not that usual in Ireland, could you please share with us a little about that ritual?

Do you keep your baby's ashes somewhere that you can visit?

Did you have a formal funeral for your baby?

Did you have the typical Irish funeral for your baby or did you do something different?

Did you attend the funeral of your baby?

Did your family and friends attend the funeral?

How did your community respond?

How much did your religion influence your decisions about the funeral and rituals for your baby?

Whether you had a funeral or not, now you think back on it is there anything you would have done differently?

GRAVES & COMMEMORATION

People in the past often did not know where their baby was buried and sometimes chose to bury their babies close to home - we are interested in learning a little more about these decisions relating to the burial and commemoration of babies

Do you know where your baby is buried?

Where was your baby buried? For example, was your baby buried in a new or existing family grave, in the garden or a field close by?

Is there any reason why you chose this kind of burial for your baby?

Did you get a grave marker for your baby? Maybe a headstone, wooden cross or some other grave marking?

Do you or did you decorate your baby's grave?

How do you decorate the grave?

Have you always done this?

Did you ever visit your baby's grave? Did your partner?

Did you continue to visit your baby's grave - why or why not? Did your partner?

Do you have any wishes relating to your baby when you die?
Angel Plots are grave spaces designated for the burial of children. If your baby was buried in an Angel Plot:

Could you tell us why that was the case if you know?

Do you recall being asked?

Do you know where your baby is buried in the Angel Plot?

Do you decorate the grave or visit it?

REMEMBERING YOUR BABY

When you think back to when your baby died, what is your strongest memory?

How often do you think about your baby that died?

When you recall your baby that died, how do you feel?

Do you think time has made a difference to your feelings?

What do you think the hardest part of this experience is?

Do you think that having a term to describe your status as a parent of a baby that died would have helped?

When you reflect on your experience, is there anything that gives you comfort?

Do you have any wishes relating to your baby when you die?

Is there a specific way you think of your baby?

In Irish cultural traditions, many people speak of robins, angels, and feathers as symbols of connection and remembrance - is this something that applies to the way you think of your baby?

Did the concept of Limbo affect you and your feelings about your baby at all?

Do you want people to know about your baby or do you prefer to keep it to yourself?

Today there are public awareness campaigns aimed at breaking the stigma and silence attached to the death of a baby.

What do you think about such campaigns based on your own life experience?

Have current affairs or news stories (past or current) affected your feelings regarding the death and burial of your baby at all?

MEMENTOES & RITUALS

What mementoes do you have from when your baby was born?

If you received mementos (footprints, locks of hair, etc) from the hospital at the time of your baby's birth, how important are these to you?

Are these mementos as important to you now as they once were?

Do these mementoes bring back good or bad memories for you?

If you did not receive mementos from the hospital, are there other things that remain important to you?

Do you prefer your own ways of remembering or the mementoes from your baby's birth?

Do you have any other ways of commemorating your baby? For example, some parents have songs, plant trees or have other ways to remember their baby.

Do you include other people in your remembrance? For example, do you have a party or have a balloon release ceremony?

Do you attend local or annual commemorative services or gatherings?

Do you attend hospital memorial services?

Have these ways of remembering changed over time?

PARENT SUPPORTS

Did you ever seek out other parents or join a support group for parents?

Did you access parent supports online or in-person?

How long after your baby died did you seek parent support?

How long did you continue accessing parent supports?

Did you find these useful? If you did not find these useful, is there a reason why?

FINISH

Why did you decide to share your story with us?

Is there anything you think we missed, or we should know for future research?

Appendix 2: Topic Guide for Adult Children

TOPIC GUIDE FOR ADULT CHILDREN

Please include your age now, your mother's age at the time of the birth

and the year the baby was born

There are 7 Sections

These questions are designed as prompts so you understand the kind of information we are looking to gather. Answer in your own words or choose the survey if you prefer.

ABOUT YOU AND YOUR FAMILY

Could you tell us a little about yourself and your family?

What county did your parents live in at the time this baby was born?

Did your parents live in rural area or an urban centre at the time your baby sibling died?

When did you find out about the baby who died?

When thinking about the baby who died, what name would you like to use?

