How grandparents experience the death of a grandchild who had a life limiting condition

Michael Jefferson Tatterton

MSc; PGDip

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Faculty of Health and Medicine
Lancaster University

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

Thesis abstract

Traditionally, family-centred, children's hospice care extends to parents and siblings of children with life limiting conditions. Few studies have focused on the needs of grandparents, who play an increasing role in the families of children with life limiting conditions.

Aim:
To explore the experience of grandparents during the life, and following the death of a grandchild with a life limiting condition.

Methods:
A purposive sampling technique was used to recruit participants who: (i) identified themselves as fulfilling a grandparenting role; (ii) were bereaved for between six and 24 months; (iii) had a grandchild that died from a life limiting condition. Grandparents who were the principal carers of the deceased grandchild were excluded.

Semi-structured, individual, face-to-face interviews were conducted and audio-recorded in participants' own homes. Field notes were taken during and immediately following the interviews. Interviews were transcribed and interpretative phenomenological analysis used to analyse the resultant data.

Findings:
Seven individuals participated in this study. Findings indicated a number of contextual factors that affected the experience of bereaved grandparents, including intergenerational bonds, identity and perceived changes in role following the death of their grandchild. Bearing witness to the suffering of their child and an inability to '*make things better*' were recurrent themes. The essence of grandparents' experiences was interpreted as focusing on fulfilling a parenting role to their child.

Conclusions and implications:
The research identified that the primary motivation of grandparental support stems from their role as a parent, and not as a grandparent.

The breadth of pain experienced by grandparents is complicated by the multigenerational positions they occupy within the family. The transition from before to after death exacerbated the experience of pain. The findings from this study suggest the development of practice to better understand and support grandparents of children with a life limiting condition during life, in addition to bereavement support.

Key words:
Bereavement, children, family centred care, grandparent, hospice, palliative care

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Dedication

Dedicated to the memory of Norah and
Jeff Beck – truly wonderful grandparents.

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Chapter 1: Introduction: grandparents, family, bereavement and society

1.1 Background

Until around 20 years ago the term *'paediatric palliative care'* was unfamiliar to many. Initiated by children's hospices in England, there has been an international, multidisciplinary surge of interest over the last two decades in meeting the needs of children and young people (hereafter, children) with life limiting conditions (LLC), together with their families. In England alone, it is estimated that more than 40,000 children (0-19 years) are living with a LLC, a prevalence of 32 per 10,000 population (Fraser *et al.*, 2012).

To help focus the work of children's palliative care, and to place it in the context of child health services, the following definition is widely accepted:

> *'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.'*
>
> (Association of Children's Palliative Care (ACT) and Royal College of Paediatrics and Child Health (RCPCH) 1997:9)

Bereavement support is an integral element of children's palliative care, which enables families, as well as children themselves, to prepare for and cope with their losses. The progressive and degenerative nature of many childhood LLCs means that multiple losses are experienced by the child and witnessed by families, for example, independent mobility, the ability to eat and drink orally, speech and neurological function, and death. Bereavement support takes many forms across children's palliative care services. British children's hospices have taken various approaches to meeting the bereavement needs of families in their care (Mash and Lloyd-Williams, 2006); the degree of emphasis on bereavement support within hospices varies throughout the UK (Wilkinson *et al.*, 2007). Services typically include pre- and post-bereavement groups for siblings and parents, home-based individual support following the death of a child as well as support for those with particular needs, such as parents of neonates, South Asian mothers and children with the same genetic condition as their deceased sibling (Devanney, Bradley, and Together for Short Lives, 2012). Although these innovations demonstrate that children's hospices are offering bereavement care to meet a variety of needs, it is not yet standard that services support grandparents.

This thesis focuses on the experiences of grandparents. Traditionally, bereavement care that follows the death of a child is extended to their parents and siblings with very few services offering specialist support to members of the extended family. As with the majority of bereavement services, research exploring the effects of child death on a family has focused on the experiences of parents and siblings, with little that has examined the perspective of grandparents (Gilrane-McGarry and O'Grady, 2011). Current understanding of the emotional support needs of grandparents is limited to the generalisation of work undertaken with parents, siblings and health workers (Gilrane-McGarry and O'Grady, 2012). In fact, grandparents are not often considered part of the *'bereaved family'* when discussing bereavement (Nehari, Grebler and Toren, 2007). Anecdotally, children's hospices are experiencing increased involvement with grandparents, both in terms of direct contact, and where hospices are increasingly seeing parents rely on grandparents to support the family, through the provision of care and financial, practical and emotional support. This has led to a growing interest amongst UK children's palliative care services, in particular, hospices, in the needs of the extended family.

1.2 Family centred care

Family centred care is at the core of modern children and young people's nursing, however Smith, Coleman and Bradshaw (2002) suggest that the perpetual evolution of society's understanding, construct and value of *'family'* make defining family centred care difficult. For the purposes of this study, family centred care is defined by Smith *et al.*, (2002:22) as *'the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation'.* It is a multifaceted concept that has developed over the last 60 years, evolving within the culture of children's nursing to a point where it has become inextricable from practice. Family centred care has evolved to reflect the social context of family, moving from parental presence, through parental participation and partnership to what is currently regarded as contemporary family centred care (Smith and Coleman, 2010). The practice of family centred care has been influenced by factors including changes in society, current government policy, research and development of the theoretical underpinnings of family centred care and the responses of parents and clinicians to family centred care (Smith and Coleman, 2010).

Shields *et al.* (2012) acknowledge the potential benefits and challenges associated with the provision of family centred care, but suggest that a lack of staff education and understanding of family centred care has resulted in the questionable commitment to the model of care. There is some conflict in the literature, which whilst recognising the benefits of the implementation of family centred care, such as the reduction of the stress experience of family members of hospitalised children (Melnyk, 2004), families' stress may be exacerbated due the expectations on members of the family to provide input into the care of their child beyond their expectations or capabilities (Shields *et al.,* 2012). Although occasionally acknowledged in the inclusive definition of 'family' when discussing family centred care (Shields *et al.,* 2012; Malcolm *et al.,* 2008; Lyon, 2009), the specific needs of grandparents are not explored in current literature on family centred care.

An acknowledgement of the extended family, and the effect of a sick child on those within the family, is becoming increasingly common. Together for Short Lives, the leading UK charity that champions palliative and hospice care for children and families, have produced a care pathway, in which they state that amongst other family members, grandparents '*should be encouraged and supported to continue their caring role with the child.*' (Widdas, McNamara, and Edwards, 2013:29). Despite contemporary definitions of family centred care and statements which acknowledge the role of grandparents within families by organisations, anecdotally many services are not embracing the broad definition of *'family'* when developing or delivering care services to children and families, which, like current research, focuses largely on the needs of the sick child and their parents. The result of this is that grandparents, and therefore their needs, remain invisible (Coall and Hertwig, 2010; Nehari, Grebler and Toren, 2007); this is demonstrated by the lack of dedicated support services available to grandparents of children with LLCs, despite their increasing presence and role within children's hospices.

1.3 Grandparents

Grandparents play an important and increasing role in the lives of children affected by LLCs and their family (Coall and Hertwig, 2010). The grandparenting role in general has been described as both *'tenuous'* and *'ambiguous'* (Reitzes and Mutran, 2004) due to few explicit norms in the role and function of a grandparent in Western culture.

1.3.1 The social context of grandparenthood

Before considering grandparents' experience of bereavement, it is important to consider the changing social context of grandparenthood in the UK, in order to gain a more robust and relevant understanding of the role and expectations of grandparents within a family. Changes in Western society, such as mortality, fertility, higher divorce rates and greater proportion of mothers in employment, mean that grandparents potentially have greater opportunities to fulfil a grandparenting role (Corsaro, 2014).

The changing demographics of British society over the past century, namely lower birth rates, a reduction in mortality rates and increased life expectancy (Bennett, 2000) as well as proximity of living (Seltzer and Bianchi, 2013) have had a significant and multifaceted impact on families. In 2011 there were more than 14 million grandparents in the UK, of which, 1 in 10 was under 50 years of age (Grandparents Plus, 2011). The average 10 year old has three living grandparents, compared to two in 1950. It is also estimated that 80% of 20 year olds have at least one living grandparent. The current life expectancy in the UK has reached the highest levels on record, at 78.1 years for males, and 82.1 years for females (Office for National Statistics, 2011), which look set to continue to rise. These statistics illustrate that grandparenting is no longer confined to the last decades of life, despite it being regarded as the last stage in the family life cycle (Bennett, 2000).

Numerous researchers have considered the grandparenting role both in general and in the context of illness, however this is often from the perspective of and from research conducted with parents, and is often in isolation, rather than in the context of their family (Gilrane-McGarry and O'Grady, 2011; Nehari *et al.*, 2007). It is important to appreciate grandparenting both individually and within the context of their family. This is illustrated by Kornhaber (1985:171), who argues that *'families are, after all, a natural state for humans. They are recreated every time a child is* *born. That can never be biologically extinguished no matter how much they are ignored or disdained socially'.*

1.3.2 Grandparents, identity and family

Humans actively construct identities within their roles in response to the context in which they exist. As we progress through life, we acquire new roles, while at the same time either maintain or relinquish those already held. In grandparenthood, role duality is often seen, where individuals can simultaneously occupy both parenting and grandparenting roles. Reitzes and Mutran (2004:pS213) note the unusual nature of role acquisition of a grandparent, which is *'not dependent upon the actions of the person but on the fertility of one's children.'*

Context is important in the establishment and recognition of identities and in the fulfilling of roles within a family; roles do not exist in isolation but in contrast to and in negotiation with related roles (Stryker and Burke, 2002). Thus, it is expected that there is some overlap and shared elements of generational roles within a family, such as those between the roles of a parent, grandparent and great-grandparent; indeed, Reitzes and Mutran (2004) describe grandparenting as an extension of the parenting role.

From a family perspective, grandparenthood can be described as a dual transitional process (Reitzes and Mutran, 2004), in which adult children become parents and their parents become grandparents. Existing literature suggests ambiguity in the role of the grandparent, describing grandparenthood as being peppered with negotiation and the establishing, maintaining and enforcing of role boundaries by both the parent and the grandparent. This is neatly illustrated by (Corsaro, 2014:32), where grandparents are described as *"volunteer firefighters' who are 'required to be on the scene when needed but otherwise keep their assistance in reserve".* Silverstein and Marenco (2001) recognise the gatekeeping function of parents, who regulate the quantity of contact and therefore the quality of the relationship between grandparent and grandchild, which therefore impacts on the identity as a grandparent, as well as the meaning, value, authority and recognition of the role.

Grandparent identity and the opportunity to fulfil the functions associated with grandparenthood can enhance the wellbeing of older adults, where they hold the position of a valued elder within the family, as well as providing a link to their past, in which they fulfilled a parenting role (Youngblut *et al.*, 2010). Reitzes and Mutran (2004) found a positive correlation between the identification as a grandparent and a heightened sense of self-regard for the grandparent, and suggest that identification as a grandparent enables a sense of immortality, where individuals continue through subsequent generations and the continuity of the family.

1.3.3 Grandparents and grief

A number of papers have been written on grief and bereavement within a family unit which refer to grandparents, however understanding of grandparental grief is based on the perceptions of bereaved parents, frequently surrounding perinatal deaths (O'Leary, Warland and Parker, 2011; White, Walker and Richards, 2008; Youngblut *et al.*, 2010). The unique position of grandparents within a family and the effect of this on their grief is widely acknowledged (Kohn and Moffitt, 2000; Potts, 2005; Young and Dowling, 2012). The characteristics of grief in grandparents are multifaceted and appear to be affected by many influences, responding to the social context in which the family exist. Grandparents appear to share many of the same responses to the death of a child as parents, however these are not expressed at the same frequency or intensity as bereaved parents (Fry, 1997).

Hayslip and White (2008) note that parents control the quality of grandparents' relationship with grandchildren, influencing the impact of the grandchild's death on grandparents, suggesting a correlation between the quality of the relationship and grief experience. Despite this, little scientific attention has been afforded to the bereavement perspectives of grandparents (Hayslip and White, 2008). Ponzetti and Johnson (1991), Ponzetti (1992) and Stroebe *et al.* (2008) found that the intensity of the grief responses of grandparents correlated to the intensity of the intergenerational bonds between parents and grandparent. Strong intergenerational bonds are seen most frequently between maternal grandparents and mothers (Easthorpe, 2003). Conflicting intergenerational needs during bereavement may become a source of tension which can lead to the breakdown of relationships, if not resolved effectively (O'Leary *et al.*, 2011).

The high expectations placed on grandparents by bereaved parents are widely documented. The multifaceted expectations include being available to provide emotional and practical support, assistance in organising and paying funeral expenses, assisting with care of surviving grandchildren, in addition to other instrumental support (Danielsbacka *et al.*, 2011; Youngblut *et al.*, 2010). Statham

(2011:12) reports that grandparents who actively contribute to family life by providing support and care to their grandchildren benefit from '*an enhanced sense of purpose, even if they find childcare physically and emotionally draining*'. White, Walker and Richards (2007) found that comfort was felt by parents in grandparents '*being present*' or in '*acknowledging the significance of the loss*'. However, poorly-chosen, well-meaning statements, given with the intention of conveying understanding and support to '*move on*' or '*get over it*' (Hayslip and White 2008) can exacerbate familial tensions. Clumsy support and a lack of knowledge of the needs of parents are frequently cited as a source of conflict and friction. White *et al.* (2007) reported that this kind of '*unhelpful*' advice and support is most frequently associated with that offered by maternal grandmothers and appears to cause the most distress to mothers. Hayslip and White (2008) suggest that this is because of the level of expectation that mothers place on maternal grandparents (Easthorpe, 2003).

Current literature suggests that grandparents do not show their grief, owing firstly to a desire to protect parents from additional '*sadness*' by hiding their own grief and secondly putting aside their own grief *to 'attend to the needs of their children and surviving grandchildren'* (Hayslip and White, 2008:445). The lack of visible grief can further compound grandparents' experiences. Stroebe *et al.* (2008:451) argue that this situation can lead to the depravation of social support needed by bereaved grandparents and *'undermine the likelihood that they will ask for help with their feelings, complicating the grieving process further'*. Hayslip and White (2008) discuss disenfranchised grief, describing grief that is considered unimportant (Doka, 2002) by others, therefore not affording survivors the right to grieve (Fry, 1997), or that support at the time of a child death is foucsed on parents, rather than grandparents, earning grandparents the label of *'forgotten grievers'* by Ponzetti and Johnson (1991). The concept of disenfranchised grief was also found in research pertaining to the loss of grandchildren with conditions such as acquired immune deficiency syndrome (AIDS), which, in addition to the specific stigma associated with AIDS itself, it is a condition were those with the illness are expected to die, similar to children who use children's hospices in the UK.

1.4 Building on existing knowledge

The importance of considering context and its effect is well established in social research. Although some work has been undertaken with grandparents that focuses on experiences of loss, this has not been from the perspective of those bereaved from grandchildren with LLCs. The nature of childhood LLCs present a unique set of circumstances, shaping the experience of families, including, but not limited to, a high association between LLCs and profound disability, the progressive nature of many of these conditions, as well as the longevity and trajectory of LLCs in childhood. This study will explore the grandparenting experience from the perspective of individuals fulfilling a grandparental role in the context of their family.

Societal changes in western culture have resulted in an increased presence and demand for grandparents within contemporary family life. This is amplified in families with children affected by LLCs, due to the needs of the sick child, and the consequent needs of the child's parents in meeting those of their child.

1.5 Purpose of the study

The purpose of this study is to develop and expand knowledge of how grandparents experience the death of a grandchild from a LLC by seeking a richer understanding of how they define their experiences. Furthermore, it intends to enhance the understanding of how social and familial influences affect the context of their experiences.

1.6 Terms used

Within this thesis, unless otherwise stated, relationships highlighted are from the child's perspective; *'child'* is used for discussing the youngest generation, *'parents'* refer to the parents of the child and the term *'grandparent'* or *'great grandparent'* used to describe those in a grandparenting role. Names of individuals have been changed to gender-appropriate pseudonyms, and organisation names omitted to protect the identity of those discussed. The term LLC is used to describe conditions from which children are likely to die in childhood or early adulthood; this inclusive term includes all conditions, including those where there is no formal diagnosis.

Chapter 2: Literature review

2.1 Introduction

The purpose of this literature review is to systematically search, analyse and synthesise existing literature that explores the experience of grandparents following the death of a grandchild from a life limiting condition (LLC).

2.1.1 Choosing a review method

'Research methods should be chosen based on the specific task in hand' (Silverman, 2013:10). This literature review aims to explore the experiences of bereaved grandparents, specifically those whose grandchildren had a LLC. Although there are a number of review methods that would go some way to answering the question, it is the construction of the experience that is of particular interest. Provisional pre-thesis reading and the author's professional experience of working within children's palliative and hospice care, explored further in section 4.1, suggest that the context of the bereavement experience has a profound impact on an individual's experience of grief and coping. It is therefore important that the chosen review method enables the context of the individual studies to be maintained, while facilitating concurrent analysis, producing a review that critically captures what is already known and identifies gaps in knowledge that require further research. This is best explored using qualitative methods.

Qualitative studies are concerned with how people understand and make sense of their lived experiences. Systematic amalgamation of findings from multiple qualitative primary studies can be beneficial, adding depth and breadth to existing understanding through the generation of comprehensive and generalisable theory (Thomas *et al.*, 2004). There are a growing number of qualitative research synthesis methods, particularly those surrounding heath-related research, as well as a developing interest in the use of such synthesis to inform both policy and practice (Barnett-Page and Thomas, 2009). It is important that the researcher can distinguish between methods of qualitative synthesis, selecting a method that is appropriate and likely to produce a desirable end product considering the study being undertaken. Barbour and Barbour (2003) suggest that *'explanatory context'* of individual studies is often lost in the combining of qualitative studies; a meta-synthetic approach enables the preservation of context (Toye *et al.*, 2013) through the provision of tabulated summaries of each paper included, detailing the aims of each study, the sample, setting, method and key findings (Thomas and Harden, 2008). The capturing and preservation of context is a central aim of this study, which can be achieved by using a meta-ethnographic approach.

Contextual preservation is a fundamental principle and value, which runs throughout this thesis, owing to an acknowledgement that the context of the lived experience has a profound effect on the construction and understanding of experience by the individual. Other approaches of qualitative synthesis (Barnett-Page and Thomas, 2009) were considered, including framework synthesis, textual narrative synthesis and meta-narrative, but were deemed less appropriate, owing to the belief that mere integration would not be appropriate in enabling better understanding of the experience.

Qualitative meta-synthesis is a type of qualitative enquiry that uses findings of existing qualitative studies that are linked by the same or an associated focus and relate to the specific research question of the synthesiser (Zimmer, 2006). The aim of meta-synthesis is to develop conceptual understanding, rather than to aggregate findings (Toye *et al.*, 2013). Meta-synthesis is described in various but related ways (Zimmer, 2006) across human science research; Noblit and Hare (1988) describe a variation of meta-synthesis, *'meta-ethnography,'* that differs from the grounded theory-based approach of Glaser and Strauss, focusing on the synthesis of interpretative research. Since its introduction in 1988, the method has become increasingly popular in human science research, which has led to the refining of the process by a number of researchers seeking to develop the contribution of the meta-ethnographic approach. Toye *et al.* (2013) suggest that the interpretative method enables the development of conceptual understanding across studies, rather than simply aggregating findings from multiple studies, leading to deeper understandings of a particular phenomenon. In this study, it is important that the context of individual experience is preserved - clinical practice suggests that the experience of individuals within a family is unique to them. It was therefore important to preserve the individual accounts presented in primary studies. Atkins *et al.* (2008) note that this approach enables a higher level of analysis, using the seven-phase approach detailed below. The key strengths of the meta-ethnographic model lie in its aim to preserve the properties of primary data included in the meta-analysis through the retention of specific terms used and the reciprocal translation of studies into each other (Dixon-Woods *et al.*, 2004). The themes identified in one study are compared to and amalgamated with findings from other included studies, ensuring that *'each transfer is valid and whether there are any reasons that understandings gained in one context might not be transferred to another'* (Thomas and Harden, 2008:11).

2.2 Method

The synthesis of evidence can be described as a process involving the extraction of data from individual studies, interpreting and representing them in a collective form (Campbell *et al.*, 2011). Noblit and Hare (1988:13) explain that using a structured meta-ethnographic approach *'reduces the accounts while preserving the sense of the account through the selection of key metaphors and organizers'.* A meta-ethnographic approach is suited to synthesising a small number of studies (Toye *et al.*, 2013) and is used widely in healthcare. Reviews of the suitability of meta-ethnographic research suggest that the number of studies included ranges from three to 44 studies (Campbell *et al.*, 2011; Dixon-Woods, Booth, and Sutton, 2007; Hannes and Macaitis, 2012).

Meta-ethnographic synthesis is a seven-phase, iterative research process, providing a robust, systematic framework for the synthesis of qualitative studies, which extends beyond the descriptive approach associated with a narrative literature review (Noblit and Hare, 1988), as shown in table 1 below. Although their model provides a clear and structured process, the authors suggest that their method is best considered as a continuum of iterative processes, rather than a set of separate decision points.

Table 1: Seven stage meta-ethnography process
(adapted from Hubbard, McLachlan, Forbat and Munday, 2012)

Phase one:	Getting started Identifying and defining the area of interest
Phase two:	Deciding what is relevant Conducting a systematic literature search for relative studies
Phase three:	Reading the studies With particular attention on metaphors used by the authors to describe or explain the grandparents' experience
Phase four:	Determining how studies are relating to each other Listing key metaphors in each study using a tabular format to compare studies
Phase five:	Translating studies into each other Exploring relationships between metaphors within a study and between studies.
Phase six:	*Synthesising translations* Determining whether some metaphors can encompass other metaphors, using '*reciprocal translation*', where similar studies can be translated into the metaphors of others
Phase seven:	*Expressing translations* Formation of the written meta-ethnography

Noblit and Hare (1988:18) highlight the interpretative elements of a meta-ethnographic study, suggesting that:

> *'an interpretation enables the reader to translate the case studies into* [their] *own social understanding: interpretative accounts, above all, provide a perspective and, in doing so, achieve the goal of enhancing human discourse.'*

The seven phases of the Noblit and Hare (1988) process are discussed in turn below, referencing this particular review.