Does this name have some special meaning for you or your family?

Is this name recorded in any official way?

Was your baby sibling's birth, death or stillbirth officially registered?

If your baby sibling was stillborn, did your parents retrospectively register the birth after the Stillbirth Registration Act 1995?

What effect did registering the stillbirth have for you and/or your parents?

Is the story you are telling us about one or more babies?

If you had more than one baby sibling who died, would you like to share their first names and the years they were born?

ABOUT THE BIRTH

Could you tell us about the birth of your baby sibling?

Where did this birth occur? (Hospital, home, private nursing home, etc)

Who delivered the baby? (Midwife, GP, etc)

Was your father present at the birth of the baby?

Was the baby baptised?

Did your parents get to meet their baby?

Did your parents ever describe any aspect of the birth of the baby in hospital?

SAYING GOODBYE

Could you share with us how your parents said goodbye to their baby?

Were your parents present when their baby died?

If your parents were not present at the death of their baby, how was this communicated to them?

Did your parents ever receive an explanation for why their baby died?

Did your parents experience the death of the baby differently to each other? If so, how?

If one of your parents died before the other, did this affect how the surviving parent felt about the baby that died?

Did your parents ever experience any of these feelings in relation to your baby sibling's death? (shame, stigma, anger, isolation, guilt, etc)

Did you ever experience any of these feelings in relation to your baby sibling's death? (shame, stigma, anger, isolation, guilt, etc)

When you think about your family now, what impact did this baby have? For example, did you feel your parents became overprotective?

Did you ever use other outlets to express your sadness about your baby sibling? Was there a reason why you chose to do this?

ABOUT THE FUNERAL

What do you know about the funeral arrangements for your baby sibling?

Who made the decisions relating to the funeral and burial of your baby sibling?

Did your parents spend any time caring for the baby that died before the baby was brought for burial?

Did your parents bring the baby home from the hospital before burial?

Did you have a wake for your baby sibling?

Did you have the typical Irish funeral for the baby, or did you do something different?

How much did your religion influence your parents' decisions about the funeral and rituals for their baby?

In the late nineteenth and early twentieth century, people often used whatever they had available, this included for example orange boxes as baby coffins. Do you know if any of these apply to your baby sibling's burial?

Cremation was unusual in Ireland until recently. If your baby sibling was cremated, could you share a little about that experience please?

Whether your parents had a funeral or not, now you think back on it is there anything they would have done differently?

GRAVES & COMMEMORATION

People in the past often did not know where their baby was buried and sometimes chose to bury their babies close to home - we are interested in learning a little more about these decisions relating to the burial and commemoration of babies

Do you know where your baby sibling is buried?

Was the burial arranged by the hospital?

Does your baby sibling have a grave marker?

Do you decorate the baby's grave? Have you always done this?

Did your parents ever comment on visiting the grave?

Is there anything we are missing about the burial or funeral of your baby sibling?

Angel Plots are grave spaces designated for the burial of children. If your baby sibling was buried in an Angel Plot:

Was this your parents' decision? Was this arranged by the hospital?

Do you know where exactly the baby is buried in the Angel Plot?

Does your baby sibling have a grave marker?

Is the baby's grave decorated?

Do you attend commemoration services at the Angel Plot?

REMEMBERING BABY

What do you recall most about the time your baby sibling died?

Do you talk about this baby now?

When you reflect on your experience, is there anything that gives you comfort?

If your parents are no longer alive, did they have any wishes relating to their baby when they died?

In Irish cultural traditions, many people speak of robins, angels, and feathers as symbols of connection and remembrance - is this something that applies to the way you think of the baby?

Did the concept of Limbo affect your parents' feelings about the baby at all?

Did the concept of Limbo affect your feelings about the baby at all?

How important were religious rites or rituals for the baby to your parents? For example, would they have memorial masses or blessings?

How important would religious rites or rituals be to you now for the baby? For example, would you have memorial masses or blessings?

Today there are public awareness campaigns aimed at breaking the stigma and silence attached to the death of a baby. What do you think about such campaigns based on your own life experience?

Have current affairs or news stories (past or current) affected your feelings regarding the death and burial of your baby sibling at all?

MEMENTOES & RITUALS

Do your parents have any mementoes from when their baby was born? (for example, a hospital bill, blanket, footprints, etc)

Did they consider these mementoes to be valuable?

If your parents are no longer alive, what significance do these mementoes now have for you?

Did your parents do other things to remember their baby?

Do you do any of these things to remember the baby?

Have these ways of remembering changed over time?

Do you attend memorial events for the baby?

FINISH

Why did you decide to share your story with us?

Is there anything you think we missed, or we should know for future research?

Appendix 3: Participant Information Leaflet

THE SPACES BETWEEN US

PARTICIPANT INFORMATION SHEET

We would appreciate it if you would take the time to read the following information as this is required for ethical approval of the study and to ensure you understand what the study is about before you proceed. Thank you for taking the time to do this.

Invitation to Participate

You are being invited to take part in a research study being carried out by the School of Nursing & Midwifery, Trinity College Dublin because you are either a parent or adult child of a parent, who experienced the death of a baby during pregnancy, at birth, or shortly after birth, before 2001.

Before you decide if you wish to take part, you should read the information below carefully. If you do not wish to participate, you do not have to. You should clearly understand what taking part in this study involves, and the risks and benefits of taking part so that you can make a decision that is right for you.

Please take time to consider the information provided about this study. Do not feel rushed or pressured to make a quick decision. You may wish to discuss your participation with your family, friends, or healthcare professional.

If you have any questions about this research that are not answered by the information below, please feel free to ask by emailing Ms Ciara Henderson thespacesbetweenusstudy@gmail.com

Who is organising and funding this study?

This research is being conducted as part a doctoral research thesis by lead researcher Ms Ciara Henderson, TCD School of Nursing & Midwifery. The project is supervised by Prof Joan Lalor (Professor in Midwifery, TCD School of Nursing & Midwifery) and Dr Georgina Laragy (Glasnevin Cemetery Trust Assistant Professor in Public History and Cultural Heritage, TCD School of Histories & Humanities).

This study has been approved by the School of Nursing & Midwifery Ethics Committee, Trinity College Dublin. There is no funding provided for this study. There are no identified conflicts of interest.

WHY IS THIS STUDY BEING DONE?

For many mothers and fathers, the death of their baby was a profound life experience. We are interested in understanding more about what happened to parents when their baby died during pregnancy, at birth, or shortly after birth, a long time ago.

Unfortunately, in the past, these experiences were not typically recorded, and parents often felt they could not talk about their baby. We have limited knowledge about how mothers and fathers were treated during and after the birth and death of their baby. We would like to know more about how parents have remembered their baby and how the passing of time may affect their feelings in relation to the death of their baby. This study asks two main questions:

- What was it like to meet and say goodbye to a baby that died around the time of birth?
- How did this experience unfold over your life?

We wish to learn so that we may improve supports for long term bereaved parents. The results of this study may also influence care models for newly bereaved parents.

WHY AM I BEING ASKED TO TAKE PART?

You are being invited to participate as you are either:

- An adult child of a bereaved parent (whose baby was born before 2001)
- A bereaved parent for at least 20 years (your baby was born before 2001) and this baby was stillborn, or died during the last 6 months of pregnancy, or shortly after birth (perinatal death)

Whilst all experiences are important to us as researchers, this study is limited to the long-term study of mourning. For this reason, if your baby was born since 2001 you are not eligible to participate in this specific study.

As we are gathering stories relating to the early and mid-twentieth century, we would like to invite the adult children of parents who experienced a perinatal death to participate in this study as they may be able to provide us with additional information regarding their family experience of perinatal death and remembrance.

This is an emotive topic for many people, if you do not feel emotionally stable enough to participate in this study, please close this browser now.

HOW DO I TAKE PART?

If you would like to participate after reading this information sheet, you can choose one of the options below. Please do not proceed until you are sure you would like to participate and agree that you have all the information that you need. All information collected in this study is done so anonymously (unless you wish to send us an audio recording). If you would like to take part, you can choose ONE of these ways:

WRITE TO US

You can simply write to us and tell us your own story, in your own words, in your own way. You can use the study Topic Guide to better understand the kinds of information we are seeking but you do not need to follow this.