2.2.1 Phase one: getting started

The specific research question that this review aims to answer is *'what is known about the experiences of grandparents following the death of a grandchild from a LLC?'*

The following selection criteria were used to determine inclusion in the review:

1. **Qualitative study design;** which explores the experience of grandparents, capturing the context and texture of the experience for their perspective.
2. **Primary research studies;** which detail findings from original research, rather than secondary analysis or meta-studies;
3. **Studies that explore experiences of grandchild loss from the perspective of those fulfilling a grandparental role;**
4. **Studies that focus on the death of grandchildren, and include deaths following a LLC,** defined by the Association of Children's Palliative Care (ACT) and the Royal College of Paediatrics and Child Helath (RCPCH) (1997). Studies included data relating to children with LLCs, however it was not always the exclusive focus of the research.

The following exclusion criteria were applied:

1. **Papers written in languages other than English,** to prevent translation bias.
2. **Studies which focused on perinatal deaths, or losses other than death**

Due to the scant amount of literature available, no date restrictions were placed on the searches. Following a meeting with the subject librarian at Lancaster University it was suggested that no restrictions were placed on the types of qualitative studies that were eligible for inclusion, again, owing to the very limited availability of published works.

2.2.2 Phase two: deciding what is relevant

Preliminary literature searches identified very little evidence surrounding the grandparental grief experiences, which was reflected in the search strategy, which:

- uses broad terms to identify papers for consideration for inclusion.
- did not include any date restrictions, other than defaults within the databases named below.

To demonstrate rigour, and to facilitate the systematic search of existing literature, a modified SPIDER (**S**ample, **P**henomenon of **I**nterest, **D**esign, **E**valuation and **R**esearch type) (Cooke, Smith, and Booth, 2013) strategy was used, shown in table 2. The SPIDER approach was considered more congruent with both the literature review question and the meta-ethnographic approach. A number of other tools were considered, but were less relevant to this study. The widely-used PICO (**P**opulation, **I**ntervention, **C**omparison, **O**utcome) method was considered to define the key elements of the review question, however the quantitative origins of the PICO approach presented some limitations, producing a strategy that was unnecessarily restricted. A number of specific qualitative tools, designed to enable researchers to consider a range of related search terms were considered, including ECLIPSE (**E**xpectation, **C**lient group, **L**ocation, **I**mpact, **P**rofessionals, **S**ervic**E**) (Wildridge and Bell, 2002), used for developing search strategies relating to health management, and SPICE (**S**etting, **P**opulation, **I**ntervention, **C**omparison, and **E**valuation) (Booth, 2006), used for studies that seek to evaluate a health service, neither of which describe the objectives of the research.

Table 2: Literature search terms using SPIDER strategy

				MeSH terms	psycINFO terms
S	Sample	*Grandparents (may include non-biological grandparents, such as step grandparents)*	Grandparent* Grandmother Grandfather	*(no terms exist)*	Grandparents (in family members, ancestors)
P I	Phenomenon of Interest	*Death of a grandchild from a life limiting or life threatening condition*	Grandchild* Granddaughter* Grandson* AND death Bereave* Grie* Palliative	*(no terms exist)* Bereavement > grief Patient care > palliative care	Grandchildren (in **family members**) Stepfamily (in **family**) Transgenerational patterns (in **family**) Bereavement, emotional states, regret, separation reactions, suffering (in **grief**) Death and dying, hospice, terminally ill patients (in **palliative care**) 'End of life care': use **'palliative care'**
D	Design				
E	Evaluation	*Their experiences*	Experience Attitudes		
R	Research type				

The identified search terms and the number of papers identified under each term are shown in table 3 below; Boolean operators and truncation searches were used to further refine the searches, as indicated.

The initial systematic literature search was conducted between 8th and 12th December 2013 which included six bibliographic databases: PsycINFO, PubMed, Web of Science, Academic Search Complete, CINHAL and Embase. Following the initial literature search, searches have been repeated on three occasions: March 2014, September 2015 and January 2016, from which no additional literature was identified after the initial search.

In addition, due to the nature of the research and the scant availability of published literature identified, an appeal for grey literature was made via *PaedPalCare (available at: http://mailman.greennet.org.uk/mailman/listinfo/paedpalcare)*, an international email-based forum which facilitates the sharing and exchange of approaches in children's palliative and hospice care and medicine. Although a *'significant and increasing proportion'* (Chillang, 2009: 1) of evidence can be found in what is regarded as *'grey literature'*, the acquisition and inclusion of such research presents a number of issues, largely relating to poor bibliographic control, rigour, objectivity, and peer review (Chillang, 2009). Despite the appeal for such literature, no additional works were identified.

The titles of the 65 papers were appraised to determine the suitability for inclusion. The yield was refined further, based on the selection criteria outlined in section 3.2.1 above. The abstracts of 45 potential papers were read, which led to the acquisition and reading of 19 full papers, as illustrated in figure 1 below, showing the PRISMA process, ultimately identifying a total of six papers for inclusion in this study.

Table 3: Literature search process

	SEARCH TERMS	Psyc-INFO	PubMed/ Medline	Web of science	Academic search complete	CINHAL	Embase
	DATE OF SEARCH:	08/12/13	08/12/13	08/12/13	09/12/13	10/12/13	12/12/13
1	GRANDPARENTS	3,277	1,610	2,791	4889	267	1,400
2	Grandparent*	3,350	2,137	3,065	4997	284	2,005
3	Grandmother*	1,601	1,881	2,641	9113	90	1,830
4	Grandfather*	645	1,054	1,645	8153	31	996
5	DEATH AND DYING	24,354	1,058	1,241	1228	196	11,836
6	GRIEF	13,468	8,966	6,522	10,821	1,291	6,504
7	BEREAVEMENT	6,747	12,561	5,463	6,516	1,255	5,465
8	TERMINALLY ILL PATIENTS	4,476	4,328	1,449	7,158	2,052	1,518
9	PALLIATIVE CARE	10,341	47,871	15,814	21,474	4,973	21,724
10	TERMINAL CANCER	1,863	44,918	1,239	15,761	91	963
11	Loss	81,636	628,859	1,000,712	520,346	9,616	597,896
12	Bereave*	8,199	6,265	6,814	7,682	1,411	6,120
13	Grie*	17,259	26,484	13,641	34,430	1,568	10,295
14	Death	69,230	569,582	565,403	501,592	13,083	593,652
15	Dying	26,509	24,875	445,023	86,205	2,086	23,104
16	Palliative	11,307	60,967	22,865	26,228	5,611	70,891
17	Hospice	13,471	14,737	6,069	11,678	2,042	12,106
18	“end of life”	5,465	11,377	12,963	70,850	2,270	15,916
19	5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18	169,003	1,287,484	1,951,882	1,059,694	29,814	1,229,380
20	1 OR 2 OR 3 OR 4	4,621	4,659	6,671	21,296	354	4,390
21	19 AND 20	583	439	598	8,254	43	48
	21 AND grandchild*				1,024		
	Included papers:	**34**	**17**	**16**	**6**	**3**	**16**
						Total	**92**
						With duplicates removed	**65**

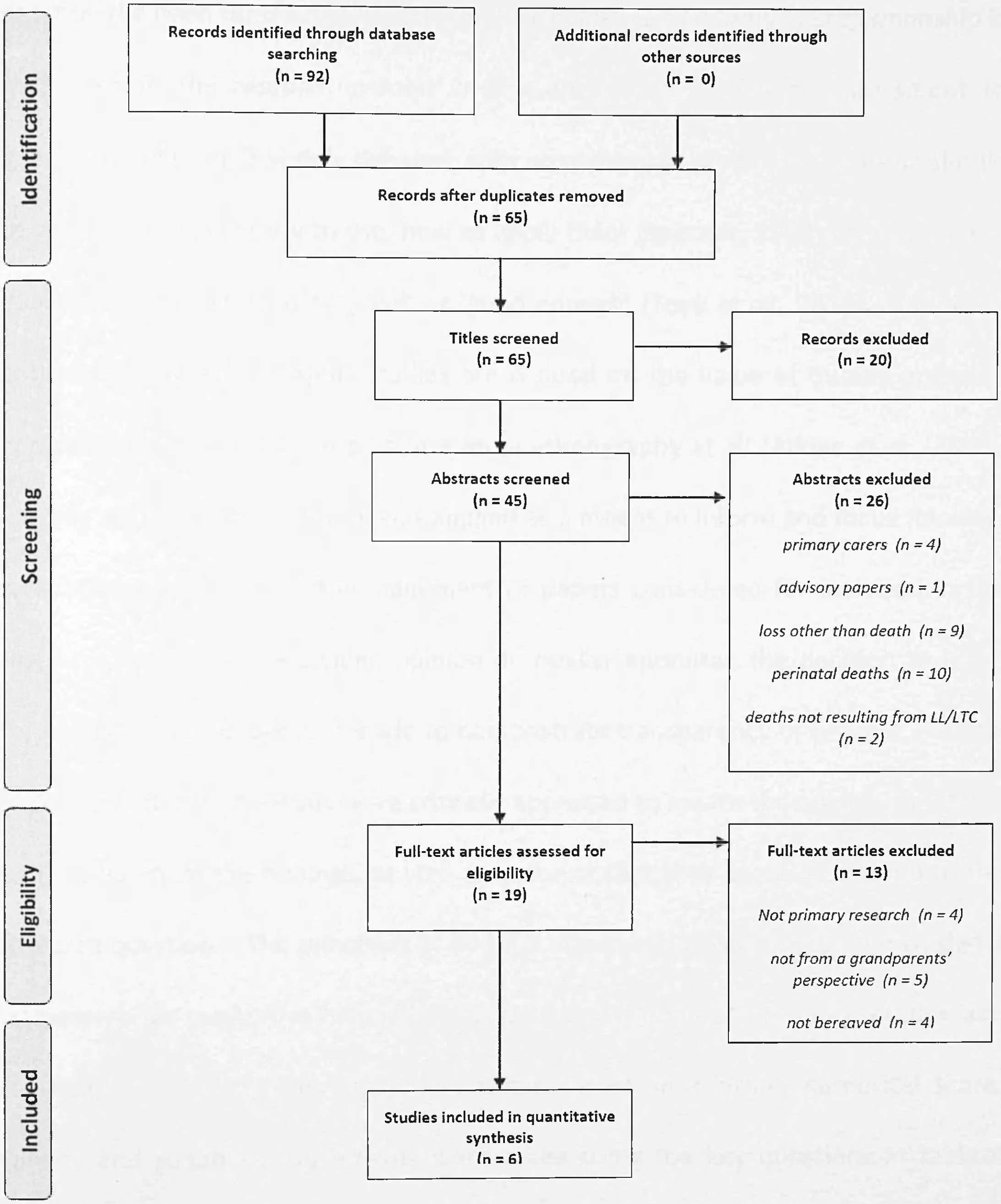

Figure 1: PRISMA flow diagram

2.2.2.1 Qualitative research: critical appraisal

Critical appraisal of published research is an essential element of meta-synthesis, preventing the inclusion of poorly conducted research where there is likely to be bias (Toye *et al.,* 2013). This is summarised neatly by Lindhal and Lindhal (2011: 263), who describe the need for transparency in the *'carefulness and quality of craftsmanship in each step in the research process'*. The application of quality assessment to qualitative research is widely debated, with no consensus on whether criteria should be applied, which criteria to use, how to apply them (Spencer, 2003) or what makes qualitative research studies 'good' or 'good enough' (Toye *et al.,* 2013). Authors of published meta-ethnographic studies are divided on the value of quality appraisal and whether it should form part of a meta-ethnography at all (Atkins et al. (2008). For this study, quality appraisal was applied as a means to inform and focus thinking, facilitating consistency in the judgement of papers considered for inclusion in the meta-synthesis. Despite divided opinion on quality appraisal, the decision to use a framework in this paper was made to demonstrate transparency of process. The six papers included in the study were critically appraised to assure the quality, suitability and credibility of the findings, as well as ensuring that they could be applied to the research question. The principles of Kuper, Lingard and Levinson (2008) provided a framework for qualitative research assessment, described as an interpretative act, requiring reflection, rather than the assignment of an arbitrary numerical score. Quality and suitability judgements were made using the key questions in table 4 below, derived from the paper by Kuper, Lingard and Levinson (2008), as they provided a comprehensive and systematic framework on which to appraise studies. Each paper was read, then reread while considering the points in table 4, to aid reflective thinking. All papers considered for inclusion were included – no studies were excluded from the meta-ethnography as a result of the critical appraisal. As no arbitrary score was applied to the appraisal process, included papers were not weighted.

Table 4: Key questions considered when determining the suitability of qualitative research studies

Was the sample used in the study appropriate to its research question?	**Were the data collected appropriately?**
The scope and range of the sample was considered alongside the research question of the paper, particularly, whether the sample was sufficient to capture the facets of the phenomenon. Transparency of the context of the sample was also important, making clear the affiliations of participants, such as culture, religion, cause of death of the grandchild etc. Limitations to the sample needed to be justified, as well as clearly articulating other sampling issues.	The data collection method was scrutinised to ensure that the process was appropriate for the research question, and justified, referencing contemporary literature if available. The approach to data collection needed to be outlined, demonstrating a systematic, organised and consistent approach. The inclusion of contextual information was important to provide a sense of the research experience.
Were the data analysed appropriately?	**Can I transfer the results of this study to my own setting?**
Papers needed to demonstrate a clear and systematic approach to data analysis, with justification given for the method used. Where data was analysed by more than one researcher, the process through which differences were negotiated need to be clear. Did the researcher include an audit trail, demonstrating how transcripts, reflective notes and other materials were used during the research process?	The potential transferability of the studies was assessed by considering the contextual information provided. For this study, considerations included the relevance of the sociocultural settings of the studies, and the effect of including deaths of children from causes other than LLCs on the discussion and conclusions of the studies.
Does the study adequately address potential ethical issues, including reflexivity?	**Overall, is what the researchers did clear?**
Researcher reflexivity was central to the quality assessments; evidence of the acknowledgement and possible effects of the researcher on the research process was sought. Evidence of ethical considerations was explored, including confidentiality, anonymity and the consequences of collecting data relating to potentially painful bereavement experiences. evidence of minimising the harm and distress, and strategies to support participants was looked for.	It was important that all aspects of the research process were clear, logical, justified, proportionate and described adequately.

Table 5: Summary of the papers included in the meta-ethnography

Authors and *country*	**Research question or *aims***	**Participants**	**Design**	**Principal themes of the study**
Fry (1997) *Canada*	Grandparents' reaction to the death of a grandchild: An exploratory factor analytic study	Grandchild death through natural causes, accident or suicide in the last three years or less. Study one: 152 participants (107F, 45M) age range: 52-82 age of grandchild at time of death: 6-32 years Study two: 17 participants	Study one: Open ended questionnaire Study two: Six-month longitudinal follow-up using in depth interviews	Study one found six emerging factors: factor one: emotional rapturing (21.0%) and survivor guilt (18.6%) of total variance. Study two: corroborated and support factor analysis results in study one.
Nehari, Grebler and Toren (2007) *Israel*	*to examine the special characteristics, needs, and grief coping strategies of bereaved grandparents*	Grandparents of children who died within two years from an oncological disease. 10 participants (6F, 4M)	Qualitative case study of a grandparent support group Observation and recording	Grandparents grief model proposed – three levels of grief: personal, family and culture

Authors and *country*	**Research question or *aims***	**Participants**	**Design**	**Principal themes of the study**
Gilrane-McGarry and O'Grady (2011) *Ireland*	*to identify and describe the experiences of grandparents before, at the time of, and following the death of their grandchild and to explore their needs and associated supports throughout this experience*	17 participants (13F, 4M) age range: 53-84 years time since their grandchild's death: 6 months – 9 years age of grandchild at time of death: miscarriage – 20 years	In depth, one-to-one, semi-structured interviews Thematic field analysis - constant comparison method (Cornin and Strauss, 2008)	Cumulative pain – describing concurrent experiences of loss of their grandchild and pain associated with their child's grief
Gilrane-McGarry and O'Grady (2012) *Ireland*	*to identify and describe the experience of grandparents before, at the time of, and following the death of their grandchild and to explore their needs and associated supports throughout this experience*	-	-	Factors that facilitate or inhibit the resolution of cumulative pain experiences by bereaved grandparents

Authors and *country*	**Research question or *aims***	**Participants**	**Design**	**Principal themes of the study**
Moules, Laing, *McCaffrey, Tapp and Strother (2012a) Canada*	*to understand, from the perspectives of grandparents, the complexity and unique character of experiences of having a grandchild diagnosed, treated, and living with childhood cancer.* (NB: participants included those with grandchildren who survived, were undergoing treatment and died from a cancer diagnosis)	16 participants (12F, 4M) all had or have grandchildren with cancer	Unstructured interviews with participants as individuals or couples	Grandparents experience complex worry, which can be doubled for their own children as well as their grandchildren which can at times be silenced in an effort to protect their children. Interpretative findings around worry, burden, silence, the nature of having one's universe shaken, of having lives put on hold, and a sense of helplessness were addressed
Moules, McCaffrey, Laing, Tapp and Strother (2012b) *Canada*				Grandparents can be resourceful and adaptable in response to family crisis. Professional's duty to respond to the needs of the whole family from the stance of respectful curiosity. Interpretations related to the notions of support, burden, protection, energy, standing by, buffering, financial shouldering, and relationship

2.2.3 Phase three: reading the studies

Papers were read to identify the findings of each study. These were then grouped together by topic, presenting the key themes, described as *'metaphors'* by Noblit and Hare (1988), which has been tabulated, as shown in table 5. Details of contextualisation, which allows the interpretation and translation of themes of each study, has been facilitated by including key information about each study. This includes information about sample size, methods and location.

2.2.4 Phase four: determining how studies relate to each other

Following careful reading of the identified papers, outlined in table 5, a list of themes, phrases, ideas and concepts from each paper was created. The idioms and terminology used by the authors have been retained as far as possible to remain faithful to the original meanings. These were then juxtaposed against each other, leading to initial assumptions surrounding the relationship between the findings of each study.

Noblit and Hare (1988) suggest three types of relationship can exist between studies:

> **Reciprocal**: direct translations can be made when studies share a similar focus;
>
> **Refutational**: where studies contradict each other, or demonstrate *'relative opposition'*;
>
> **Lines of argument**: involves the construction of an interpretation (lines of argument) to endeavour to reveal what is hidden in individual studies.

The relationships between studies included in this meta-ethnography are explored in phase six below.

Eight common and recurring themes were identified, which were organised into three superordinate themes, as illustrated in figure 2. The first two themes represent different aspects of how the grandparent's relationship with their grandchild before and during their death influences their bereavement experience. The next two themes illustrate the influence of the family on grandparental experience; firstly, focusing on the specific role of the grandparent within their family unit, and secondly on wider family dynamics and how these can affect their experience. The final superordinate theme of 'pain' refers to and amalgamates four recurrent themes, which explore factors that cause or exacerbate emotional pain in participating grandparents. These are *'disenfranchised grief'*, which includes status, acknowledgement and social positioning; *'bearing witness'*, which explores the effects of observing grief reactions of others in the family unit; *'cumulative pain'* which explores the effects of fulfilling multiple familial roles, i.e. that of a grandparent to the deceased and surviving grandchildren, in addition to a parenting role and finally *'survivor guilt'*, which refers to the feelings of guilt that some participants expressed in outliving their grandchildren and defying *'natural order'*.

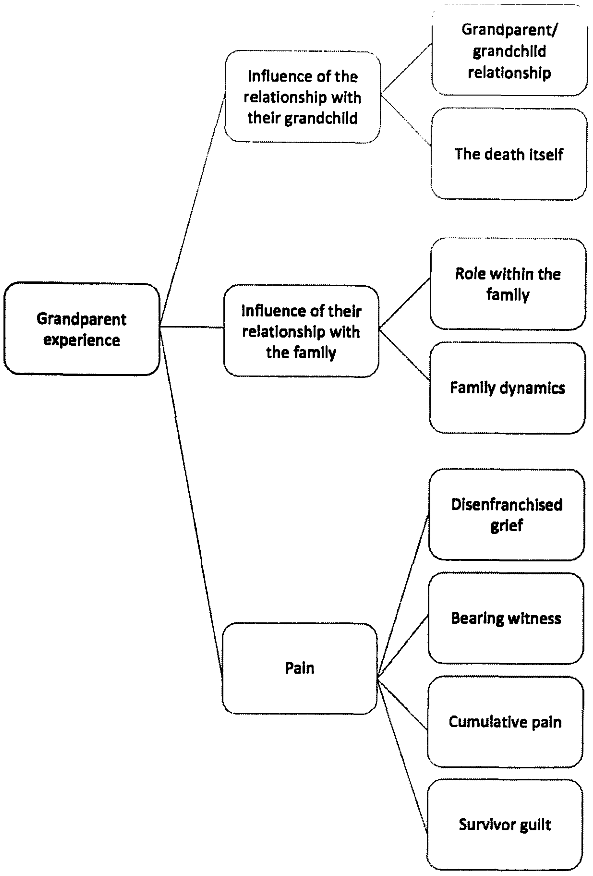

Figure 2: Key themes identified from the papers included in the meta-ethnography

2.2.5 Phase five: translating studies into each other

Noblit and Hare (1988:28) suggest that translation must go beyond simply analogising studies, to *'protect the particular, respect holism, and enable comparison'* between studies.

Having identified the key themes following the initial reading of the papers, a detailed search was then undertaken on rereading the six papers to determine the presence or absence of the key themes below. These are shown in table 6.

Table 6: Themes identified in each study

	Influence of the grandchild		Influence of the family		Pain			
	Grandparent /grandchild relationship	The death itself	Role within the family	Family dynamics	Disen-franchised grief	Bearing witness	Cumulative pain	Survivor guilt
Fry (1997)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nehari *et al.* (2007)	Yes	-	Yes	Yes	-	Yes	Yes	-
Gilrane-McGarry and O'Grady (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Gilrane-McGarry and O'Grady (2012)	Yes	-	Yes	Yes	-	Yes	Yes	-
Moules *et al.* (2012a)	-	-	Yes	-	Yes	Yes	Yes	Yes
Moules *et al.* (2012b)	-	-	Yes	Yes	Yes	Yes	Yes	-

Synthesis began with the earliest published paper, progressing through the papers in chronological order of publication. Table 6 above summarises the core findings or theory from each paper, relevant to the research question. Understanding of the experiences of grandparents was developed further by translating the studies into each other, completed by using the themes identified in the first study, adding others as they emerged. Reciprocal translations enabled the development of a table, which explores cross-study comparison of the key themes, using quotes from participants of each study to explain the themes.

Table 7: Cross-study theme comparison

Theme	**Paper**	**Quotations from participants in primary studies**	**Interpretations of findings offered by authors**
Grandparent / grandchild relationship	Fry (1997)	-	Experiences vary, depending on the intensity and diversity of the relationship
	Nehari *et al.* (2007)	*I lied to him, I can't forgive myself for lying to him. I promised him that everything would be all right.* (p.71)	Conflicts of whether or not to lie to the sick grandchild.
	Gilrane-McGarry and O'Grady (2011)	*His eyes were so sad. They showed wisdom way beyond his years, just whole acceptance when you looked at his eyes my god it just broke my heart...* (p.173)	A unique and significant relationship often exists between grandparents and grandchildren
	Gilrane-McGarry and O'Grady (2012)	*He was a very important little person and he deserves to be spoken about and known. I love talking about him.* (p.180)	-
		I want you to see how lovely my grandson is and we're proud of him. (p.180)	-
The death itself	Fry (1997)	*All of a sudden this thing hits you. You feel like a part of you has been not just lost, but torn out of you and jabbed out of you (p. 128)*	Sudden impact of their grandchild's death
	Gilrane-McGarry and O'Grady (2011)	*Unbearable pain. I felt my heart was going to burst ... unbelievable bloody awfulness ... there is never a sense of relief that he died ... some people say, 'Ah it was happy for him, a release for him'... Maybe I am selfish but I would have held onto him, I wouldn't have let him go...*(p.173)	Pain associated with waiting for their grandchild to die.
		'...the baby was there and the nurses were encouraging us to hold him and not to be afraid. I had to be very careful of his little head because it hadn't properly come together. And I was willing him to breathe ... please breathe... But it wasn't to happen.' (p.173)	The pain of holding the dead grandchild
		-	Poor bereavement outcomes are often associated with perceptions that the deceased had poor quality end-of-life care (184)

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Grandparent role within the family	Fry (1997)	*I wish I could take away Gina's pain, but I know I can't. She will have to let go of it herself. But I feel responsible as her mother to help her with her pain.* (p.129)	-
		There's no way I can make the hurt any better for his parents because it is too major a tragedy, for them. (p.129)	-
	Fry (1997)	*It was time to be parents and grandparents again. We felt we were needed and could be useful again.* (p.131)	-
		There were other children to think about, and the other grandchildren whom we had neglected for a while. (p.131)	Focusing thoughts and energies on others and reorganising interactions and family relations
	Nehari *et al.* (2007)	-	Grandparents have an important function in the bereaved family
	Gilrane-McGarry and O'Grady (2011)	*'I just couldn't do enough for her. If I could have taken her pain, I would have taken a triple double pain myself'* (p.174)	-
	Gilrane-McGarry and O'Grady (2012)	*'I felt surplus to requirements. The parents didn't want me there. It took me a long time to get over that feeling of being left out.'* (p.181)	-
		'When people came to view the body, I was standing like a spare part and many had no idea who I was so they passed me by … I didn't know what my role was. If I was included then it would have helped me.' (p.181)	-
		'When their little girl became ill, it was the three of us that did the 24-hour watch in the hospital and we developed a very strong reliance on each other. My four children have become very close which makes me think they'll be ok for the future.' (p.182)	-
		'We were shut out and not let in … the lack of involvement was dreadful.' (p.181)	-
		My son-in-law would ring and say "I can't handle it anymore" so I would go down and hold my daughter.' (p.183)	Having opportunities to provide emotional support helped several of the participants

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Grandparent role within the family *(continued)*	Gilrane-McGarry and O'Grady (2012)	*'I remember thinking "We will offer to pay for the funeral", but it was all rejected.'* (p.183)	with their own grief. Feeling they were 'wanted' by their distressed son/daughter provided a sense of fulfilment.
	Moules *et al.* (2012a)	*Try to keep everything as calm and same as possible … supper's done; the dishes are done and every- body's got their bath; they're ready for bed … so there's normalness to stuff … nurturing and caregiving for everybody… so that it's less traumatic at home… it's a little bit of saneness.* (p.124)	Grandparents put their own lives on hold to help retain some normalcy in the lives of their children's families
		Needless to say, it does make me feel good when they do call on me to do things and it makes me feel good that they appreciate me. (p.126)	-
	Moules *et al.* (2012b)	*…different part of life right, because I've got the time to go up there… good health, and I've got some money.* (p.135)	-
		I remind myself that I'm not a parent because my nature is to butt in and so I step back so I don't butt in too much. I don't act if I'm in charge. (p.136)	-
		The phone would be ringing every five minutes … people want to know what's happened and you're rehashing and telling everybody so it's almost like you were buffering her because she couldn't talk about it without getting upset. (p.136)	In standing back, however, the vantage point allowed grandparents to protect and buffer their children
		I don't consider it a burden being on the standby . . . I'm excited and delighted when I can do some- thing because as a grandparent you feel kind of useless after a while. (p.136)	
Family dynamics	Fry (1997)	*I worry that my son is so distressed that he'll neglect his other children. Its not fair to the other children either.* (p.129)	-
	Nehari *et al.* (2007)	*I am afraid to love [sibling of the deceased grandchild]. I am not attached to him the way I was to [deceased grandchild].* (p.72)	The difficulty of the emotional relationship to surviving grandchildren
		In the beginning the illness brought us together. Now we have stopped talking about it and it's frightening. It's impossible to talk about it with my daughter. There is too much [emotional] distance. (p.73)	The grandparents talk about the emotional distance, which makes it impossible for them to support their child or be supported by

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Family dynamics (*continued*)	Nehari et al. (2007)		him/her or even get practical help as they grow old.
		I [grandparent] used to be the head of the family [before the death]. I am no longer the head. Now I just get in the way. (p.73)	-
	Gilrane-McGarry and O'Grady (2011)	-	Many placed their own pain second to supporting family members. This put them under extraordinary physical, mental, and emotional strain.
	Gilrane-McGarry and O'Grady (2012)	*One day she said to me "You don't understand—you haven't lost a daughter." I said, "My God I have lost a daughter and a grand- daughter which makes it twice as hard."'* (p.135)	-
	Moules *et al.* (2012b)	*As a grandparent or any kind of parent, your aim or goal in raising your children is to protect them and make things better for them.* (p.137)	-
		It started affecting my other relationships. Like with my mother, with my sister. (p.137)	-
		Very much closer . . . He'd never phone [before] and now when goes to hang up he always says, I love you Mom and Dad. Always you know. (p.137)	-
		He understands totally and he's right there... a lot of times; I don't have to explain, he understands. (p.137)	Some grandparents found their strength and support from within their own relationship
		We've always talked a lot about everything... we have our glass of wine before supper and we've always had that happen... we sit down and have a drink and we talk. (p.137)	-
		My strength came from [wife] and I think her strength kind of came from me, I mean we kind of supported each other through the whole thing... did different roles in the family too. (p.137)	-

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Disenfranchised grief	Fry (1997)	*I feel somehow I can handle my own pain 'cause I've been there before. My son is young, and for him his son's death is worse because there is no way out for him for a long time. I can handle the pain.* (p.129)	-
		I do not think too much about my own grief, but try to give as much support as possible to other grieving families, and to my children. (p.132)	Grandparents became committed to suppressing their own grief out of their concern to protect their children and surviving grandchildren from further hurt.
	Gilrane-McGarry and O'Grady (2011)	-	Because of their age, it is often assumed that grandparents will have had many experiences of death (Reed, 2003). They may be perceived as being immune to grief or as having developed coping strategies and hence requiring less support
	Gilrane-McGarry and O'Grady (2012)	*When you lose a grandchild, it doesn't get the same recognition as when you lose a child.* (p.181)	-
		'[I] received no acknowledgment at all. People didn't understand that some recognition at that time would probably have helped me. (p.181)	A grandmother expressed her disappointment that the entire focus was on the bereaved parents—she felt that she 'didn't matter'.
	Gilrane-McGarry and O'Grady (2012)	*'I tried to look after myself but everything else gets in the way, especially the focus on my daughter. When I would think about my own grief, I would immediately think of her pain and put my grief to one side.* (p.184)	-
	Moules *et al.* (2012a)	*I felt as a grandparent I wasn't as important as they (parents) were… different people come in tend to not necessarily address the grandparent either. My issues weren't as important. I noticed, (some professionals named)… would nod to me and say hello and then sort of turn away… the message I got was that what I was doing wasn't very important.* (p.123)	-

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Disenfranchised grief *(continued)*	Moules *et al.* (2012b)	*We can't dump our worries, and our fears, and our problems… they've got way more than they can handle already.* (p.134)	Not burdening takes work and effort on the part of the grandparent
		I'm supposed to be the strength. (p.134)	Always parents themselves, the grandparents stepped in to care for the parents; the grandparents' hearts broke for their children and their grandchildren
		I probably do put myself as a second class citizen because the parents are the primary people and I kind of keep that in mind. I put myself there. (p.136)	-
Bearing witness	Fry (1997)	*I wish, somehow, I could take their pain away, my children's pain.* (p.129)	GPs feelings of deep sadness, hurt and pain for their adult child
		The pain of not being able to comfort Martha, my daughter, just eats away at me. (p.129)	'GMs sheer inability to separate their grief from the grief that they feel for their children'
	Nehari *et al.* (2007)	-	Helplessness in the face of the disease, fear of the unknown, lack of knowledge, and uncertainties came up repeatedly
	Gilrane-McGarry and O'Grady (2011)	*'I feel their pain, my son's pain. I wish I could relieve them of this but you can't, they have lost their only child. I find it very hard to cope with my son's pain.'* (p.174)	There were feelings of helplessness and inadequacy at not being able to take away the pain of the parents
		'I would never wish it on anybody, the abiding pain; the worst was feeling useless, I couldn't stop my daughter's pain. That is the most god awful pain, it's the worst thing I ever felt in my life.' (p.174)	
	Gilrane-McGarry and O'Grady (2012)	-	For some of the grandparents the need to protect their bereaved son or daughter was immense. Often the participants refrained from disclosing the full intensity of their grief, perceiving it to be secondary to the parental grief. (181

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Bearing witness *(continued)*	Moules *et al.* (2012a)	*We have cancer.* (p.122)	-
		You see your children going through this and there's nothing you can do for your child never mind your grandchild who's suffering. (p.125)	Parents always want to protect their child, to make it right, to take away the pain, and in this situation where grandparents wish to protect their children and make everything alright, there is nothing to be done that can erase what is happening
		The toughest thing with being a grandparent . . . you just wish you could take it away for them, but you feel that pain more than your child. So to see them suffer is just so . . . and there nothing you can do. (p.125)	-
		She's been very strong . . . when around her boys, I never saw her shed a tear . . . but when she was by herself or with me, she would cry. (p.127)	-
		It's amazing how strong she's been. We've all been just so proud of her . . . I've thought if I were her, would I be as strong as she is? (p.127)	-
	Moules *et al.* (2012b)	*You're a bystander . . . but you've involved. I think that's what the grandparents do. They're a bystander but then they're so involved in it but you still have to be that bystander.* (p.136)	-
Cumulative pain	Fry (1997)	*I feel it is not only Ronnie (grandson) who has been taken away, but also my daughter, and her children who have been taken away suddenly.* (p.128)	-
		Your grandchild dying is worse than any death I've experienced before. Even when my husband died I was more ready for it 'cause you know he was old. (p.128)	-
		It is hard to believe, but I feel my own sadness, and then it hurts even more 'cause I feel sad for Gina, my daughter, and it hurts all over again, and more. (p.129)	-
		My pain will go away, I know, but its ten times more awful when I think of Gina's pain. If I could make the hurt and pain better for Gina, I think my own sadness would go away. (p.129)	-

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Cumulative pain *(continued)*	Nehari *et al.* (2007)	*I suffer doubly for my daughter and my grandson. I have a great vacuum in my heart. When my daughter smiles, I am happy. When she is down, my world falls apart.* (p.73)	The grandparents talk of their double pain over their child and their grandchild
		-	Grandparents, additionally, experience the pain of separation, distance, isolation, and inability to help their children, which is their role as parents.
	Gilrane-McGarry and O'Grady (2011)	*Now I have lost a daughter and a granddaughter. I feel that I've lost part of my daughter.* (p.174)	The notion of cumulative pain emerged from the interviews. This pain had five components (Figure 1): • Pain from previous bereavements • Pain from the loss of the grandchild • The pain of witnessing the son or daughter's grief • The pain of witnessing subsequent negative changes in the son or daughter Pain that is common to all grief. (173)
		Every other grandchild's birthday you're thinking, "What would he be doing now? Whose pet would he be? (p.174)	
	Gilrane-McGarry and O'Grady (2012)	*'It's a very sad situation to have lost a lovely grandchild but also to lose a daughter. It is like this wall, which is higher than me: I can't see over it, I can't see around it … So where do we go?'* (p.181)	-
	Moules *et al.* (2012a)	-	the suffering of grandparents when a child dies is multi-layered
	Moules *et al.* (2012b)	*You're getting a double dose because you suffer for your kids and also the grandkids. You have more to worry about . . . instead of worrying about your kids; you got two generations to think about.* (p.134)	The position of the grandparents within the family system thus often seemed to carry implications for providing support through a protectiveness, at once closer than anyone else to the parent–child unit but at the same

Theme	Paper	Quotations from participants in primary studies	Interpretations of findings offered by authors
Cumulative pain *(continued)*	Moules *et al.* (2012b)		time removed from it.
		It's a double, it's a double hit. Because you don't want, as a mom, your kids to have any pain; you can't protect them all the time . . . to see him and them going through, it's unbelievable. (p.134)	*The sense of a doubled impact for one grandmother led to an acute sense of wanting to protect her own child.*
		First of all, you're going there because it's your grandson and then there's your daughter and her pain and suffering. (p.134)	-
Survivor guilt	Fry (1997)	*Fair would be if I could have died, 'cause I am old. I've had my life, but he was so you, you know, wasn't supposed to go before his grandparents and parents.* (p.128)	Frail and elderly grandmother who expected to die soon, reflected her sorrow about the unfairness of life for the sake of her own son whose child had died, reflecting much 'survivor guilt'
		Why couldn't it have been me in the coffin? I had died in place of David, it would have been alright... it would have made so much more sense. (p.128)	-
	Gilrane-McGarry and O'Grady (2011)	*This was heart-wrenching pain. You would prefer to be dead yourself. It is against the grain and the wrong way around.'* (p.174)	-
	Moules *et al.* (2012a)	*Why is it him, why isn't it me? With old people you expect that to happen and with young people I just don't. I just don't think it's fair.* (p.122)	-

2.2.6 Phase six: synthesising translations

Rereading of the concepts and interpretations included in table 7 above, the relationship between the studies became apparent: similar thoughts, feelings and experiences were described by participants, and similar observations were made by the authors. No refutation between studies was seen in any of the papers included in this review, even when particular metaphors are not identified on individual papers, as illustrated in table 2, although it is acknowledged that only a small number of studies were included. The relationship between the papers appears to be reciprocal, from which lines of argument have been developed, these are explored in detail below.

2.2.6.1 Lines of argument

A lines of argument synthesis concerns inference – what can be said of the whole (culture, organisation etc.), based on selective studies of the parts (Noblit and Hare 1988). Within this synthesis, the included studies have been used to successively build lines of argument that conceptualise a picture of the whole, developing an overarching interpretation of the bereavement experiences of grandparents, as illustrated in figure 2 (Lee *et al.* 2015). The lines of argument synthesised from the included papers are expressed in sections 2.3 onwards.

2.2.7 Phase seven: expressing the synthesis

Identified papers were read and reread in order to develop a more robust understanding of each of the studies and to recognise different expressions of synonymous metaphors. The findings or results sections of the papers were hand coded on paper before being transferred to an electronic spreadsheet, according to the content and arranged into themes that defined characteristics of the phenomena explored in the studies. The formation and population of table 7 enhanced the richness of the perspectives beyond single study accounts, developing and expanding the understanding each metaphor through reciprocal relationships between study findings. The main themes are: the influence of the relationship with their grandchild, the influence of the family, and pain. Each theme is discussed below, arranged by superordinate theme. Selected quotes from table 2 are repeated in order to illustrate or corroborate statements and conclusions made.

2.3 Influence of the relationship with their grandchild

There is great diversity in the roles that grandparents play within families, both in terms of scope and intensity, which in turn affects the intensity of their bereavement experiences following the death of their grandchild. This point can be applied to many of the metaphors below, however Fry (1997) notes specifically that bereavement experiences of grandparents vary depending on the relationship with the grandchild before death. Other researchers reported similar phenomena, in specific situations. Two subordinate themes which relate to the influence of the grandparent/grandchild relationship, the grandparent/grandchild relationship, and the death itself, are explored below.

2.3.1 Grandparent/grandchild relationship

Few studies focused on the experiences of grandparents during the child's illness, however the quote below demonstrates love and despair during her grandchild's illness:

> *'His eyes were so sad. They showed wisdom way beyond his years, just whole acceptance when you looked at his eyes my god it just broke my heart...*
>
> Gilrane-McGarry and O'Grady (2011:173)

Examples of the deep affection that grandparents feel for their grandchildren were captured recurrently:

> *'All of a sudden this thing hits you. You feel like a part of you has been not just lost, but torn out of you and jabbed out of you.'*
>
> *Fry (1997:128)*
>
> *'He was a very important little person and he deserves to be spoken about and known. I love talking about him.'*
>
> *'I want you to see how lovely my grandson is and we're proud of him.'*
>
> Gilrane-McGarry and O'Grady (2012:180)

Gilrane-McGarry and O'Grady (2011:170) suggest that a *'unique and significant relationship often exists between grandparents and grandchild'* and that due to the general increase in life expectancy, it is becoming more common for grandparents to experience the death of grandchild having reached adolescence, adding to the complexity of the grief, due to strong grandchild-grandparent friendships. The concept of friendship was implied in the study by Nehari *et al.* (2007) and the challenges that this created within grandparents, specifically the conflict between the expected protective role of a grandparent vs. honesty, valued in a friendship. The below quote, made by a grandparent following the death of her grandchild illustrates the conflict of whether to lie to a sick child.

> *I lied to him, I can't forgive myself for lying to him. I promised him that everything would be all right.*
>
> Nehari *et al.* (2007:71)

2.3.2 The death itself

Grandparental experiences of the time during and immediately following the death of a grandchild was not the focus of, nor explored in detail, in any of the studies included, however the sudden impact of the death, despite the child's life limiting illness was captured by Fry (1997:128):

> *'All of a sudden this thing hits you. You feel like a part of you has been not just lost, but torn out of you and jabbed out of you'*

The concept of disbelief and hope was also expressed by the following grandmother when holding her grandson:

> *'...the baby was there and the nurses were encouraging us to hold him and not to be afraid. I had to be very careful of his little head because it hadn't properly come together. And I was willing him to breathe ... please breathe... But it wasn't to happen.'*
>
> Gilrane-McGarry and O'Grady (2011:173)

An association of poor bereavement outcomes where the grandparents perceived poor quality end of life care was reported by Gilrane-McGarry and O'Grady (2011:173). They also identified the pain caused by differing goals within the family unit:

> *'there is never a sense of relief that he died... some people say, 'Ah it was happy for him, a release for him'... Maybe I am selfish but I would have held onto him, I wouldn't have let him go...'*

2.4 Influence of relationships within their family

Grandparents' perception of their role within a family, and of the dynamics within the family have varying effects on the experience of grandparents, reported widely in the studies included. The two subthemes below represent the wider context of grief, highlighting the influence and contribution to the experiences of expressed pain.

2.4.1 Role within the family

Grandparents have an important function within the bereaved family (Nehari *et al.*, 2007). This was a widely acknowledged element of the grandparent experience, mentioned by participants in all of the studies included. The role within the family can be further refined into two distinct contexts; the role that grandparents assume, and that which the family expect.

A number of studies (Fry, 1997; Gilrane-McGarry and O'Grady, 2011; Moules *et al.*, 2012b) found that much of the focus of grandparents was preoccupation with their efforts to reduce the pain of the child's parents, rather than with their own grief.

> *'I just couldn't do enough for her. If I could have taken her pain, I would have taken a triple double pain myself*
>
> Gilrane-McGarry and O'Grady (2011:174)

Despite the expressed altruism, grandparents showed an awareness of the complexity of the pain, at the same time as appreciating their dual role as both a grandparents and parent. Grandparenting experiences did not always focus on the sick child, but included taking a broader responsibility in meeting the needs of the family. The perception of *'being needed'* within a family could have a positive effect on the experiences of grandparents:

> *'It was time to be parents and grandparents again. We felt we were needed and could be useful again.'*
>
> Fry (1997:131)

Equally, grandparents with a less defined role following the death of a grandchild expressed sadness in relation to their function, stating that they felt *'surplus to requirements'* Gilrane-McGarry and O'Grady (2012:181). These feelings were in addition to the sadness they felt following their grandchild's death.