You do not need to sign your name. The postal address is provided below. By posting your story to us, you have completed the study. As your story is collected anonymously it is not possible to withdraw your information after you post it.

The Spaces Between Us Study
c/o Prof Joan Lalor
TCD School of Nursing & Midwifery
24 D'Olier St
Dublin 2

SEND US YOUR STORY ONLINE

You can choose to write your story in your own words at your leisure and send it to us electronically. You can use the study Topic Guide to better understand the kinds of information we are seeking but you do not need to follow this

Choose the Online Study option. You will then be able to type directly into a freeform text box or you can cut & paste from another document. By pressing submit, you have completed the study. As your story is collected anonymously it is not possible to delete it after you submit it, as we will not be able to trace back to you.

DO THE SURVEY

You can choose to submit your story to us by completing a survey. These questions are the same as those in the Topic Guide.

Each question on the survey provides you with a choice of how to complete it. You can choose to answer some questions in your own words and some in a structured format if you prefer. You may skip any sections you do not wish to answer. If you choose to complete the survey, this should take approx. 15-20 mins of your time. By pressing submit, you have completed the study. As this data is collected anonymously it is not possible to delete your data after you submit it.

In all cases, all data is collected and analysed anonymously. If you reveal any information which could identify you, we will delete it.

RECORD YOUR STORY AS AN ORAL HISTORY

If you prefer, you can choose to record your story in your own words at your leisure and send it to us electronically. You can use the study Topic Guide to better understand the kinds of information we are seeking but you do not need to follow this

If you choose to send us an audio recording, you must indicate your explicit consent, on the audio recording form. Audio recordings are subject to GDPR and as such, data rights apply to your recording. You must include a phrase at the start of your recording confirming your wish to take part and that you have read the Participation Information Leaflet.

You will need to record your story on a recording device such as your mobile phone, tablet or computer. When you are ready to send us your audio recording, you can do so via this secure form. You may, under GDPR, choose to later withdraw from the study. Once your story is collected securely, it will be transcribed and irreversibly anonymised anonymously it is not possible to delete it after you submit it, as we will not be able to trace back to you.

There is no time limit for completing any of these options and we will be accepting submissions until 31 May 2021.

Please note the Topic Guide is only an indication of the kinds of questions relevant to this project. You are not compelled to answer any of the questions and can simply skip the ones you do not wish to answer. You may like to contribute something we have not considered. Each option allows you to tell us your story in your own way if you wish.

Given the sensitive nature of the research, we recommend that you may find a quiet place to complete the study, without being disturbed.

WHAT IF I CHANGE MY MIND?

Your participation is completely voluntary. You can withdraw from the study at any time without penalty and you do not need to provide any reason to do so. If your data is entered online, we do not collect any tracking or IP information. This means your data is submitted to us anonymously. If you begin the study online and decide that you do not want to continue, you can close the browser tab and your data will be deleted. All data collected in this study is done so anonymously and thereby cannot be withdrawn after submission.

WHAT ARE THE BENEFITS?

Taking part in this study may not directly benefit you. However, research performed with insights directly provided by parents and their adult children can help us as researchers better understand the impact of perinatal death on families.

Some participants may benefit from having the opportunity to share their story about their child. As a parent or adult child of a bereaved parent, you may find comfort in looking at the results of this study when they are published as you will be able to compare your own experiences to those of other families.

Some participants may benefit from knowing the story of their family has been noted for the historical record and is contributing to the cultural history of Ireland in the twentieth century.

Participants may benefit from knowing their contributions may be used to inform how support is given to long term bereaved parents as well as newly bereaved parents.

Finally, participants may benefit from knowing that findings from this study may influence international research in midwifery, grief, and bereavement theory.

WHAT ARE THE RISKS?

The main risk to you as a participant is that you may become emotionally distressed by participating in this study. You are under no obligation to complete the study, even if you have started.

As a Parent, you will be asked to reflect on your experience of the pregnancy, birth, and death of your baby. As an adult child you will be asked to reflect on your experience of the death of your sibling.