A stark contrast in the role of grandparents before and after the death of the child was apparent across the studies. Grandparents play an active role in the care of the child during their illness:

> *'When their little girl became ill, it was the three of us that did the 24-hour watch in the hospital and we developed a very strong reliance on each other.'*
>
> Gilrane-McGarry and O'Grady (2012:182)

This is perceived by some grandparents to change following the death:

> *'We were shut out and not let in ... the lack of involvement was dreadful.'*
>
> Gilrane-McGarry and O'Grady (2012:181)

The perceived lack of role following their grandchild's death exacerbates the grief experience; as discussed previously, grandparents can focus on the needs of the family, rather than their own needs. The removal of a specific role or function, which follows the death of their grandchild can lead to the grandparent having to address their own feelings of grief, due to the lack of distraction (formerly created in caring for the dying child, or their family), compounded further by their perception of being distanced from the family in which they had previously held a significant, meaningful and active role.

2.4.2 Family dynamics

The death of a grandchild had profound and wide-ranging effects of the experience of grandparents, from bringing families closer together (Gilrane-McGarry and O'Grady (2012) and Moules *et al.* (2012b)) to creating tension, strain and emotional distance throughout the family. This was reported to fluctuate throughout the child's illness, during and following death:

> *'In the beginning the illness brought us together. Now we have stopped talking about it and it's frightening. It's impossible to talk about it with my daughter. There is too much [emotional] distance'*
>
> Nehari *et al.* (2007:73)

Nehari *et al.* (2007) found that the death of a grandchild affected the emotional relationship with surviving grandchildren, where one participant disclosed feeling '*afraid to love*' the deceased child's sibling. The death of a grandchild also affects dynamics outside of the child's immediate family:

> *'It started affecting my other relationships. Like with my mother, with my sister.'*
>
> (Moules *et al.*, 2012b:137)

As highlighted in 3.4.1, the act of believing their own emotional needs as secondary to those of the child's immediate family places grandparents under *'extraordinary physical, mental, and emotional strain'* Gilrane-McGarry and O'Grady (2011:171). Some grandparents found strength and support within their marriages or personal relationships:

> *'My strength came from [wife] and I think her strength kind of came from me, I mean we kind of supported each other through the whole thing'*
>
> (Moules *et al.*, 2012b:137)

2.5 Pain

Pain was the most prolifically discussed metaphor throughout the studies and one that could be broadly applied to almost all findings. Four discrete metaphors are explored below: disenfranchised grief, bearing witness, cumulative pain and survivor guilt; however there is a clear link between these representations and a convergence of boundaries between each of them, each having an effect on the other.

2.5.1 Disenfranchised grief

Disenfranchised grief, a phenomenon that results from others failing to appreciate a person's experience of bereavement, was widely discussed by participants across all studies and can be further divided into subcategories: society's perception and disenfranchisement exacerbated by grandparents themselves.

> *'[I] received no acknowledgment at all. People didn't understand that some recognition at that time would probably have helped me.'*
>
> Gilrane-McGarry and O'Grady (2012:181)

The altruism displayed by grandparents, always as parents themselves (Moules *et al.*, 2012b), endeavour to protect their children and surviving grandchild by suppressing their own grief and pain.

> *'I do not think too much about my own grief, but try to give as much support as possible to other grieving families, and to my children'*
>
> Fry (1997:132)

Their ability to provide continuing support to the family and their age and experience (Gilrane-McGarry and O'Grady, 2011), meant that grandparents could be perceived as immune from intense grief and therefore requiring less support. These assumptions were reinforced by participants:

> *'I'm supposed to be the strength.'*
>
> *'We can't dump our worries, and our fears, and our problems* [on them] ... *they've got way more than they can handle already.'*
>
> Moules *et al.* (2012b:134)

A failure to acknowledge the feelings and experiences of grandparents was seen outside of the family too, including that by professionals involved in the care of the dying child:

> *'I felt as a grandparent I wasn't as important as they (parents) were... different people come in tend to not necessarily address the grandparent either. My issues weren't as important. I noticed, (some professionals named)... would nod to me and say hello and then sort of turn away...the message I got was that what I was doing wasn't very important.'*
>
> Moules *et al.* (2012a:123)

2.5.2 Bearing witness

Bearing witness to their grandchild's illness and death, their desire to protect their children and their inability to do so was a recurrent cause of emotional pain discussed in all included studies. The act of watching and subsequent helplessness in being unable to take the pain away from their child caused immense emotional pain

(Gilrane-McGarry and O'Grady, 2012), the full extent of which was often not disclosed to parents in an effort to protect their children, exacerbating their disenfranchisement further:

> *'You're a bystander... but you've involved. I think that's what the grandparents do. They're a bystander but then they're so involved in it but you still have to be that bystander.'*
>
> Moules *et al.* (2012b:136)

> *'The toughest thing with being a grandparent... you just wish you could take it away for them, but you feel that pain more than your child. So to see them suffer is just so... and there nothing you can do.'*
>
> Moules *et al.* (2012a:125)

In addition to the pain caused by the death of their grandchild, grandparents also feel pain in their capacity as a parent:

> *'I feel their pain, my son's pain. I wish I could relieve them of this but you can't, they have lost their only child. I find it very hard to cope with my son's pain.'*
>
> Gilrane-McGarry and O'Grady (2011:174)

Existing research suggests that the experience of bearing witnesses is a multifaceted phenomenon that surrounds the witnessing of multiple individuals within their family. The above quotes demonstrate that 'grandparents' are not only fulfilling a grandparenting role, but also experience the loss from the perspective of a parent.

2.5.3 Cumulative pain

The concept of cumulative pain was highlighted to varying degrees in each of the studies included, including the suggestion of double (Reed, 2000) or triple pain:

> *'You're getting a double dose because you suffer for your kids and also the grandkids. You have more to worry about... instead of worrying about your kids; you got two generations to think about'*
>
> Moules *et al.* (2012b:134)

The synthesis of findings from each of the included studies suggests that cumulative pain is more complex than simply grieving for multiple generations, but that there are other cumulative factors that influence grandparents' experiences. These include subsequent changes in their son or daughter:

> *'Now I have lost a daughter and a granddaughter. I feel that I've lost part of my daughter.'*
>
> Gilrane-McGarry and O'Grady (2011:174)

In addition to pain caused through bearing witness and perceived helplessness, their feelings of social isolation caused by a lack of perceived social recognition in addition to the change in role (Nehari *et al.*, 2007). The compounding of these factors can create an overwhelming sense of insurmountable pain and emotional disorientation:

> *'It's a very sad situation to have lost a lovely grandchild but also to lose a daughter. It is like this wall, which is higher than me: I can't see over it, I can't see around it... So where do we go?'*
>
> Gilrane-McGarry and O'Grady (2012:181)

2.5.4 Survivor guilt

A number of participants across studies expressed a perception of guilt and unfairness in surviving their grandchildren, which in turn added to their experience of emotional pain:

> *'Fair would be if I could have died, 'cause I am old. I've had my life, but he was so you, you know, wasn't supposed to go before his grandparents and parents.'*
>
> Fry (1997:128)

In the majority, the expression to die in place of their grandchild appears to be due to their desire to correct the *'natural order'* or generational death, however some participants suggested that to die would be a way to avoid the pain associated with the death of a grandchild.

> *'This was heart-wrenching pain. You would prefer to be dead yourself.'*
>
> Gilrane-McGarry and O'Grady (2011:174)

2.6 Discussion

The first stage of analysis revealed themes that explain the prominent experiences of grandparents immediately prior to, during and following the death of a grandchild. The subsequent *line of argument* approach developed the understanding of these themes and explored interactions that compound or intensify others in addition to exploring the contributory factors of each of the experiences.

There are clear similarities in grief responses to childhood death by parents and grandparents (White, 2002); however Ponzetti, (1992) found that these were expressed less often by grandparents. The findings suggest that grandparental experience of grief is a multifactorial construct and varies significantly in terms of intensity, depending on the nature of their relationship with the deceased child, their family and the circumstances that surround the death. The synthesis of translations concludes that many of the attributing factors of the grandparent experience are present due to their multi-generational position within the family, occupying dual the positions of both grandparent and parent.

Families have been shown to have a substantial influence on the bereavement experiences of grandparents; not least as they gate-keep the amount and quality of the contact between the grandparent and grandchild, and the rest of the family. The relationship between grandparents and their sick grandchild affected the way individuals experienced death. Those grandparents who had close, regular contact with their grandchildren suffered the greatest emotional pain. It follows that these grandparents not only had strong relationships with their grandchildren, but robust multigenerational bonds within their family, through which much emotional support was given. The impact of these effective multigenerational relationships manifested in numerous forms, like ripples throughout the experience of individuals. Grandparents who perceived themselves as occupying a fulfilling role within a family, where they felt valued experienced a sense of control, belonging and support. Although these individuals experienced intense emotional pain following the death of a grandchild, it was met with the support and love of their family, as well as the value of memories shared with their grandchild.

Emotional pain was a recurrent element of grandparenting experience highlighted across the studies. The milti-generational position of the grandparent, simultaneously occupying both parental and grandparental positions meant that individuals experienced emotional pain in witnessing the experience of those within the family. Grandparents talked extensively of witnessing the experience of their children. Bearing witness was closely associated with helplessness – each phenomenon following the other. Grandparents discussed the anguish of seeing the pain in their own children, but feeling powerless to help them. Comprehension of this was mixed – some grandparents appeared to accept the inevitability of parental pain, accepting it as an unavoidable element of the grieving process; others really struggled in not being able to take away or 'make better' the emotional pain of their children. The intensity of the perception on helplessness correlated with the quality of multigenerational relationships; those with effective relationships perceived less helplessness.

Social positioning of grandparents within the family was a recurrent theme, highlighted by multiple participants and at multiple stages throughout the timeline, spanning from recognition or diagnosis of a life limiting condition, through to the family's bereavement. Relationships within the family have shown to have a significant effect on the experiences of grandparents (Young and Dowling, 2012). As illustrated in the diagram below, the demands placed on grandparents throughout the child and family's journey oscillates, depending on the needs of the family and the health state of the child at any particular time. This fluid context and family dynamic results in uncertainty in the grandparents, contributing to feelings of isolation, frustration and helplessness.

The concept of pain, and more specifically cumulative pain was cited widely with elements of pain highlighted across most metaphors. This extends beyond the generational considerations discussed above to include other cumulative variables, the most commonly expressed of which is witnessing the suffering of the child's parents.

2.6.1 Limitations

Of the six papers included in this meta-ethnography, three included grandchildren that had died from causes other than LLCs (Fry, 1997; Gilrane-McGarry and O'Grady, 2011; 2012). It follows that the findings, discussion and conclusions of these papers present a broader perspective of grandchild death, which should be noted when considering the findings of this meta-ethnography. Thus, as noted by Hubbard *et al.* (2012), the findings of this review should be considered as stimuli for further enquiry, rather than an end in itself.

Four of the studies shared two sets of participants (Gilrane-McGarry and O'Grady, 2011; 2012; Moules *et al.* 2012a; 2012b). This narrows the perspective of the synthesis, which is essentially based on four participant cohorts. The implications of relying on a relatively small amount of data in terms of both studies and participant cohorts was considered, specifically that conclusions drawn from the data may be overstated or subject to errors or bias owing to the limited number of voices and contexts within the sample. It is important to note that although small, the included papers remain the only published papers that explore the phenomenon of bereavement following the death of a grandchild with a LLC.

Given the known association between complex health needs and children with life limiting conditions, the fact that the experience of grandparents of children with complex health needs was not explored in any of the primary studies constitutes a limitation of the present synthesis. There was also little exploration of the cognitive processes used by grandparents to make sense of the death of their grandchild.

The trajectory of childhood life limiting conditions (Hain, Heckford, and McCulloch, 2012; Noyes *et al.*, 2013) often result in many families facing the death of their child on multiple occasions (Rodriguez and King, 2009; Wood *et al.*, 2010). Families of children are recurrently readied for the death of a child during an acute worsening of their condition or worsening of symptoms; it is not uncommon for children to recover slightly from and to survive the acute episode of exacerbation. Families may experience this situation a number of times before the death of the child. These phenomena, and the effect on parents is acknowledged in wider literature, however it was not referred to in the studies synthesised with this analysis.

2.6.2 Further research

Further research is needed on the experiences of grandparents, with particular focus on the contextual implications of childhood life limiting conditions, which include complex health needs and profound disability. Existing literature demonstrates that grandparents are playing a significant role within families through the provision of various support, including financial, practical and emotional assistance to their children and grandchildren; yet the effect of this on grandparents has not been explored in detail, particularly from the perspective of those in a grandparenting role.

Although the meta-ethnographic approach taken to reviewing the existing literature has led to cross-study links and supposition, these should be explored in primary research. Research should focus on meaning making, in addition to the effects of grandchild death on relationships within the family and how these evolve throughout the experience.

Chapter 3: Research methodology

3.1 Introduction

This chapter outlines the research methodology, designed to answer the research question *'how do grandparents experience the death of a grandchild with a life limiting condition?'*

Methodology, the study of method, requires more than simply the detail of the methods used in a piece of research (Clough and Nutbrown, 2012), containing detail on the way in which the research has been approached, the assumptions made by the researcher, and how these factors affect the research study. This chapter begins by exploring the philosophical position of the researcher, outlining the epistemological and ontological views, discussing how these have influenced the choice of method and demonstrating congruence between the research question, data collection technique and method of data analysis.

3.2 Obtaining knowledge

Having identified the research question, the focus is now on establishing how the question should be answered. In selecting a method, the researcher makes a number of philosophical assumptions based on their fundamental understanding of 'truths' in relation to their research and research question. These understandings, referred to as a philosophical paradigm are discussed below.

A philosophical paradigm can be defined as '*a system of ideas, or world view, used by a community of researchers to generate knowledge. It is a set of assumptions, research strategies and criteria for rigour that are shared, even taken for granted by that community*' (Fossey *et al.,* 2002:718). Willig (2008) suggests that the philosophical paradigm guides the researcher to philosophical assumptions that underpin decisions surrounding the tools, strategies, participants and methods employed in a study. Philosophical assumptions of research, which provide a frame of reference (Brannen, 2005), are based on a researcher's *epistemological position*, that is their understanding of what constitutes knowledge and how can it be obtained, and *ontological position*, their understanding of what constitutes reality and how existence can be understood.

This study focuses on human experience, which is informed by the intentions, meanings and understandings of that experience by the individual (LeVasseur, 2003). The paradigm the researcher has adopted in order to develop this study is the *constructivist* paradigm (Walsh and Downe, 2005), which is underpinned by a *relativist* ontological perspective (Bowling and Ebrahim, 2005) and is congruent with the researcher's nursing background. Relativism proposes that reality cannot exist without context and believes that there are multiple mental constructions of reality that are influenced by experiences and social interactions. Relativism searches for meaning in the experience of individuals and believes that each person experiences their own reality.

Constructivism adheres to the relativist position, positing that meaning and reality are based on interaction with the social environment and that it is therefore possible to have multiple, socially constructed realities. In this study, although the family have all lived through the death of a child, their experiences are considered individual, acknowledging that their role, levels of contact, emotional resilience, perception of control and previous experiences of grief, loss and grandparenting affect their understanding of the death, and the meanings they attribute to it. The epistemological position on which constructivism is based considers the researcher and participants as co-creators of the research findings, owing to the interaction between the participant and researcher.

The professional experience of the researcher, of nursing within the British children's hospice movement, has led to the adoption of a philosophical paradigm which aligns with qualitative inquiry, enabling research and producing findings that are context, participant and time specific (Thomas and Harden, 2008). Within nursing, this specificity is referred to as being child/person/family centred, and is a key commitment to health service users (Noyes *et al.,* 2013).

This study seeks to develop the understanding of the experience of grief in grandparents, whilst simultaneously exploring the context of the family in which the participant is fulfilling a grandparenting role. To some extent, this could be achieved using quantitative methods such as surveys; however, it is the influence and impact of context that is of interest in this study, which is more effectively explored using qualitative methods. (Dixon-Woods *et al.* , 2004; Smith, Flowers and Larkin, 2009; Thomas and Harden, 2008; Willig, 2008)

3.3 Benefits of qualitative research

Qualitative methods aim to explore research questions that seek to represent experiences (Elliott, Fischer and Rennie, 1999), develop an understanding of participants' perspectives, and the dimensions of meaning and experience (Fossey *et al.*, 2002). Qualitative inquiry is concerned with the quality and texture of experience, rather than the identification of cause and effect relationships (Willig, 2008). Such methodologies demand comprehensive exploration and analysis of a phenomenon, seeking rich description, usually of a small sample (Gilbert, 2008). Variation in the culture, context and comprehension of the participant is recognised to some extent by both qualitative and quantitative studies (Yardley, 2000), however in qualitative work, individual variation is often preserved and used to develop understanding during analysis.

Qualitative approaches are useful in areas that are complex and under-researched or novel (Silverman, 2013). Due to the limited amount of research that has been conducted surrounding the specific needs of grandparents, bereaved following the death of a grandchild with a LLC, an exploratory study has been designed using a qualitative methodology.

Elliott *et al.* (1999:216) suggest that in order to measure scientific value, research methods '*must be evaluated in the light of its ability to provide meaningful and useful* *answers to the questions that motivated the research in the first place'*. With this in mind, it is important that the chosen method selected to answer the research question is conducted with sufficient rigor and due scientific process.

3.3.1 Choosing a qualitative method

Qualitative research offers a variety of means by which lived experiences can be explored (Bryman, 2008), providing frameworks to develop idiographic studies of participants' experiences and their social realities, and that reality or context affects their understanding (Biggerstaff and Thompson, 2008). Methods include a diverse range of approaches, which include conversation analysis, discourse analysis, ethnography, grounded theory, and phenomenological studies. Cohesion exists among these methods with the core purpose of enriching our understanding of the phenomena in question.

Qualitative approaches enable the exploration of construction and negotiation of meaning and the texture and quality of experience, which have implications for the research design (Silverman, 2013). Willig (2008:22) suggests that there is no 'right' or 'wrong' in methods, rather that some methods of data collection and analysis are *'more or less appropriate to our research question'*. The aim of research is to generate useful understanding, and as such, the research question and methods of both data collection and data analysis need to be congruent and appropriate to enhance understanding of the phenomenon under scrutiny.

3.4 Phenomenology

Phenomenology is the philosophical approach surrounding the study of experience, focusing on experiences of the world by human beings within a particular context and at a particular time, rather than in abstract statements about the nature of the world in general (Gallagher, 2012). Phenomenology is concerned with how the world presents itself to humans, that is *'the phenomena that appear in our consciousness as we engage with the world around us'* (Willig, 2008:52). In phenomenology, subjects and objects cannot be separated from our experience of them – subjects and objects present themselves to us as *something*, and their manifestation of that *something* constitutes an individual's reality. From a phenomenological perspective, this means that people experience and perceive the same subject or object in fundamentally different ways, therefore, multiple truths are inevitable and that to understand the experience of an individual thoroughly, one must capture the context of that experience. The underpinning philosophy of phenomenology evolved through objection of the positivist paradigm, which asserted an ordered, logical and rational reality that could be objectively measured and was independent of human interaction (Reiners, 2012). Phenomenology sits in the constructivist paradigm, the countermovement to the positivist paradigm, which asserts that reality is based on individual interactions with the world, and that knowledge is achieved by interactions between individuals (participants) and researchers.

The aims and core values of phenomenology are congruent with those of this study. There are a number of publications that recognise the effect of perception on experience within families (Kirk and Pritchard, 2012; O'Connor and Barrera, 2014;

O'Leary *et al.*, 2011; Reitzes and Mutran, 2004; Shields, Pratt, and Hunter, 2006; Wilkinson, *et al.*, 2007), supporting the anecdotal experience of the researcher that the perception of experience following a shared situation varies between individual family members, notably where multiple generations or mixed gender groups are present. The use of a phenomenological method enables the identification of individual grandparenting experiences to be identified, facilitating the exploration of the effect of the context of family through and the effect of that through rich narrative.

3.4.1 Philosophical foundations of phenomenology

Husserl (1859-1938), considered by many as the founder of modern phenomenology, was a German mathematician who believed that phenomenology was based on the meaning of an individual's experience, was related to consciousness and that it suspended all suppositions (Reiners, 2012). Husserl developed the concept of *intentionality*, which describes the relationship between the processes occurring in consciousness (perception, thought, imagination, memory and emotion) toward the object. Consequently, Husserl developed descriptive phenomenology, where he argued that in order to understand an experience, one must separate or *'bracket'* implied or preconceived understanding, in order to concentrate on describing everyday conscious experiences.

Heidegger (1889-1976), one of Husserl's students, marked the move towards hermeneutic phenomenology in his divergence from Husserl's work. Heidegger developed interpretative phenomenology, emphasising the concept of the lived world (LeVasseur, 2003) focusing on being in the world, rather than knowing the world (Reiners, 2012). Heidegger rejected the need for bracketing, believing it was impossible to negate personal experiences related to a phenomenon. Heidegger asserted that human existence is more fundamental than human consciousness and knowledge (Dahlberg, Dahlberg and Nystrom, 2008) and that consciousness could not be completely separated from the world (LeVasseur, 2003). Heidegger developed the concept of hermeneutic phenomenology, which strives to move beyond descriptive phenomenology to interpret meanings that are embedded in everyday occurrences.

Merleau-Ponty (1908-1961) shared Heidegger's belief in contextualised phenomenology, but unlike Heidegger, Merleau-Ponty described the embodied nature of our relationship with the world. He argues that as humans, our strong sense of self is holistic and that we engage in looking at the world, rather than being incorporated within it: *'the body no longer conceived as an object of the world, but as our means of communication with it'* Merleau-Ponty (1962:92). Merleau-Ponty's theory suggests that while we can observe and empathise with others, ultimately we can never share another's experience entirely: *'the grief and the anger of another have never quite the same significance for him as they have for me. For him these situations are lived through, for me they are displayed'* (Merleau-Ponty, 1962:356) and that the lived experience of another can never be entirely captured. This final quote by Merleau-Ponty makes two interesting points; firstly, it relates to our ability as humans to empathise – as already discussed, context can affect the understanding and interpretation of an experience, which are not often understood by those other than the individual who has lived the experience. This brings into question our ability to truly empathise with another person without exploring the context of the experience. Merleau-Ponty's second point, which relates to 'displaying' a lived experience, relies on the ability and will of an individual to share their experience. The reluctance of grandparents to share the entire experience with those around them, as suggested in the literature review adds a further element of complexity to developing understanding.

3.4.2 Hermeneutic phenomenology

Schleiermacher (1768-1834) developed theories, describing hermeneutics as an *art* that surrounded understanding, in contrast to explicating, applying or translating it (Forster, 2008). He considered interpretation to include a range of skills, including intuition, describing it as a craft, rather than following a list of *'mechanical rules'* (Smith *et al.*, 2009). Schleiermacher considered hermeneutics as a universal discipline, which should be applied to all subject areas, mediums and languages etc. (Corliss, 1993). Schleiermacher described interpretation that involved both linguistic and psychological interpretation, considering both the language used and textual meaning, and what is distinctive about the author or speaker.

Heidegger's work was based on his concept of *'Dasein'*, derived from the German words *da* (there) *sein* (being), to mean *presence* or *existence*. Dasein refers to the experience of *being* that is unique to human beings. Heidegger also introduced the concept of *intersubjectivity,* referring to the overlapping, shared nature of an individual's engagement with the world. He argued that Dasein is always intersubjective, perspectival, temporal and in relation to something; consequently, interpretation of meaning-making activities and processes is therefore central to understanding (Smith *et al.* 2009). Gadamer (1900-2002) elaborated on Heidegger's work surrounding philosophical hermeneutics, theorising the concept of *'historically-affected consciousness'*, which emphasises and recognises the importance of history and culture, which shapes the consciousness of people. In contrast to the work of early phenomenological philosophers, including Schleiermacher, Gadamer argued that meaning is not reducible to the authors (or participants) intentions, but is dependent on the context of interpretation.

3.4.3 The hermeneutic circle

The hermeneutic circle describes the relationship between a reader (researcher) and a text or author (participant), which aims to understand the intention of the author.

> *'when we fail to conjoin a man's intention to his words we lose the soul of speech, which is to convey meaning and to understand what is intended to be conveyed'*
>
> Hirsch, in Fry (2012:37)

It describes a process of understanding, conceptualising the notion of cumulative understanding, where understanding of a whole comes from understanding the individual parts, and that individual parts cannot be understood without understanding the whole. Smith *et al.* (2009:28) neatly illustrate how the relationship between the part and the whole can be applied at many different levels, as illustrated in figure 3 below.

The part	*The whole*
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The interview	The research project
The single episode	The complete life

Figure 3: The relationship between the part and the whole

The hermeneutic circle encapsulates the iterative nature of qualitative analysis, in which researchers move back and forth between the data and processes of data analysis to develop understanding and interpretation, leading to the discovery of 'different *perspectives in the part-whole coherence of the text'* Smith *et al.* (2009:28). Gadamer described the hermeneutic circle as a means to merge historical horizons (Crotty, 1998).

'Understanding' starts as soon as analysis begins, formed on an imagined, expected or assumed sense of the whole. This understanding develops, as the context of the text becomes known, as the researcher progresses through the text. The circular nature of the interpretative engagement process ensures the perpetual evolution of understanding, which is grounded in the text, rather than on assumptions.

The principles of the hermeneutic circle can be extended beyond historical and textual gulfs and applied more broadly to the merging of social, cultural and interpersonal horizons. Conversations develop with a mutual developing hermeneutic process whereby participants in a discussion engage in a mutual process, acknowledging both what has been said, and the direction in which they wish to take the conversation. This approach to research enables participants to articulate links between the phenomena and their experience and understanding, allowing the researcher to observe and understand how the research participants understand their experience, and how this has been shaped by the context in which the participants exist.

3.5 Why interpretative phenomenological analysis (IPA) was chosen for this study

The aim of this study was to explore the experiences, constructs, understandings and interpretations of grandparents who have experienced the death of a grandchild who had a LLC. Existing literature shows that experiences of grandparents vary, owing to, for example, the nature of childhood LLCs and the context of the family unit in which they exist. Deductive research methods would not enable the exploration of individual experience, and therefore, an inductive method of qualitative enquiry was sought (Toye *et al.*, 2013; Zimmer, 2006; Walsh and Downe, 2005)). In light of this and the researcher's professional background and epistemological position, discussed in section 3.2, IPA was chosen as an approach because it enables the development of understanding of how individuals make sense of their experiences within a given context and the meanings they attach to them, leading to informed and nuanced research, and empathic practice.

IPA has a dual focus starting with, but going beyond a standard thematic analysis (TA) (Brocki and Wearden, 2006) to include an idiographic focus which explores the unique experiences of participants (Biggerstaff and Thompson, 2008). The broader view of TA makes it less appropriate for answering the research question associated with this study, while IPA grants latitude to explore data more deeply and to extrapolate meaning beyond the text (Guest, MacQueen and Namey, 2012). The primary aim of the research is to identify, describe and understand the participant's experience by focusing on participants' experience and understanding of the phenomena, in this study, the death of a grandchild. The focal point here is the perception and view of the participant, rather than their understanding, reflecting both the phenomenological and interpretative elements of IPA (Smith *et al.* 2009).

While both IPA and grounded theory acknowledge the influence of context on experience, the primary focus of grounded theory is to identify and develop an explanatory theory of basic contextualised social processes (Starks, 2007), or to map categories of experience (Charmaz, 2006), rather than to focus on the experience of individuals (Guest, MacQueen and Namey, 2012). In contrast, IPA aims to gain a deeper understanding of both the quality and texture of the individual (Willig, 2008), accessing the cognitive *'inner world'* of participants through *'careful and explicit interpretative methodology'* (Biggerstaff and Thompson, 2008:215). Both approaches suggest that themes should be generated from the data, and that superordinate themes are derived by the researcher, although the role of the researcher is conceived very differently by the two approaches. In grounded theory, the assumptions, previous experiences and expectations of the researcher should not influence the analysis of the data (Charmaz, 2006; Levers, 2013) – analysis should not move beyond the data. IPA acknowledges the researcher's engagement with the participant's account, recognising the interpretative element of analysis (Golsworthy and Coyle, 2001), where insights into the researcher experiences are considered to be a product of their interpretation. The personal epistemological preconceptions of the researcher are acknowledged and explored in IPA, which calls for greater reflexivity (Newton *et al.*, 2012; Rolfe, 2006) during analysis.

IPA is clear in its acknowledgement of the researcher's role in co-creating the findings by their presence in collecting, interpreting and reporting the findings; the researcher is comfortable with the high expectations of reflexivity within IPA. Finally, the aim of this research study is to explore individual accounts of a major life experience; Smith *et al.* (2009) explicitly state that the examination of such events is the commitment and concern of IPA.

3.6 IPA description and characteristics

IPA is a relatively recently developed approach to qualitative inquiry, which continues to grow rapidly. It is best known in psychology, but is gaining in popularity across other disciplines, including human, social and health sciences where there has been a distinct move away from the '*simple*' biomedical model of disease and illness in recent years (Brocki and Wearden, 2006). IPA was developed by Professor Jonathan Smith (Smith, 1996), the theoretical underpinning of which stems from the works of which stems from the works of Edmund Husserl which surround phenomenology. IPA centres around three core influences, namely phenomenology, hermeneutics and idiography.

IPA is phenomenological in that it is concerned with exploring individual, subjective reports of lived experience and perception. IPA seeks rich, detailed description of experience, commonly through semi-structured interviews (Smith *et al.*, 2009), recognising that the research process is simultaneously dependent on, and complicated by, the presence of the researcher, resulting in a double hermeneutic process of interpretation. IPA introduces the concept of double-hermeneutics in that it recognises the researcher's role in understanding and interpreting the participant's understanding of their experience. Finally, idiography, or the concern of the particular, underlines the commitment of IPA to understand both the detail and therefore depth of an experience, through the systematic, detailed examination of each account in turn, only moving to the next account once '*some degree of closure or gestalt has been achieved*' (Smith, 2004:41).

Larkin *et al.* (2006:104) suggests that '*it may be more appropriate to understand IPA as a 'stance' or perspective from which to approach the task of qualitative data analysis, rather than as a distinct 'method''.* IPA offers a detailed, systematic analytic framework (Willig, 2008) and provides detailed descriptions of the analytic process (Larkin *et al.*, 2006; Larkin, 2013; Smith and Osborne, 2003; Smith, Jarman and Osborne, 1999; Smith *et al.*, 2009; Smith and Osborn, 2007). Variation and flexibility in the analytic process is welcomed and even encouraged, resulting in the dynamic application and acceptance of IPA to studies (Biggerstaff and Thompson, 2008) in a broad range of health disciplines (Burbeck and Willig, 2014; Golsworthy and Coyle, 2001; Maxted, Simpson, and Weatherhead, 2014; Phillips, Elander, and Montague, 2014; Touroni and Coyle, 2002).

The main currency for an IPA study is the meanings that a specific experience holds for participants (Smith *et al.*, 2009). Larkin, Watts and Clifton (2006) develop this further, suggesting that the IPA researcher must consider two aims when conducting analysis. The first aim is phenomenological analysis, where the researcher must endeavour to understand the participant's world, specifically '*what it is like*', getting as close as possible to the participant's view, while recognising the account is constructed between the participant and researcher. Secondly, to develop a more overtly interpretative analysis, where individual descriptions of experience are positioned in relation to wider cultural, social and theoretical contexts, where researchers aim to provide critical and conceptual commentary on the processes and activities associated with meaning making by participants (Smith and Osborne, 2003). The commitment to rich, detailed idiographic study that IPA demands means that participant samples tend to be small (Smith and Osborn, 2007). Participants tend to be fairly homogenous, recruited to closely defined inclusion criteria to ensure that the research question carries a personal meaning for them. With regards this particular study, the use of IPA enables the research to focus on personal meaning and sense making in the particular context of individual grandparents, all of whom have experienced the death of a grandchild. The small, homogenous sample of individuals allows focus to be directed towards the expressed interests, experiences and understandings of participants, enabling the research to take an inductive approach, consistent with IPA and its focus on the interpretation of meaning (Smith *et al.* 2009).

3.6.1 Philosophical assumptions of IPA

IPA has roots in both the hermeneutic school of phenomenology (Brocki and Wearden, 2006; Smith, 2004), and is strongly influenced by symbolic interactionism (Brocki and Wearden, 2006; Golsworthy and Coyle, 2001). These epistemologies hold that humans are not *'passive perceivers of an object reality'* (Brocki and Wearden, 2006:88), but rather they construct and use biographical stories to help them to understand, interpret and give meaning to their realities. Symbolic interactionism proclaims that participant-assigned meaning is of paramount importance, and that meaning is only accessible through interpretation (Smith, 1996). IPA is phenomenological, in that it does not seek absolute truth, but rather on subjective understanding, recognising the dynamic and perpetually evolving nature of research and understanding (Smith, 1996).

IPA assumes that humans self-reflect (Chapman and Smith, 2002). IPA aims to explore the processes behind the self-reflection to form an understanding of the participants understanding; this is referred to as a *double hermeneutic* approach (Phillips *et al.*, 2014; Pringle *et al.*, 2011; Rodham, Fox, and Doran, 2013). Brocki and Wearden (2006) describe the interactive role of the researcher, where the researcher must be skilled in enabling the participant to explain and articulate their experience, noting the *eloquence* of the participant and their ability to summarise their point. Of course, the analytic skills and abilities of the researcher are also key in the process (Baillie *et al.*, 2000).

3.6.2 Limitations of IPA

Willig (2009:66) suggests that, like other methods of phenomenological analysis, IPA has a number of conceptual and practical limitations that concern *'the role of language, the susceptibility of accounts and explanation verses description'*.

Language is the primary way in which participants communicate their experience to the researcher. In phenomenological research, it is the experience itself that is of interest, and therefore researchers must assume that language '*provides participants with the necessary tools to capture that experience*' (Willig, 2008:66), thus relying on representational validity of language. It can be said that interviews (and transcripts) demonstrate more how an individual *talks about* an experience within a given context, than about the *particular experience*, and raises questions surrounding the ability of participants to articulate the '*rich texture of their experience*', particularly to enable the expression of '*subtleties and nuances of their physical and emotional experiences*' (*Willig (2008)*:67).

IPA focuses on perception, therefore the participant must also be able to explain, rather than describe, their experience. Exclusive focus on appearance rather than origin limits the understanding of phenomena and that in order to understand an experience we must have an awareness of what gave rise to the experiences in the first place. Willig (2008:68) notes that these *'may be found in past events, histories or lie in the social and material structures within which we live our lives.'*

These limitations are not exclusive to IPA and phenomenological research, and are implied to any language-based investigation. The role of the researcher is strongly implicated here. There are a wide range of data collection techniques that produce quite different kinds of data. Data collection techniques in qualitative research must be participant-led, flexible and open-ended in order to allow the emergence of new, unanticipated, participant-generated findings and meaning to be explored (Bryman, 2008). The ability of the researcher to obtain a sufficiently comprehensive account of an experience, while at the same time as being cautious not to lead or influence the narrative is of critical importance. This point is explored more in the methods chapter.

3.7 Chapter summary

This chapter has introduced and discussed the process through which the research methodology was considered and selected to answer the question *'how do grandparents experience the death of a grandchild with a life limiting condition?'* The researcher's underpinning philosophical assumptions relating to the acquisition of knowledge are made clear, where the congruence between a constructivist qualitative ontological perspective and the researcher's palliative nursing background are stated. The process of refining the chosen research methodology is discussed, demonstrating relevance and appropriateness of IPA for the phenomenon under study: bereaved grandparenthood. The philosophical foundations of IPA are discussed, exploring the influences of Husserl, Heidegger and Merleau-Ponty on the development of IPA. Hermeneutics, and the hermeneutic cycle are discussed in relation to cumulative understanding and the relationship between the researcher and research participant. Finally, the rationale for IPA is made clear, with a description of the assumptions of the methodology, as well the applicability and suitability to answer the research question.

The following chapter explores the method of using an IPA approach

Chapter 4: Method

This study extends current understanding of the experience of grandparents following the death of a grandchild using an interpretative phenomenological analytic approach. As outlined in section 3.1, the primary interest of the study is to understand the perspective of individual participants, and how their perspective is shaped by the context in which they *'exist'* as a grandparent within their family.

This chapter has been written using the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury and Craig, 2007) framework to demonstrate transparency, reflexivity and rigor through the systematic reporting of aspects of the study listed in the 32-item checklist. Since writing, the standards for reporting qualitative research (SRQR) guidelines (Brien *et al.,* 2014) have been published; these guidelines have been considered in addition to the COREQ guidelines prior to submission.

4.1 Research team and reflexivity

The researcher is male and a Nursing and Midwifery Council registrant with consolidated experience of delivering and managing care for children with palliative care needs, together with their families, predominantly based in children's hospices. None of the participants were known to the researcher, however the researcher had worked in two of the children's hospices from which grandparents were recruited, reducing the likelihood of participants feeling pressurised to conform with social norms and not to discuss divergent views or experiences (Richie and Lewis, 2003). Participants were aware that the researcher was undertaking the research as part of a PhD and of his professional background, which included association with the hospices that facilitated participant recruitment.

Richie and Lewis (2003) highlight the importance of seeking objectivity and neutrality through reflexivity, which describes the continuous process of reflection, examining oneself as the researcher, and the research relationship. The researcher strove to maintain reflexivity through the keeping a self-reflective journal throughout the research process, and actively engaging in discussions and critical thinking with academic supervisors and online IPA forums. Brocki and Wearden (2006) discuss how an IPA approach encourages researchers to go further than other qualitative approaches in addressing issues surrounding reflexivity, which explicitly recognises the interpretative facet of IPA in its theoretical grounding (Brocki and Wearden, 2006; Larkin, 2013; Newton *et al.*, 2012; Smith, Flowers, and Larkin, 2009). Academic supervisors read sections of analysed transcripts, which were then discussed and challenged during supervision. The initial literature review completed prior to the empirical research helped to ground the researcher in existing research, reducing personal bias and ensuring access to multiple, evidence based perspectives of grandparental grief, rather than relying on only those of the researcher gained through clinical practice.

4.2 Study design

4.2.1 Ethical considerations

Due to the nature of the proposed research, there were a number of ethical considerations, which are discussed in the research application, found in appendix 1.

Consideration was initially focused on the necessity for such research, owing to the realisation that participation in such research can cause emotional distress (Dyregrov, 2004). After making the case for the study though the completion of the literature review, practical ethical considerations included the recruitment and selection of participants, interview conduct including the management of distress, and the handling of data, analysis and confidentiality. These considerations are explored in detail below.

4.2.2 Research ethics committee approvals

Research ethics committee approval was sought from and recommended by the Faculty of Health and Medicine Research Ethics Committee (see appendix 1) and granted by the University Research Ethics Committee, Lancaster University in December 2013 (see appendix 2). Due to the nature of the research, which involved the interviewing of bereaved individuals, advice was sought from the chair of the Yorkshire and the Humber National Research Ethics Committee (REC) who confirmed that an application to NHS REC was not necessary, providing that grandparents included were not the principal carers of the deceased child (see appendix 3).

4.2.2.1 Participant selection

Purposeful sampling, a recruitment strategy commonly seen in IPA research (Brocki and Wearden, 2006) was used to recruit grandparents who had experienced the death of a grandchild. IPA studies generally seek a closely defined group of participants through purposeful sampling (Smith *et al.*, 2011; Ballinger, 2013; Brocki and Wearden, 2006; Efstathiou and Walker, 2014) for whom the research question will be meaningful. For this study, it is important that the group of participants share some defining characteristics, defined below.

4.2.2.2 Inclusion criteria

Those eligible for inclusion in the research:

- identified themselves as fulfilling a grandparenting role;
- were bereaved for between six and 24 months;
- had a grandchild that died following a life limiting or life threatening condition (ACT/RCPCH, 1997);
- were able to speak English.

Inclusion was not restricted to biological grandparents; anecdotally it is accepted that the secondary caring role of a grandparent is on occasions provided by those who are not biologically related to the child. This may include those in relationships with biological grandparents (such as formal or informal step grandparents) or individuals such as aunts and uncles who consider themselves to fulfil a more proximal, grandparenting role within the child's family. Inclusion was open to all of those who identify as a grandparent.

The time window of six to 24 months prevents the inclusion of the most vulnerable grandparents, who may not have has sufficient time to make sense of their bereavement, and therefore not being conducive to narrative reconstruction (Robertson, Jay, and Welch, 1997; Steeves *et al.*, 2001; Williams *et al.*, 2008). An upper limit of 24 months has been imposed to ensure that participants are able to vividly recall their experiences at the time of, and immediately following the death with sufficient depth to allow the texture of their experience to be represented during the interviews (Cook, 2001; McPherson and Addington-Hall, 2004).

4.2.2.3 Exclusion criteria

Grandparents who were the principal carers for a child (i.e. occupying the parenting role) were not eligible for inclusion. This included grandparents who are subject to a legal or Children's Services order with delegated full or shared parental responsibility, including interim care orders (section 38 of Children's Act, 1989) or special guardianships (section 31 of Children's Act, 1989 (amended) Children and Adoption Act, 2002).

4.2.3 Recruitment

Various recruitment methods were considered and discussed, however due to a number of practical challenges faced by the researcher, recruitment through children's hospices was selected. Alternative recruitment sources were considered, at the time of participant recruitment, there were two UK national charities that supported grandparents – Grandparents Plus and The Grandparents Association; both organisations were approached directly, but did not have details, or offer any support to bereaved grandparents. The two leading national bereavement organisations, The Compassionate Friends and Cruse Bereavement Care were approached, however neither organisation held records which would enable them to identify those they support as grandparents, so these possible avenues were not pursued further.

4.2.3.1 Recruitment selection

Participants were recruited through children's hospices, as outlined below. Children's hospices provide an efficient source of participants for a number of reasons, namely:

i. Children's hospices provide care for children with life limiting and life threatening (LL/LT) conditions, and therefore provide assurance that participants recruited for inclusion have had a grandchild with a LL/LT condition, as defined by Association of Children's Palliative Care (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) (1997).
ii. Targeted recruitment can be facilitated, as the children's hospice will send packs to eligible families.
iii. As the grandparent is known to a children's hospice, contact can be made and assistance sought should the research process provide emotional discomfort.

4.2.3.2 Recruitment method

Four children's hospices who were members of a regional Children's Palliative Care Network in the North of England agreed to be part of the study. Information packs were sent to and distributed by the hospices to bereaved parents of children that were known to their services. Direct contact with grandparents was not possible, as the contact details of grandparents were not held by any of the hospices who agreed to take part in the study. A covering letter was included, explaining the study and asking parents to pass the information pack onto grandparents. Grandparent packs were distributed to grandparents via the parents of the deceased child that contained a covering letter, participant information sheet, expression of interest form and a prepaid envelope. Grandparents were asked to return the expression of interest to indicate their willingness to participate, or to request further information. Grandparents were then telephoned using the details provided to arrange an interview. A copy of the pack is provided in appendix 4. This strategy risked a poor response rate, but was unavoidable, as the included hospices did not hold the correspondence details of grandparents, making direct forms of contact difficult.

A total of 37 recruitment packs were distributed by the five hospices as detailed in table 8 below.

Table 8: Distribution of recruitment packs

Number of children's hospices	Number of packs sent	Number of replies received	Number of individuals contacted	Number of individuals interviewed
4	37	8	8	7

It is anticipated that using parents as a conduit between the researcher and grandparents risked that not all grandparents would receive the packs as intended. The approach taken means that reasons for non-participation could not be explored.

4.2.3.3 Consent

Described as the *'linchpin of ethical behaviour'* (Gilbert, 2008:150), informed consent was sought from participants. The procedure of gaining consent was a two stage process. Participants were provided with a written information leaflet and expression of interest form in the information pack that was completed and returned to the researcher, indicating willingness to partake in the research, as shown in appendix 5. At the time of interview, details of the interview, study and the participants' right to withdraw were provided verbally by the researcher, at which time participants were asked to sign a consent form, shown in appendix 6.