You will be asked about your feelings relating to this time and since this time and how the death of this baby affected you and your family. Reflecting on these may cause you to become upset or uncomfortable.

If you feel uncomfortable you can stop. If you are completing the study online, you can close the web page. This will end your response and any data you have given so far will be deleted.

If you experience any distress during or after the study, talking to family, friends, or professionals may help. A list of support services is provided below and on the research website.

WHAT WILL HAPPEN TO THE DATA I SUPPLY?

The data you provide will be analysed by the research team. We understand each participant has the right to remain anonymous and we respect that right. We do not request any personal identifiable information and will delete any information which could identify you.

If you participate electronically (either via online or survey) this data is submitted completely anonymously. It is not possible to withdraw your data after submission. Please ensure you are happy to contribute your story before you press the Submit button.

If you post your story to us, it will be transcribed for analysis and the hard copy immediately destroyed.

In all cases, any information which could identify a person, will be anonymised. Information you provide maybe combined with archival material to produce an academic work. As such, copyright of material which you provide may not be retained by you. All data collected from this study will be stored securely for five years after the research has been published. It will then be deleted.

IS THE STUDY CONFIDENTIAL?

We understand that each participant has the right to remain anonymous and have designed the study to allow this. We do not request personally identifiable information (for example, your name). Your story will be treated with confidentiality.

It is possible that in completing this study you may reveal personal information that identifies you or other people. In these cases, we will anonymise the data as necessary to protect your confidentiality. It is important that you understand that there remains a small chance you may be identifiable to those that are familiar with you, for example, and that whilst we endeavour to protect your identity, we cannot guarantee this.

You will not be prompted to complete the study. You will not be contacted by the research team after you submit your story. You will not be contacted to inform you of the results or publication of this study.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The findings of this research study will be presented at conferences and may be published in professional journals, academic journals, presentations, books, creative works (including print and online publications, education, public performance, exhibition and broadcasting) and shared through the media, social media and on the study website.

SUPPORT SERVICES

As this is an emotive subject, we urge you to review the Topic Guide and Study Information before deciding if you wish to take part. Unfortunately, the research team is unable to offer direct emotional support to participants. If you decide to participate and find you become distressed while completing this research, please stop and take time to think about whether you wish to complete it. If you require peer or professional support, here are the contact details of some of the organisations that may offer you support and guidance.

CONFIDENTIALITY

This research operates under the University Research guidelines. As all data is collected at source anonymously, data subject rights do not apply however as this research constitutes historical research in the public interest, any data that may be disclosed to us inadvertently, will be protected in accordance with General Data Protection Regulations until anonymisation. A Data Protection Risk Assessment has been completed indicating a low level of risk of identification.

Please note that as the data is disseminated in the public domain, you may be identifiable to those that know you. We have and will make every effort to ensure that this does not happen. The research team have completed training in data protection and comply with the School of Nursing & Midwifery ethical guidelines. All electronic data will be stored in an encrypted file that is password protected throughout the duration of this project and after the project. This includes written submissions received and then transcribed. Original written submissions once transcribed for analysis will be immediately destroyed.

REIMBURSEMENT AND COMPENSATION

Your decision to take part in the study is voluntary and there are no enticements or compensation for your participation in the study.

WHO DO I CONTACT FOR FURTHER INFORMATION ABOUT THE STUDY?

For Further information on the Study:
Lead Researcher: Ms Ciara Henderson thespacesbetweenusstudy@gmail.com

For Concerns or Complaints:
Research Supervisor: Professor Joan Lalor j.lalor@tcd.ie

WHO DO I CONTACT IF I WISH TO MAKE A COMPLAINT ABOUT THE STUDY?

For complaints related to consent or ethical concerns:
TCD School of Nursing & Midwifery Research Ethics Committee
snm.ethics.com@tcd.ie

For queries on Data Protection:
Data Protection Officer: dataprotection@tcd.ie
Thank you for reading this information sheet and for your interest in this research

Appendix 4: Recruitment Advert

FIGURE 18: RECRUITMENT ADVERT A

FIGURE 19: RECRUITMENT ADVERT B