4.2.4 Data collection

Described as the exemplary method by Smith and Osborne (2003), semi-structured interviews are utilised in the *'vast majority'* of IPA studies (Brocki and Wearden, 2006:90). Semi-structured interviews were chosen for this study to enable the exploration of the experience of individuals, as reflected in the interview guide, designed to encourage participants to discuss their experiences of grandparenting freely, focusing on the impact of their grandchild's illness and death on themselves, and how this affects their position in the family. The design also aimed to minimise the influence of preconceived ideas of the researcher (Burbeck and Willig, 2014). A semi-structured interview schedule was developed using the guidelines by Smith *et al.* (2011) and based on examples of published IPA studies (Ballinger, 2013; Burbeck and Willig, 2014; Efstathiou and Walker, 2014; Golsworthy and Coyle, 2001; Maxted, Simpson, and Weatherhead, 2014; Murray and Holmes, 2013). The interview guide is shown in appendix 7. For IPA, Biggerstaff and Thompson (2008) support the use of a flexible approach to interviewing using a prompt sheet to guide the conversation which should neither prescribe nor limit the expressed interests of participants.

User involvement in the development of the guide was sought through an annual bereaved grandparents' group at a children's hospice, however the group was cancelled due to a lack of attendance. Consultation was obtained from professionals involved in providing emotional and psychological support to bereaved families, including grandparents. Existing literature (Coall and Hertwig, 2010; Crosnoe and Elder, 2002; Hayslip, White, and Hayslip Jr., 2008; Kohn and Moffitt, 2000; Potts, 2005; White, Walker and Richards, 2008; Youngblut *et al.*, 2010) was also used to shape the development of the interview guide.

A distress protocol was also in place to manage any disproportionate emotional discomfort expressed or experienced by the participants during an interview; this can be found in appendix 8.

One of the defining foci of this research is the effect of context on experience; contextualisation was achieved using specific biographic questions relating to the child and grandparent. This included the completion of a biological genogram. The template is shown in appendix 9.

Field notes were not taken during the interviews; however reflective and observational notes were made shortly after leaving the participant's home. This was a purposeful decision in an effort to maintain the rapport with the participant. The anonymous notes were amalgamated to form the reflective journal, which is referred to throughout the analysis and discussion chapters.

Interviews were conducted on a one to one basis; only the participant and the researcher were present at the time of interview. In the case of two of the grandparent pairs, 1:1 interviews were conducted consecutively in an order to suit the participants. Both interviews were completed on the same day, during the same home visit.

At the time of interview, participants were offered the chance to review their transcripts and initial findings of the interview, however all seven participants declined the opportunity. No participant feedback has been provided.

4.2.4.1 Setting

Consideration was given to the ethical and methodological implications of the interview setting (Moore, 2005; Parnis *et al.*, 2005). Participants' homes are frequently cited as the place of choice for interview (Roberts and Clare, 2013; Touroni and Coyle, 2002), even when an alternative location of interview was offered (Burbeck and Willig, 2014; Golsworthy and Coyle, 2001). In order to instil a sense of control and to reduce the provocation of anxiety, participants were offered a choice in their place of interview, either at home or in the children's hospice used by their grandchild. All interviews were conducted in the home of the participants.

4.2.5 Transcribing

Interviews were digitally recorded using a portable voice recorder; these were transferred to a password-protected drive on an encrypted computer, after which the file on the recorder was deleted.

Audio recordings were transcribed and verified by the author using *ExpressScribe*. There is great variation in the approaches taken to transcribing interviews for the purposes of IPA analysis. Consequently, the approach below has been adapted and amalgamated using published, peer-reviewed IPA studies. Transcription was completed exclusively by the researcher in three stages:

i. **'Everything audible':** in addition to the words spoken, pauses, crying, sighing, laughing, partial words, stuttering, repartition and interjection was also transcribed, as well as recoding speech volume, including shouting and whispering (Biggerstaff and Thompson, 2008; Murray and Holmes, 2013).

ii. **Validation:** the audio was listened to again and cross-checked against the original transcript. Each participant was offered a copy of their transcript for comment or correction on concluding their interview. None of the seven participants wished to see a copy of their transcript. In accordance with conventional ethical procedure (Clark, 2010), transcripts were anonymised using gender-appropriate pseudonyms. Gender-appropriate pseudonyms were assigned by the researcher and allocated randomly. Place names were changed to generic terms such as *'children's hospice'* or *'district general hospital'*.

iii. **IPA formatted**: based on the recommendations of Smith *et al.* (2011), transcriptions were then formatted into a table containing a large margin at either side, with initial comments recorded in the left margin, and emergent themes recorded on the right. An example of annotation using such formatting is included in appendix 10.

Initial coding was completed on paper, where notes were made about preliminary connections, associations and relevant thoughts that occurred to the researcher when reflecting on the interview (Phillips *et al.*, 2014). Subsequent analysis was conducted, and recorded using *NVivo* software. The transcripts were coded by the author using qualitative thematic analysis, enabling the development of rich idiographic descriptions, contextualised in the lived experiences of individual participants. Codes have been generated directly from the data (*verbatim* interview transcripts). *A priori* codes have not been used. This is explored in more detail below.

4.2.6 Analysis

Smith *et al.* (2011) note that existing literature does not prescribe a single method to analysis in IPA and notes a *'healthy flexibility'* in analytic development. That noted, a number of completed studies were drawn from to inform the analytic approach taken (Maxted *et al.*, 2014; Phillips, Elander, and Montague, 2014; Smith, Jarman, and Osborne, 1999; Smith and Osborn, 2007 and Touroni and Coyle, 2002). The analytic process in IPA is designed to facilitate reflexive engagement with the account of participants, and is characterised by common processes that focus attention towards the participants' attempts to make sense of their experiences.

The aim of IPA analysis is to develop an *'organised, detailed, plausible and transparent account of the meaning of the data'* (Larkin, 2013). Described as both an iterative and inductive cycle (Smith, 2007), IPA analysis enables flexible application of analytic processes that draw on a number of strategies, and a demonstrable commitment to understanding the point of view of research participants, with a focus on meaning making in their particular context.

The approach to analysis in IPA is iterative and dynamic: Smith *et al.* (2011) suggest a fluid and multi-directional approach, utilising various methods of analysis, only fixing *'through the act of writing up'.* Smith *et al.* (2011) advocate a five-stages approach to analysis, however this has been modified by a number of researchers to a four stage process (Biggerstaff and Thompson, 2008). Despite the variation in the number of iterative steps, the aim of analysis remains the same – that is, to identify how participants ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman and Osborne, 1999). To ensure engagement with the data and the principles of IPA analysis, the integration of guidelines by Smith *et al.* (2011) were followed, as outlined below.

4.2.6.1 Step one: reading and rereading

The lengthy transcription process discussed above and subsequent repeated reading of each transcript ensured familiarisation with each of the participants' accounts.

4.2.6.2 Step two: initial coding

Transcripts were read line by line. Each account was read and reread, examining the linguistic content, such as the use of pronouns and metaphors (Phillips *et al.*, 2014). The left-hand margin was used to record linguistic comments and observations made during the interviews, as well as *'summaries of content, connections between different aspects of the transcript and initial interpretations'* (Touroni and Coyle, 2002:196), referred to as codes. Themes were developed from the codes.

4.2.6.3 Step three: developing themes

Using NVivo, themes from individual accounts were recorded, identified using either the participants words and thoughts, or the researcher's interpretations, without reference to any theoretical model (Phillips *et al.*, 2014). Smith *et al.* (2011) suggest that this reflects the synergistic process of description and interpretation, capturing and reflecting the researchers understanding of the individual experience (Touroni and Coyle, 2002).

4.2.6.4 Step four: searching for connections across themes

Themes were listed chronologically, then reordered into clusters of related themes. Relationships between themes were also considered, leading to the development of superordinate themes, and those with oppositional relationships which focus on difference rather than similarity. Numeration was recorded, that is, the frequency with which a theme is present; although this is not the only indicator of importance. For example, Smith *et al.* (2011) note an awareness of numeration can reflect the relative importance of a theme, and that numeration is particularly useful in transcripts of interviews where a more open-ended or unstructured style was used, as was practised in this study.

Finally, the thematic structure of each account was brought together in graphic form, illustrating the themes that led to the development of superordinate themes, as well as those themes with an oppositional relationship.

4.2.6.5 Step five: moving to the next account

Steps one to four were then repeated, in turn, for each of the remaining accounts. The rigor of systematically following the Smith *et al.* (2011) method ensured that each account was regarded individually, and that themes are grounded in each case, minimising the influence of what has been found in previously analysed accounts.

4.2.6.6 Step six: looking for patterns across accounts

The thematic structures (completed at step four) of each of the seven accounts were then examined collectively to identify connections and relationships between themes, specifically:

- Reciprocity
- Opposition
- Potency
- Recurrence
- Lines of argument

Two kinds of patterns were explored: patterns that illustrate connections between identified themes, recognising the idiosyncratic nature of individual experiences, and higher order, conceptual patterns that are shared across the accounts.

4.2.7 Validity

Although these are the central concerns of IPA, Smith *et al.* (2011) note that conclusions will be double-hermeneutic, that is, an account of *'how the analyst thinks the participant is thinking'* and as such truth claims in IPA are always *'tentative* *and subjective'*. That said, the transparent, rigorous and systematic application of the analytic process and presentation of findings enable the reader to subsequently quality assure.

There has been significant debate surrounding the validity and rigour of qualitative studies (Pringle *et al.*, 2011), due in part to ongoing dissatisfaction with the persistent application of measures designed to assess quantitative research being applied to qualitative studies (Smith *et al.*, 2009). A number of tools have been created to enable the assessment of validity in qualitative research (Rodham, Fox and Doran, 2013), however the principles of Yardley's (2000) assessment guidelines have been used. Yardley's (2008) principles occupy a pluralistic stance, therefore enabling application in IPA studies. Yardley (2000) describes four principles of quality assurance, as discussed below.

4.2.7.1 Sensitivity to context

Sensitivity to context is demonstrated at numerous stages of the research, indeed Smith *et al.* (2009) suggest that the rationale for the method itself can display sensitivity. Sensitivity during data collection is fundamentally important; Smith *et al.* (2009) note that a *'close awareness'* of the IPA interview process is required, demonstrating empathy and an ability to identify and address interactional and *'power-play'* difficulties, enabling participants to feel at ease, encouraging meaningful disclosure. Sensitivity continues in the analysis and discussion of findings, where *verbatim* extracts have been used to ground analytic claims and to validate interpretation. Finally, referral to existing literature has been used to orientate and endorse emerging theory.

4.2.7.2 Commitment and rigour

The demonstration of commitment and rigour is largely synonymous with Yardley's first principle, discussed above. Yardley calls for prolonged engagement with the topic; as a researcher, this has been demonstrated through the comprehensive literature immersion surrounding both grandparental grief experience and IPA methodology. Yardley's description of engagement also recognises exposure by non-research means; as a practising nurse within children's palliative care, clinical experience has been gained of working with bereaved families, including grandparents. Rigour is described as the completeness of data collection, analysis and interpretation (Yardley, 2000). A meticulous attention to a systematic approach has been followed in all elements of this Participants were chosen carefully to ensure a relatively homogenous sample (Smith *et al.*, 2009). Seeking and actively engaging with regular academic supervision has helped to ensure appropriate rigour.

4.2.7.3 Transparency and coherence

Transparency is presented at all stages, ensuring that explanation and justification for research processes, assumptions and conclusions are explained in sufficient detail. This in turn demonstrates coherence with the principles of an IPA approach. The position of the researcher, as an interpreter of the participants' experience, will also be explored explicitly.

4.3 Chapter summary

This chapter outlined the practical steps taken in conducting the research. The COREQ framework has been used to develop the chapter, which systematically and logically illustrates the process through which the research question has been answered. This chapter has in great detail explained each of the steps taken to answering the research question, discussing ethical approval, recruitment strategy, data collection and data handling and analysis. The guidelines by Smith *et al.* (2011), used as a framework to structure the data analysis are discussed. Finally, validity is explored, considering the quality assurance of the study, in particular the demonstration of transparency, rigour and application of the analytic processes of IPA. The following chapter presents the detailed findings of the study.

Chapter 5: Findings

5.1 Introduction

5.1.1 Participants

The interviews took place between February and September 2014. Seven individuals participated in the study. These included three married couples, two of whom related to the same grandchild. Of the seven individuals, six were biological grandparents, the remaining participant a step-grandparent. Four of the participants were female, three were male. All participants have been pseudonymised. Four of the participants (Olive and Robert, and Jenny and John) were related to the same deceased child. Of the participants, four were female and three male with an age range of 64 to 70 years (m: 67.1 years). All participants were retired. At the time of interview, the participants had been bereaved for between 10 and 23 months.

5.1.2 Grandchildren

The number of grandchildren of each participant at the time of their grandchild's death ranged from two to nine, with an average of 4.1 grandchildren per participant. The grandchildren discussed in the interviews had varying life limiting conditions including genetic, progressive neurodegenerative and oncological conditions. All children had a diagnosed LLC at the time of death (as opposed to having an 'undiagnosed LLC', which represents approximately 8% of all children with LLCs in the UK (Fraser *et al.,* 2012). All participants reported that their grandchild died in the family's preferred place of death, either at home or in hospital. The children were aged between two and 10 years old and had lived with their diagnosis for between seven months and almost 10 years.

5.1.3 Interviews

The interviews lasted between 32:08 minutes and 1:42:31 hours. The mean length of all the interviews was 1:03:46 hours. The average interview length for female participants was 1:14:23 hours, and for male participants 49:30 minutes. All participants were interviewed once; no repeat interviews were conducted.

The chapter begins with an overview of the findings from the collated themes, followed by detailed explanation of the findings, using extracts from each of the interviews to illustrate the findings.

5.2 Research themes

Findings have been presented thematically, as superordinate and subordinate themes that were generated during analysis. Using the methods outlined in the previous chapter, a total of 470 codes were generated from the seven interviews, which were analysed and interpreted to form themes, shown in appendix 11. A total of 17 subordinate themes were found in at least three of the seven participant interviews. These were arranged into four superordinate themes. Following the principles of IPA, each theme is illustrated with pseudonymised, verbatim quotes to ensure that themes are grounded with examples of experiences of individuals (Brocki and Wearden, 2006). The superordinate themes, and how they have been arranged into subordinate themes is illustrated in table 9 below.

Table 9: Identified themes relating to grandparental experience

Superordinate theme	Subordinate theme
'A hurt you can't undo': **The experience of emotional pain in bereaved grandparents**	Cumulative pain
	Bearing witness
	Survivor guilt
	Family tension
	Disenfranchisement
'The other hat': **Satisfying the demands of conflicting roles of both grandparent and parent**	Parental role
	Boundaries between parenting and grandparenting
	The total support of grandparenting
	Validation
'Where do I fit now?': **Transition from before to after the death of a grandchild**	Helplessness
	Changes within the family
	Identity
	Enduring features of grandparenting experience
'It's a love that gets you going': **Sources of motivation, drive and resilience in bereaved grandparents**	Sense of duty
	Responsibility for the family
	Continuum of hope
	Love

Although the themes have been arranged into the subordinate themes above, there is overlap between the themes, which is examined in the findings and discussion chapters.

5.2.1 The experience of emotional pain in bereaved grandparents

This superordinate theme consists of five subordinate themes, reflecting the participants' experience of pain. All participants expressed pain in some form, with most of the experiences relating directly to the other superordinate themes discussed below. The experience of pain is complex, multidimensional and cumulative. It is exacerbated by a reluctance to acknowledge pain both by participants themselves and to their family and friends, leading to disenfranchisement from their usual support networks, where their pain is not recognised by the groups in which they exist. The context of the family in which the participants operated had an effect on their experience of pain; participants who witnessed or experienced tensions within the family expressed more pain.

5.2.1.1 Cumulative pain

Cumulative pain describes the amalgamation of emotionally painful experiences, where grandparents are unable to separate each event emotionally, and therefore experience an amassing of pain from a variety of sources, experiences and multigenerational perspectives, namely a parent and a grandparent, as well as an *'outsider'* to the family.

The cumulative effect of the grandparenting experience was widely discussed by all participants, and describes the combination of many sources of pain, including the deterioration and eventual death of their grandchild, the loss of hope, witnessing the experience of others within the family, watching changes within the family post death and their previous experiences of illness, bereavement and loss. In addition to the responses to the physical experiences of grandparents, phenomena such as disenfranchisement and guilt exacerbated grandparents' experiences of pain. This quote from Olive demonstrated the accumulation of her experiences:

> *'It was the treatment year, it was the new baby coming, losing Hannah* [granddaughter] *the stress that I saw Kate* [daughter] *go under, the grieving*

7.1.5 Hypothesis 2

A participatory approach to workplace interventions to reduce stress in call centre employees using the SRA will improve psychological wellbeing.

Paired-samples t-tests undertaken for participants present at T1, T2 and T3 found no consistent evidence of the effect of the intervention when comparing psychological wellbeing in the intervention and control groups (Appendix 19, tables 73 & 74). Even when the same statistical tests were run for the large sample of participants that were present between T1 and T2, and those between T2 and T3 no consistent indication of change in mean scores was detected over the three time points (Appendix 19, tables 75 & 76). Independent-samples t-tests for the participant samples at T1, T2 and T3 similarly failed to show any statistically significant difference in the mean scores between intervention and control groups (Appendix 19, table 77). As with hypothesis 1, the paired-samples t-tests were repeated with a split data file to identify any differences in psychological wellbeing between the Contact Centre and Collections within the study groups. The analysis, run for both the T1-T2-T3 sample (Appendix 19, tables 78 & 79) and the T1-T2 and T2-T3 samples (Appendix 19, tables 80 & 81) again failed show any consistent change in mean scores over time for either study group or department.

Alongside these analyses a mixed between-within subjects ANOVA was conducted to assess the impact of the intervention over the three time points (table 19). There was a significant effect for time (Wilks' Lambda = .889, $F(2, 60) = 3.734$, $\rho = .030$, partial Eta squared = .11) with the mean psychological wellbeing score in both groups reducing between T1 and T2, but then increasing between T2 and T3. Similar to the effect seen on the Demands stressor in Hypothesis 1 it is possible that this is due to the workload impact of the adverse weather event, particularly as there was main effect detected for study group.

The measure of participant's intervention exposure was used to consider how this might affect psychological wellbeing. Paired-samples t-tests showed no statistically significant effect of the intervention across from T1-T2, see table 20 & 21, with the mean psychological wellbeing score

5.2.1.2 Bearing witness

The effect of bearing witness on the experience of participants was the most frequently coded theme in the dataset. Participants discussed witnessing the experiences of their grandchild's immediate family, most commonly the pain and anxiety of their grandchild's parents and siblings, with particular emphasis on the experience of their own son or daughter:

> *'I had to be the strong person. There was me daughter that was hurting and I mean, I talk of Ben* [son in-law] *and I'm really – I felt for daddy as well, for Ben, but erm, I talk of Kate, because she's, she me own and erm, I had to be strong,'* (Olive)

Frequently, bearing witness to the experiences of parents was associated with a feeling of helplessness; a desire to make things better, and an inability to do so, leading to increased pain:

> *'I felt, I suppose I felt inadequate. You want to make it right and you can't, and I think that's a driving force with any sort of mum. She wants to make it right and explain it but you can't. That was incredibly hard to see'* (Christine)

Although the participants spoke of the trauma of witnessing the pain and suffering of their grandchildren, it was not associated with the same degree of helplessness as witnessing the experience of their child:

> *'I think erm, probably sitting with Hannah on the day she died and seeing her struggling to breathe. Yeah, I found it very hard.'* (Jenny)

Perceptions of suffering dominated participant's recollections of their grandchild's illness. This was met by some grandparents expressing a desire for their grandchild's suffering to end through death. Some grandparents were more direct in acknowledging this than others, as illustrated by John's quote below:

> *'I think there should be this euthanasia, I really do 'cos it's not fair to anybody, and it's not fair to the child or anybody else. It's just not right, suffering- if you have a dog you'd have it you'd have him put down don't you - animals. You don't let them suffer, and it it's just not right. Especially when it is going to be, when it is terminal. Yeah, I really believe in that they should do something about it. I think it would've made life a lot easier for everybody.'* (John)

These disclosures led to increased feelings of guilt, due to an awareness of the taboos and associated with wishing the death of their grandchild:

> *'part of you doesn't want him to fight anymore, you want him to just go to sleep and I think that's - it's something else you feel you can't voice to people because people have got this sort of you know, 'you shouldn't feel like that, you would want him to live' and I – no, in all honestly I didn't want him to live. I didn't want to see him suffer. If he was out of, not in any pain, that's a different thing, but he was always in pain. Tough.'* (Christine)

The conflicting and controversial feelings illustrated in the above quote compound the experience of social isolation and disenfranchisement, stemming from a reluctance to voice these feelings, as explored in more detail below. These were largely around negative experiences, but included some positive observations, which helped the grandparents to cope.

> *'slowly they have changed one or two little things at home you know, that was a really big thing I think actually, 'cos up until then Darcey did have her space still in the house erm, so I suppose you know, it showed a slight moving on emotionally in a way – to everybody else, you know.'* (Anne)

For Olive, the most overwhelming memory of her experience was her granddaughter being left alone, indeed it was an issue that she visited repeatedly throughout her interview. Olive vividly recalled witnessing the handover of Hannah's body to the undertaker, who collected her from home:

> *'they handed her over, and this lovely lady [the undertaker], Elaine they call her, just kissed her [pause] and she were [pause] [much quieter voice] on her own then.* [...] *But I tell you, to leave her, just to leave her is so wrong,* [...] *and I think that is the biggest thing [pause] for a grandma, see- [sobs] just giving her away to a stranger and her being left in the room - I know it was a child's room and teddy bears and all her favourite toys there, [pause] that is so awful [sobs] cos I'd have sat in a fridge with her [sobs]* [...] *cos that is awful. Just awful. Its worse than her actually dying cos you're abandoning her, and she'd never been alone.'* (Olive)

Witnessing tensions within the family added to the painful experiences of the participants. Anger was highlighted recurrently, witnessed from their child, in-law or partner caused an increase in pain:

> *'Kate would get angry at the most littlest thing which I'd never seen before* [...] *and everything were stressful; it's been a much more stressful family erm, you know, the event of Hannah - her illness and death has brought a lot more stress to the family.'* (Robert)

The ability to tolerate anger and frustration within the family was discussed by some participants, with various approaches taken to its management. Most frequently, grandparents endeavoured to excuse the anger, explaining that the expression of anger is due to the loving and supportive context created by the family:

> *'He* [son in law] *was so upset he didn't know how to cope with things, and so his aggression had to come out on somebody and I think we were the nearest, and that I think comes down to - well I had to tell myself it is* [...] *you always lash out at the ones that you know love you they'll take it, and it's not always meant with such anger and nastiness.'* (Olive)

> *'a kind of anger which wells up and people hit out at those closest to them'* (Robert)

Internal frustration for being unable to tolerate the anger expressed by members of their family, particularly their children, further compounding their grief:

> *'if your loved one's angry, and probably angry at each other and less tolerant it makes you feel sad really.'* (Robert)

Participants also acknowledged their own anger, often in response to a feeling of disenfranchisement.

> *'Sometimes when our Ben comes I get a bit annoyed with him because I think he's a bit selfish sometimes in his manner. There isn't only him hurting, I know he's the father, but it's not only him what's hurting'* (John)

5.2.1.3 Survivor guilt

A guilt arising from outliving their grandchild was mentioned by three of the participants. The phenomena was neatly summarised by Christine, who stated:

> *'You know everybody's going to die, but when it comes out of sync, that really upsets it all. Erm, you don't expect to lose your children before you, you expect them to outlive you, and you certainly expect your grandchildren to outlive you. And I think that's very hard. And something you can't come to terms with, because you don't feel it should be.'* (Christine)

Participants discussed the desire to be able to *'exchange'* their lives for the life of their grandchild, talking about the unfairness of their death in childhood. One grandmother reflected on the life of her own mother, who was living with dementia with an increasing poor quality of life, and discussed a wish for her life to end in exchange for her grandson:

> *'I wish* [my daughter] *would get his life back and my mother just go, you know, you wish you could exchange it really'* (Christine)

One grandfather suddenly became emotional when acknowledging his guilt around outliving his granddaughter:

> *'I think with her being so young. In fact I told her I'd change places. If you could do that* [started to cry and walked away from the table and stood in the corner of the room]' (John)

For John in particular, the emotional pain of outliving his granddaughter was clear; these feelings appeared to be exacerbated in his reluctance to talk about them and the pressure he placed on himself to control his emotions. This was demonstrated by physically walking away from the table during the interview, and referring to his granddaughter's maternal grandfather whom he referred to as 'blubbering' when discussing his crying following Hannah's death.

5.2.1.4 Family friction and anger

Participants discussed how friction and anger within the family exacerbated their experience of emotional pain. Most frequently, the anger extended to the child's parents, siblings and grandparents, however participants also discussed ripples of anger that extended beyond the child's immediate family, extending into the families of the grandparent's other children. This was often discussed from the perspective of a parent, where participants discussed conflict between their children.

Tension within the family has been discussed from the perspective of bearing witness, however grandparents discussed tensions more widely, including their own stress, anxiety and involvement in the tensions that were expressed by other family members:

> *'I think that there can be, it can cause friction. Sometimes there's an anger. Anger in the family, and that anger comes out to those that are nearest to each other, and sometimes there's anger between Kate and her mum, and sometimes there's anger between Ben and Kate and sometimes there's anger between, Kate and me - there's a kind of anger which wells up and people – it hits out at those closest to them and then there's a lot of apologies afterwards. That's something I've felt and yeah, there is an anger sometimes.'* (Robert)

The effect of the illness of the grandchild, and the challenge of balancing the needs of the wider family, particularly the demands of their other children was highlighted. This was a particular issue for those grandparents involved in the provision of regular childcare to their grandchildren, prior to their sick grandchild's diagnosis.

> *'I'm talking about the two family groups. One whose got four, and one who's got two* [children] - *it's got nothing to do with the numbers, but it's just as the needs sort of arise. To try and get it right and as a mother you you've done that for your life anyway, to try and make it right for your own children and then again when they're grandchildren you're doing it for your children and for their children as well, you know.'* (Anne)

Anne provided regular childcare to her younger daughter's four children before Darcey became ill, at which time her older daughter's family became her priority. Anne described the situation as *'really big ball for me to balance and juggle'* because of her younger daughter's reaction to her reorientation of childcare. Anne suggested that this tension extended long after Darcey's death, almost 18 months before the interview took place:

> *'Even now that balancing is still having to be managed because people remember when people had to sort of give up their turn or you know, or I was obviously having to concentrate on one more than the other, for various reasons so its a big issue that a lot of grandparents will try to manage'* (Anne)

5.2.1.5 Disenfranchisement

Experiences of disenfranchisement were discussed by participants throughout their experience, beginning shortly after their grandchild's diagnosis and continuing throughout their treatment, death and bereavement. Experiences of disenfranchised grief were characterised by feelings of isolation, insufficient emotional support and empathy from social support networks and poor understanding from those who they would normally seek support.

Participants appeared to accept the lack of understanding from their peers, due to an inability to appreciate the enormity of the situation by those who have not experienced it.

> *'I don't think people realise, I mean I don't think you can put yourself solely in that position until you've experienced it really. But some people have more empathy than others.'* (Christine)

However, participants appeared to be more hurt by disenfranchisement from their families:

> *'I think there's this thing, where they obviously, are grieving and very sad about what's happened, but they don't seem to think that anybody else is grieving'* (Gary)

On discussing the relationship with her daughter following her grandchild's death, she described feeling ostracised:

> *'I do feel sort of outside of it, and I can't say not considered, that doesn't sound right - but I almost feel she doesn't think that we feel so hurt as we do…'* (Christine).

Like other participants, these responses from their children and support networks are often perpetuated by a grandparent's reluctance to acknowledge their grief externally:

> *'…but I, there's no way that I would tell her I don't think – they have got so much to cope with themselves. I know how I feel as a grandmother but how I would feel if I was the mother, I can't get there you know, because its just sort of an indescribable when it happens to people and you just think oh God, I can't really put myself there. I can empathise but I can't put myself there. I can't feel as she feels.'* (Christine)

Much of the reluctance appears to stem from the parental stance taken by the participants, who frequently discussed their desire to protect their child from their own feelings of sadness and pain. This is explored in more detail in section 4.2.2.1 below.

5.2.1.6 Summary

The experience of emotional pain in grandparents is multifaceted and complex. Although discussed thematically above, rarely are the sources or causes of pain discussed in isolation; highlighting the cumulative effect of painful experiences, which occur throughout the experience, starting with the diagnosis or recognition of the LLC and continuing throughout the child's illness, death and into bereavement. The phenomenon of bearing witness, highlighted by all participants repeatedly throughout their experience, consisted of watching the experiences of others within the family unit. Most commonly, participants described the pain caused by witnessing the child's parent's grief, but also included observations of their sick grandchild's suffering and the grief of well grandchildren. For the male participants only, bearing witness of the experience of their partner was also highlighted as a cause of emotional pain.

The context in which the grandparent exists has a direct impact on the experiences of the individual. Experiences of pain appear to be exacerbated when there is anger or friction within the family. In this context, *'family'* was used by the participants to include their other children and their family units (usually containing other grandchildren), demonstrating the broad perspective of grandparents within a family and explaining the phenomenon of *'juggling'*, highlighted by participants.

Helplessness was closely associated with the experience of pain; participants highlighted increased pain where they perceived greater degrees of helplessness. Conversely, participants with a clearly defined role described less pain.

Participants' reluctance to share some aspects of pain exacerbated their experiences; participants expressed a reluctance to voice thoughts that created a sense of guilt, such as that associated with living beyond their grandchild and the taboos related to thoughts surrounding suffering, quality of life and the relief that resulted from the death of their grandchild. In addition, participants expressed an unwillingness to share their sadness and pain with their families and peer group, due to the parental role taken by participants, where they did not want to add to the burden of their family, nor did they wish to take support away from the parents by acknowledging their pain within their peer group. As discussed above, this disenfranchisement exacerbated the experiences of pain in participants, who were largely left feeling isolated and unsupported with grief that was not recognised by the society in which they exist.

5.2.2 Satisfying the demands of conflicting roles of both grandparent and parent

All participants described the multiple roles within their experience, highlighting the expectations of others and their own foci, and the challenge of keeping these in balance. This superordinate theme is an amalgamation of four subordinate themes that relate to these roles. The predominant role expressed by participants was that of parenting; all seven participants discussed their experiences through the lens of a parent. The secondary caring role of a grandparent was widely discussed, with some participants accepting this, while others struggled with this boundary, enforced by the child's parents, professionals involved in the care of their grandchild and their partners. Participants discussed validation, and their need to be recognised as playing a meaningful role within their family unit, mostly by the child's parent and on some occasions, by the professionals involved in caring for their grandchild.

5.2.2.1 Parental role

The parental role fulfilled by grandparents was the largest theme, accounting for nearly a fifth of all codes in the dataset. Participants predominantly told their stories from a parenting perspective, with a focus on supporting their child.

> *'they were the first front line, they were the decision makers. We had to just support them two to keep them, to give them strength, to take away a lot of every day pressures so they could be as best as they could, still in pieces, but the best they - we had to support them to keep them in the best way of being able to cope with what they were given.'* (Olive)

Involvement in the care of their grandchild also stemmed from a desire to support the parents. The quote below is an example of how grandparents talk about their grandchild in relation to the parent, again suggesting that their focus at the time of involvement was on parenting, not grandparenting:

> *'All I could give Hannah was love and time and by giving time and all the support to Kate and Ben that enabled them to be at their best as possible to look after their little girl.'* (Olive)

Participants discussed their role in attending hospitals, again with a primary focus of parenting, even when this created stress and anxiety within the individual:

> *'I would go in and sit with Darcey for one or two hours during the day so Laura could just get out and walk round, so she could see a little bit of the pace of life for an hour, and if I was there with her on my own I was always very anxious really. I mean I laughed at myself, for all the nappies I've changed over the years, once she had all her tubes in I just said to Laura I can't take the responsibility, because I just didn't want to dislodge anything - I knew I wouldn't do it, but I always used to press the buzzer and somebody else would come in and, and sort her out for me.'* (Anne)

The support offered by grandparents included emotional, practical and financial support. The ability to provide support gave participants a sense of focus and meaning; it enabled grandparents to take an active role, contributing in a variety of ways to the family through the provision of time, money or meeting the practical needs of the family:

> *'There was also the big issue, which I got very involved in, which in fact in many ways was a God send to me, although it was also a bind, was doing the washing.* [...] *In fact in many ways it was quite good for me because it gave me something physical do to that was involved, and I felt I was contributing, even if it was just a washerwoman! It gave me a reason to be going - well, I'd been going in and out anyway but you know, I had to keep up to date with it.'* (Christine)

Financial support was provided, however this added to the stress of some participants:

> *'Financially it had an impact* [...] *basically, and I was, our income was supporting two and our savings was supporting two households, so that had a considerable impact. And that went on probably for the year. So that was a heavy sort of financial burden - not a burden but a responsibility.'* (Robert)

The ability to provide support created tension between grandparents. Participants compared their ability to provide financial support to that of their in-law's parents:

> *'they're not without money, so of course, obviously they [pause] they showered her with gifts and we, we weren't able to do that, cos were not in that financial position* [...] *you do want to spoil them but, as I say, we're not in that position to be doing it. And I don't always think it's a good thing.'* (Jenny)

The provision of practical support also contributed to strains between grandparents; particularly surrounding opportunities to spend time with their sick grandchild at the time of death:

> *'So much I wanted to be there, but I never said. Because I knew Kate knew Harry was being looked after, and erm, that helped her, cos if she knew her mum's looking after Harry, he's going to be loved and played and things, but I really really did want to be with her, and I've only ever told you. I envied the other grandparents, cos they came and they were there from morning until night; and my role was looking after - they never come and wanted to take Harry out so that I could have gone and had an hour. He had to be looked after, to give Kate and Ben the best chance of coping with Hannah.'* (Olive)

Like Olive, participants expressed a desire to protect their children, which frequently included hiding their feelings and emotions from them, and a frustration when this was not shared by the child's other grandparents:

> *'I don't think [my daughter in law's] father helped right much because he was always blubbering and all the time. I mean we were all upset about it, but you've got to try and control yourself. He used to upset them, you know. And obviously then when erm, obviously the baby would feel that as well, blubbering away.'* (John)

5.2.2.2 Boundaries between parenting and grandparenting

Participant opinion on the *'fine line'* (Olive) between parenting and grandparenting was divided into those that accepted the difference, and those that were frustrated in the lack of control afforded to them by their grandchild's parents as a secondary carer. Largely, participants were accepting of their role as a grandparent and secondary carer:

> *'when she was ill I felt very strongly that I'm in the background, that its her parents, and Grace* [her sibling] *that are in the driving seat, and we're* [grandparents] *there to come along with them in the backseat as it were. All the time when she was ill I was very aware of being supportive, but not being the leader or anything like that - that wasn't my role.'* (Anne)

As discussed above, participants frequently viewed their experiences through the lens of a parent, which sometimes resulted in crossing the generational line, assuming the role of the primary carer. In most cases this was due to the participant's desire to protect their child, shielding them from potential sources of pain, stress and anxiety-provoking events:

> *'I mean he was hours screaming in pain and I think to see that, I did- er, we did get him calmed down, I sat, just sat with him and I said, and cos Emma was getting up- she was in tears, I said look, just just go out the room, just leave him with me and and I'll deal with him and and I'll calm him down cos you know, they pick up on if somebody else is not happy and, and he did eventually calm him down'* (Christine)

One participant spoke of the benefits of remaining objective as a grandparent, giving him a perspective that others in the family were unable to achieve:

> *'he* [a consultant paediatrician] *would ask Emma how Jake had been, but Emma got emotional about it; and I - whereas I tried to be step by step and logical about it, and I used to ask them had they done this, had they done that, had this test been done, and as it turned out, a couple of times they hadn't done the test.'* (Gary)

When asked directly about how it felt to take a secondary care role, Gary explained:

> *'it's frustrating. Erm, in business I was always fairly outspoken and you know, if I thought something wasn't right, I would say it, but I didn't say much, I have to take the backseat and say, not say a lot. You just have to watch these things go on. I suppose every now and then I might say something, but erm, no it's sad and it's frustrating, that the only way I can really describe.'* (Gary)

5.2.2.3 The total support of grandparenting

At the beginning of her interview, Olive shared a quote from a gift she has been given by a friend: *'Grandmas are like buttons - they hold everything together!'* said with a smile, Olive went on to discuss the holistic support she and her husband were able to offer her daughter and her family during their granddaughter's illness and death and her family's bereavement which followed. The concept of total support was echoed by other grandparents, with emphasis on the responsiveness and selflessness of the care provided. As Christine explains: *'whether it be we've given financial support, wherever we you know, whenever, literally whenever it's been asked. Erm, and never put sort of ourselves first'*. Participants also considered the role of the grandparent to be unspoken and reliable:

> *'she knows that I was always there to support her.'* (Anne)

The notion of total support was shaped differently for Anne, who linked her supportive role with her desire to provide her daughter and son in law with a sense of control:

> *'I would always say 'what do you think', 'would you like', you know because I felt with Darcey it it it was a rollercoaster - there were very few things that they could feel in control of so certainly I wanted them to feel that they could in a way have control of what I was saying and doing and thinking.' (Anne)*

Participants described the time they committed to their families, often involving the provision of round the clock support and daily visits, often at short notice or in response to a crisis.

> *'I always made sure I was there every day.'* (Olive)

> *'I've done as much and as possible support as I can be to them – I'm always there at the end of the phone an erm, and up there as soon as I could get there, we've done the traveling of the country [laughs] which has never been a pr- issue, never been a problem, I'll do , you know, always done what I could do.'* (Christine)

The time given to their families impacted on the grandparent's ability to socialise. The following quote from Robert is an example of the how the identity of *'family'* changes. In the statement below, the *'family life'* Robert is referring to surrounded himself and his wife, which broadened to include his daughter's family once Hannah became ill. He discusses the impact of this on their plans for the future, particularly as Robert was readying for retirement at the time of Hannah's diagnosis.

> *'the impact on our family life was [pause] we had no time for e- each other, we'd no time for socialising - I'm not saying that's important in that kind of situation but, that's the kind of impact it has, no time for us at all really, it was,* [...] *there was no time er- for any erm, anything outside of, of the, of the support that we were providing. There was no time for entertaining or perhaps for going out nor nothing really. Erm, because it was a full time.' (Robert)*

The decreased social exposure led to a decrease in participant's social support networks, exacerbating the perception of isolation and disenfranchisement from friends and peers:

> 'It's *people's reaction, and I think that al- also has been hard to cope with you know, why [pause] we'd sort of had this to cope with which is fine, didn't put it on anybody else, but [pause] when you need support you need your friends. And people, some people will - it is a minority but, go the other way and and don't want to talk to you and I mean, it's probably because they don't know what quite what to say or how to broach it, but but I mean it its worse not to do anything.'* (Christine)

5.2.2.4 Validation and recognition

Recognition of their role was not important to all participants, but it was expressed very strongly by those who needed it. Within the data set it was the grandmothers who discussed their need for validation, with the exception of Jenny. Participants discussed validation prior to the death of their grandchild. Whilst explaining her role in caring for her granddaughter in hospital, Olive recounted an occasion when she returned to the children's ward after visiting another person in the same hospital:

> *'when we come back this one nurse, come up to me and she just touched my arm she just 'thank goodness you're back' and I said 'why' and she said 'oh, she has cried for you Olive' and I thought ah, and I said, and it was something the nurse said - and another one said it - 'you've got a wonderful relationship with your granddaughter' and, and I said 'oh' and you know, I expect everyone to have this relationship, you know, but obviously the people don't. And it*

> *was just little things like that that kept me positive, that what I'm doing is right, you know.* (Olive).

Christine spoke of the hurt caused by her daughter, who she perceived as taking her for granted:

> *'you see she never ever said thank you to me for that, and you just, it's just the little things, you think [pause] oh, I don't know, and that hurt, really hurt. She she thanked all her friends for, but she didn't thank me and I'd, you know, you just think that's a bit of taken for granted and erm, and it's a hurt that you can't undo.'* (Christine)

All female participants spoke of how much it meant to them to be recognised by hospital staff and to be referred to by name. It gave the grandparents pleasure to be known not only by their name, but also by their role as a grandparent. Participants used the interview to validate themselves, using the other grandparents as a benchmark:

> *'they loved Hannah very much, but she didn't know them as like she knew me'* (Olive)

5.2.2.5 Summary

The primary role discussed by participants was that of a parent; this was demonstrated through their focus on the needs of their child, and the impact that their role had on their child. The parenting role has been found across all superordinate themes in this dataset.

Some participants experienced internal conflict with regards their role, struggling with the boundaries between the primary role of a parent, and the secondary role of grandparent. This conflict resulted in some frustrations, which manifested as anger, jealously or helplessness in participants. Participants highlighted their need to feel useful and their need to provide various forms of support, including practical, emotional and financial support, the latter being cited most frequently by the male participants.

The concept of total support was perceived and described by all participants, who considered the role of a grandparent to be one that could only be filled by grandparents due to their peerless ability to provide care that was boundless. Participants also discussed how their grandparenting role afforded them with unrivalled closeness to the family that could not be replicated by any other person, other than a grandparent, despite the relationship or intention of the individual. Participants spoke of the time involved in providing responsive care, particularly at the time of their grandchild's illness and death. The investment of time was not without cost to the participants, who spoke of their reduced ability to socialise and maintain friendships outside the family, intensifying perceptions of social isolation and disenfranchisement. Participants also highlighted how their role required a change in plans and expectations for an 'idyllic retirement' and the life they'd expected in their later years.

Some participants highlighted their need for validation and recognition; those participants with secure intergenerational relationships and who exist in more stable family systems required less external validation. The lack of validation received by some participants led to an increased perception of helplessness and therefore was a significant source of emotional pain.

5.2.3 Transition from before to after the death of a grandchild

The changes associated prior to and following the death of a grandchild presented four subordinate themes, discussed below. Almost all participants described helplessness, where a feeling of inadequacy was discussed frequently alongside bearing witness to the broad experience of their children and grandchildren. In addition to the roles played by participants (discussed in 4.2.2 above) changing following the death of a child, so too did their identity within the family. Participants described a distal move away from the centre of the family unit in bereavement. There were a number of features that endured the transition; these included the love of their grandchild, characterised by the sharing of memories of a time before their grandchild's diagnosis or recognition of their life limiting condition. All participants highlighted the importance of photographs, and referred to them throughout their interviews.

5.2.3.1 Helplessness

The perception of helplessness was closely associated with pain and was often experienced when bearing witness to a traumatic event within the family, deriving from a desire to parent.

> *'Erm, and you're just helpless you know. There's nothing you can do. Erm, so, you feel like a spare part if you understand me. You know, if you could do owt about it then you, it would be better.'* (John)

> *'you feel so absolutely inadequate and unable to help'* (Christine)

> 'I *guess I did feel angry, but erm it were anger through helplessness to be honest, you know, like I erm, I can't do anything; I mean what can you do? You just can't. Erm, I can't put it right'* (Robert)

Olive's feelings of helplessness were expressed from her perspective as a grandparent, where she discussed her inability to actively contribute to the decisions surrounding the care of her granddaughter. In the quote below, Olive goes on to discuss the support she is providing the family, describing a passive, secondary care role:

> *'If there was anything I could of helped, I'd have felt very happy to be told something, but there's nothing - I can't make decisions for her can I? I couldn't, they had a mummy and daddy and they made the decisions. If they needed, if it was the parents that needed some, if Kate or Ben wanted to sound off* [...] *then I'd have something to contribute, but there is nothing a grandparent can do but offer support and give them everything they can to keep them going through this absolutely awful time.'* (Olive)

The same sense of helplessness is echoed by Robert, who attributes his sense of helplessness to an inability to fulfil his parenting responsibilities:

> *'you feel strong all your life, you're always there and if there's any problem for your daughter, any problem for your son, you can usually sort it out and and erm either with mo- in my case, I've been fortunate either sort it out with money or sort it out with support, but this one I couldn't do it. You know, this one was beyond anything really. It's that helplessness that left you sort of a bit bereft because when your daughters saying 'help me' and you can't.'* (Robert)

Gary described a variation in helplessness; during his interview, he discussed how initially his grandson's father struggled with his condition, at which time Gary stepped in to provide support to his stepdaughter by attending hospital appointments, playing a temporary parental role. Once the child's father had come to terms with his diagnosis, he began to attend the appointments with his wife. This change in role within the family left Gary feeling helpless, on this occasion, stemming from the change in power created by his reduced role:

> *'So it makes you not able perhaps to to offer some of the help that you you feel you could give. So therefore you you start to stand back and let things progress I suppose.'* (Gary)

5.2.3.2 Changes within the family

This theme captures the perceived changes within the family in the transition between the life and death of their grandchild. Numerous changes, and their effects on participants were discussed widely. Most of the changes, or the connotations of those changes discussed were negative and generally surrounded either bearing witness or a significant change in role, both of which have been discussed under other superordinate themes.

All participants, with the exception of John, began their narratives at a time close to the diagnosis or recognition of the child's LLC. All seven participants discussed the diagnosis or recognition; the ways in which this was perceived varied, depending on the type of condition their grandchild had. Gary's grandson had a progressive neurodegenerative condition, but for a long time had no diagnosis. Gary described a view that focused on the child's physical presentation and abilities, discussing gradual deterioration over a long period of time:

> *'its its really just a case of him being a normal toddler to suddenly becoming a child that could do less and less as the years went on, erm, and gradually deteriorating I suppose over the years' (Gary)*

In contrast, Robert's perception of his granddaughter's illness was affected by the diagnosis, particularly the word *'cancer'*, describing the sudden and *'traumatic'* effect on the family. This was despite Hannah being unwell for a number of months prior to receiving a diagnosis, which was attributed to routine childhood illnesses.

> *'it was like our whole world changed on the* [date Hannah was diagnosed with cancer], *and erm, basically, erm, the, the, the family just. Everything changed.'* (Robert)

Robert's reaction to an oncology diagnosis was similar to the three other participants with grandchildren with cancer, and may be related to the perception of hope. This is discussed in more detail in section 4.2.4.3.

All participants discussed changes in the grandchildren; most commonly detailing the symptoms witnessed, without knowledge of the details of the treatment plans, prognosis or test results. There also appeared to be an acceptance of the palliative nature of the condition:

> *'I think when she became ill then [sigh] I guess the feelings changed then because you know, I wasn't going to see this little girl grow up to be erm, or I was unlikely to see this little girl grow up to fulfil her life and all the wonderful things she should have experienced.'* (Robert)
>
> *'It isn't cos that I didn't want her to die, but I didn't want her to live like she were doing, in pain and not, not knowing anything.'* (Olive)

The notion of suffering was a recurrent focus of the interviews, with participants expressing a desire to end the suffering:

> *'I didn't want him to suffer this anymore. He's suffered enough.'* (Christine)
>
> *'I just thought that when he'd gone you you have to kind of come to terms with him not being there erm, but also not forget how much he suffered.'* (Gary)
>
> *'they say they're at peace but they seem to suffer to me. Suffering. Yeah.'* (Jenny)

Participants were conflicted in these feelings, expressing a reluctance to acknowledge them with their children in fear of adding to their upset:

> *'we only want to do what erm, they feel comfortable with, so I'm [sigh] frightened to voice how I feel because I I don't want to upset Emma'* (Christine)

Of the participants, only Gary felt that his son would support his opinion. Gary's interview commenced by, and was peppered with discussions of perceptions of the prolonged and unnecessary suffering of his granddaughter, and his support of euthanasia, which he insisted were supported by his son, Hannah's father. These disclosures were accompanied by outward displays of anger, including the use of raised voice and banging a fist on the table.

> *'Oh yeah, yeah, aye. [pause] yeah its erm, I don't know, it's very hard. Like I say, shouldn't not be prolonged [banged the table with his hand], no way should it be, for anybody. And that I think, that is the worst part is er, just waiting [pause] it, I think it's disgusting to be honest [sigh] [pause] I do.* [...] *and I hope that that that you can take that bit in and get that into your writing about this euthanasia thing cos [exhales] I really think that should happen, and I'm sure every parent, erm, parent would say the same.'* (Gary)

The enormity of the change in the family following death was articulated by some participants as an *'emptiness'* or *'hole'*:

> *'I just felt that erm that's just a huge hole in the family now that just, just everything eh- it was like a tsunami just hit us'* (Robert)

> *'You can't really put it into words how [pause] big a hole he's left.'* (Christine)

Robert used the simile of a tsunami to portray the overwhelming devastation within the family following the death of his granddaughter. Similar metaphors used by other participants included *'an explosion of everything'*, and for others, they explained it was impossible to find the words to articulate their feelings of devastation following the death of their grandchild. For Christine, she discussed her surprise at the hole left in the wake of Jake's death:

> *'I suppose, whereas if I look back at Sophie, her life and how much interaction we'd had with her, which we, though Jake's illness, we couldn't have with him, erm, you would think perhaps it wouldn't make such an impact. And I think that's what's surprised me, he he was very ill, or his condition meant that we couldn't, you know, the things that you take for granted, you do take for granted.* [...] *Erm, our experiences with him were very sort of narrow, because the only thing that he really really really showed any joy for [...] didn't really involve you, if you see what I mean? And I think it's those surprising things [...] and I suppose you think well, so he hasn't, he hasn't been vocal, he hasn't you know, hasn't been interactive really with us, to that degree, only, you know, what he could do. erm, [pause] but yeah, I wasn't expecting such a big hole.'* (Christine)

Given that the participants had been bereaved for at least 10 months, there was some focus on positive changes that have occurred within the family:

> *'they had a beautiful holiday last year which they couldn't do before. Erm, they go out more, Emma goes out with Sophie, they go swimming together, they do things together now.'* (Gary)

> *'the good thing for them is that they have become a really good family unit, which wasn't always the case, which is lovely to see, and I wouldn't have that any other way.'* (Christine)

> *'the pain of losing Hannah will never go away, er, she's in our hearts, but I can see Kate's levelling out now, and I'm backing off. I'm not having the need to support'* (Olive)

> *'I mean they they're both back at work, you know, and they're they're busy at work, bo- neither wish to be at work because its not what they really want, you know, to be there, but erm, that's the process that they're having to go through isn't it, you know, to get their head around things.'* (Anne)

5.2.3.3 Identity

Within the participants there was a shift in their identity in terms of their location within the family. Before the death of their grandchild, participants usually possessive pronouns such as *'we'*, *'us'* or 'our' when discussing the grandchild and family, indicating their inclusion within the immediate family.

> *'we knew right from then that she would never get better and they wanted her to be at home and not in the hospice'* (Jenny)

> *'as I said we knew it was, it was coming for a few days'* (Olive)

> *'We knew there was going to be a possibility of a bone marrow or stem cell transplant, but obviously they [the medical team] wanted to wait until she was about a year old'* (Anne)

Following death, the possessive pronouns changed to *'they'*, *'theirs'* or *'them'*, suggesting a perceived shift in the positioning of the participant in relation to the rest of the family. This was irrespective of the centrality of the participant's role within the family:

> *'I think they're they're a much more – they're a much more better unit now, and they seem to be, they probably wouldn't like to admit it, but I think they are in many ways happier because they've had the burden of of of looking after Jake taken away from them'* (Gary)

> *'I just didn't think it were right for me to share, they were hurting, they were losing their little girl'* (Olive)

> *'When she died, it had to be them as a family, not us - they were together [pause] [crying]. Yeah, we are on the edge, it looks as that you're looking in on something to be honest. [Whispers] it's like you're looking in on something.'* (Robert)

Robert was not the only participant to highlight the feeling of being an observer. Participants described the a similar phenomenon – a combination of helplessness and bearing witness, using metaphors including *'looking down on yourself'*

5.2.3.4 The enduring features of the grandparenting experience

As already highlighted, the death of their grandchild marked a change in the focus of the discussions surrounding experience. There were however, a number of features that endured the transition of the grandparents role from before to after death, namely the love of their grandchild and the significance of memories, and the need to parent, both of which impacted on the perceived role of the participants.

Love is discussed as a drive for grandparents in section 4.2.4.4, however in relation to the role of grandparents, it appeared that grandparents associated their role with ensuring the lasting memory of their grandchild:

> *'you like to have that little bit of time I suppose sometimes you you think about him, or you s- we've got lots of photos of him and you kind of think about him, look at them and think erm, what a lovely little boy and all the rest of it.'* (Gary)

5.2.3.5 Summary

This superordinate theme represents the changes experienced by participants following the death of their grandchild, often comparing the contexts pre and post death. The most widely discussed phenomenon in this subset was that of helplessness, which, as discussed above is closely associated as a source or contributing factor to emotional pain and is frequently discussed alongside bearing witness. The notion of helplessness is discussed from dual perspectives, again demonstrating the twofold position taken by those in a grandparenting role, where their role as both a grandparent and parent are intricately, and sometimes conflictingly, woven into their experience. The conflicting priorities of the dual perspectives, together with the changing demands and expectations of the child's parents throughout the family journey can exacerbate the perception of helplessness within participants.

Changes within the family were discussed from the point of diagnosis or recognition; where children had a confirmed diagnosis, or a diagnosis which followed an acute event, changes were discussed more prominently. Conversely, where children had no diagnosis, although changes were discussed as the needs of the child progressed, the changes appeared to be more subtle, evolving in response to the changing needs of the grandchild.

In all cases, the grandchild provided a focus for the whole family. Throughout the child's illness, participants identified strongly within the family unit, which correlates with the well-defined roles played by grandparents. Experiences of the child's illness and deterioration were shared from a perspective from within the family, using *'we'* and *'our'*, indicating unity and togetherness, with the child's immediate family. This proximal positioning continued up to and included the time of death, where participant's descriptions of events changed subtly, using *'they'* and *'theirs'* in place of *'we'* and *'our'*, implying a perceived relocation of participants to outside of the immediate family unit during bereavement, at which time participants discussed the reforming of the child's family unit. The movement away from the child's immediate family was discussed explicitly by participants, who described feelings of isolation and reduced support and attributed these to the reduction or cessation of the role they had established during their grandchild's illness; again, participants discussed these experiences from the perspective of an observer, over which they had little or no control of the direction or outcome of the experience.

Finally, there were elements of the experience that endured the transition from before to following death, most notably, that of love. Participants discussed at length the love they held for their grandchild, child and child's family; indeed, the experience of emotional pain appears to be most prominent where emotional and affectionate bonds are stronger, particularly in parent-daughter or grandparent-grandchild intergenerational relationships.

5.2.4 Sources of motivation, drive and resilience in bereaved grandparents

The drive and motivation for their role was affected by the perspective of the participants. All participants discussed their primary drivers, which could be divided into two broad categories of either a drive to fulfil the traditional responsibilities of a *'normal'* grandparent, providing childcare in a similar way to their peers with well grandchildren, or a drive to support their own child, from the perspective of a grandparent. All grandparents discussed a drive to maintain hope at various stages of their experience, spanning the time before, during and after the death of their grandchild. Some of their hopes related to the family as a whole, to their child, grandchild or themselves specifically. Strongly related to the individual's ability to cope with their reality, hope appeared to be a dynamic feature of the experiences described, evolving throughout the stories to reflect the reality and context of the time in which the hope is placed.

Love was a recurrent and prominent feature of the interviews. Grandparents highlighted a love of their child most frequently, followed by a love of their family collectively, their grandchildren, the status of being a grandparent and the lifestyle that being a grandparent afforded.

5.2.4.1 Sense of duty

A sense of duty was discussed overtly or implied across all of the interviews. The sense of duty was directly related to their role as a parent. Robert described how he considered his supporting his own and his daughter's household financially as a *'heavy sort of financial burden – not a burden but a responsibility.'* Other examples of the parenting focus of participants include:

> *'we had to just support them two to keep them, to give them strength, to take away a lot of every day pressures so they could be as best as they could, still in pieces, but the best they - we had to support them to keep them in the best way of being able to cope with what they were given.'* (Olive)

> *'...obviously I took on a fair bit of her* [Darcey's well sibling] *care and her support and - taking her to nursery and picking her up and giving her tea, and*

> *then shooting in to the hospital to see mummy and Darcey, and then daddy would come and collect them and take them home and bath them and put them to bed and things like that, you know.'* (Anne)

In the above extract, Anne implies a sense of duty with the word *'obviously'*. The excerpt also demonstrates the broad, family focus taken by some participants, where Anne was concerned with supporting her daughter and son in law by providing regular childcare to Darcey's well sibling.

5.2.4.2 Responsibility for the family

Building upon the sense of duty discussed above, was an unspoken assumption of responsibility for the family. Although not discussed in these terms, participants implied a responsibility for the whole family unit, extending beyond that of the grandchild's family unit to include the participants other children and grandchildren. Participants discussed their role in maintaining the equilibrium within the family. Robert emphasised his role as a *'peacemaker'*, describing his role in enabling his daughter and son in law to express their grief:

> *'Cos everything was - when everything's going along smoothly you know, it's a lot easier, but er this, this thing is so traumatic [laughs] its, it just wells up, erm, and er, there can be tensions which, I don't think I saw quite as much before really to be honest.* [...] *I sup- yeah, you've got to be peacemaker sometimes and and, and stand back and er, you know, let her just let it out, right?'* (Robert)

Jenny, Anne and Gary highlighted sources of tension between their children, which often arose due to a change in the role of the participant as a result of their grandchild's illness. These realisations increased the anxiety of participants. Anne discussed how the family's plan for a birthday party had to change due to her other daughter's children having chickenpox, which meant the party was cancelled:

> *'we had to sort of protect Darcey as much as we could, and it also sort of - it was the first time that the family in a way, were slightly split up [pause] because of this illness* [cancer] *so, and this is why we had just a small party here at my house, erm, and my other daughter and husband and and four children couldn't come and again, so, that was one of the sort of, another side of the illness that came, you know, made, found its way into our family life really - it's a bigger family.'* (Anne)

This assumed role was used by some participants as a drive or focus for them, providing them with a discreet role on which to focus. Olive discussed *'crumbling'* and *'going under'* following the death of her granddaughter, but explained that she remained *'strong'* for her family:

> *'if I remain tearful and, like I'm upset now, but I remained like this 24 hours a day, I'm no good to my family, I'm no good to the grandchildren when they come in, and it, you just get more and more miserable. I'm f-, touch wood, I'm fortunate I can rise.'* (Olive)

5.2.4.3 Continuum of hope

The preservation, maintenance and protection of hope were recurrent and dynamic features in the experiences shared by all participants. When asked directly how important hope was in her journey, Anne stated *'well it it was there, it was all the time'*. The hope discussed by the participants appeared to evolve in correlation with their grandchild's deterioration before death, and the context of the family bereavement following death. Like many aspects of the participant's experience, the discussion of hope held a dual focus – simultaneously focusing on both the grandchild, as a grandparent, and on their child, as a parent.

With focus on their grandchild, following the child's diagnosis or recognition of a LLC, participants hoped for cure:

> *'I had a phone call from them later on, just to say that it was bad news,* [...] *that it was leukaemia, and my instant [pause] thing was, because I'd come across other children though my teaching and stuff who had encountered leukaemia by saying its fine, don't worry, you know, these days there are marvellous things, you know. Give it a few months and treatment and she'll be fine. So you know, we started off, me being incredibly buoyant and positive and stuff'* (Anne)

Some hopes were implied, rather than expressed so overtly, such as the quote below which suggests that Robert hopes that his granddaughter will live, changing his statement from 'wasn't' to 'unlikely', inferring the persistence of hope:

> *'I wasn't going to see this little girl grow up to be erm, or I was unlikely to see this little girl grow up…'* (Robert)

As the likelihood of cure decreased, the hope expressed changed to include a hope of living longer with the condition and not being alone. Participants discussed hope that their grandchild would survive episodes of acute or marked deterioration:

> *'It might be another false alarm, we've had so many, you know, you just sort of think mmm, and he was a fighter, so we've gone through lots of, I mean the Christmas we thought he'd gone, and and you think he's a fighter, he'll fight. I suppose all the way up I just thought ah, no, [quiet voice] he'll be alright.'* (Christine)
>
> *'There was still a little bit of hope that you know, things were going to improve, that she might have, but we knew the chances were getting less and less you know, really,* […] *and it's something that you have to tousle with you know, in your head.'* (Anne)

The changes in the focus of hope were acknowledged by Anne: *'I know that sometimes hope has to give way to other things you know, that you know, you get to the end, end of a road of what you're trying and also, you know, the moral side of it.'* Anne went on to discuss her thoughts around the morals of the treatment her granddaughter underwent relating to an aggressive form of childhood leukaemia. The moral issues she highlighted related to the *'horrendous treatments'* her granddaughter endured, as well as the ethics of NHS spending on treatments with no success:

> *'I could feel quite embarrassed when I'd be talking to my friends and saying, well I mean, because occasionally I was aware of the finance that involved in these treatments [pause] and er, in some ways you'd think it could be quite immoral when you know there [laughs] are so many other millions of other people that could with just a jab in an arm, and they'd be fine, erm, and yet a lot of money was put into her, into her recovery you know.'* (Anne)

Olive discussed the sharing of precious times with her granddaughter immediately prior to death and a hope that Hannah could hear and understand:

> *'I had precious moments that, when they had Harry in the, playing with him, I could just have time for Hannah and myself and I talked [pause] I just talked and talked [long pause] [started to cry, but continued speaking]. Talked about things we'd done, lovely things, [pause] told about her paintings, when she'd got it on her nose, and you just hoped that it were going to her.'* (Olive)

During the grandchild's death, the participant's hope for their grandchild to not being alone were extrapolated further to include heaven. This is shown in the following quote from Olive's interview.

> *'as she got nearer the time* [of death]*, and we knew [pause] I just told her that, about my mum and dad who would have adored her [pause] and that should she could be - her* [great grandmother] *would be there for her and, an I just told her - I have a faith and I just [pause] must questioned, I just pray that my belief is that there is something afterwards [pause] and she's going to go, not just wander- that she'll go somewhere they'll care for her and look after*

> *her [pause] and I just talked like to her. Not morbid, just, I told her things about each grandparent what were there so she'd know stuff if she got there, and I had a nephew that died at 17 and he'd be looking after her, and we just, I just talked to her. It might sound silly to you, but [pause] I was trying to [pause] if there is somewhere; she wasn't going frightened into the unknown. That somebody [pause] would be there to meet her [pause] and give her the love that we'd all given her.'* (Olive)

Participants discussed the hope for the continued memory of their grandchild. This appeared particularly significant to those participants with younger grandchildren:

> *'Grace remembers her with lots of amazing little memories,* [...] *she was so young that we really carefully marked things to get them into Grace's head so that hopefully that when she is older, certainly as a five year old now, she seems to be remembering quite a few things because we didn't want her to suddenly not remember having had a little sister. You know, when you think back about when your earliest memories are, you know, they're very fleeting aren't they - very small really.'* (Anne)

Photographs were of significance to six of the seven participants. Participants used photographs to introduce their grandchildren, and referred to photographs throughout the interview, often using them to introduce or conclude sections. Photographs were used as a tool to share memories of their deceased grandchild, as well as memories of the family as a whole before the death of the child.

Participants discussed concurrent hopes for the child's parents or family. Before death, these hopes surrounded the hope of control; following death, hope evolved, focusing on recovery, subsequent grandchildren and continued coping.

> *'I think they'll just stick with Grace now. I think that's [pause] you know, I'm pretty sure about that, and I am sorry about that, and if they were to change that I think it would be brilliant [laughs] to be honest [pause] erm, but, you know, that's their decision isn't it really?'* (Anne)

Male participants in particular expressed a hope that they had been perceived as fulfilling the practical expectations of their role and been deemed as *'useful'* by the parents:

> *'I just hope somehow we've done our bit'* (Gary)
>
> *'well I hope I hope we're of some assistance'* (John)

The hope to fulfil expectations was also discussed by female participants, although this was in relation to the closeness and quality of the relationship:

> *'you feel so absolutely [pause] inadequate and unable to help* [...] *and I feel that now really. [started to cry] where as I feel we* [mother and daughter] *should all be quite close, I don't feel that. I erm, we only want to do what erm, they feel comfortable with, so I'm [sigh] frightened to voice how I feel because I I don't want to upset* [my daughter]' (Christine)

5.2.4.4 Love

Love was a recurrent component of all interviews. In line with the other elements of the grandparent experience, participants presented a multifaceted perspective of love, focusing on their own child, their family and their grandchildren. Love was described as a primary driver for some participants, particularly Olive, who succinctly stated *'its just love isn't it?'*, and described the contribution she makes as a grandmother as *'it's the love of a bond, it's a love that gets you going'*.

As expected, participants presented a love of their children, which, as previously discussed, provided a primary drive for their role. Participants spoke of their sick grandchildren with great affection, describing them as *'a joy'* and *'a gift'*.

> *'before Hannah were ill I just, I you know, I doted on her* [...] *I obviously loved every - snatched time I had with her'* (Robert)
>
> *'I mean he was adorable, I mean he was just'* (Christine)

This also evoked some sadness and pain in participants, and whilst providing drive and motivation, love also proved a source of pain, as implied by Robert:

> *'you don't know how transient things can be and I think that's what Hannah's impact had on us - we had this wonderful gift to be- but it were taken away. I think er - so it makes you realise how fragile things are I think. I don't think you realise how fragile erm, erm, your life and your family is 'til something like that hits you* [...] *so, make the most of it.'* (Robert)

Linked to hope, participants discussed their love of being a grandparent and the aspirations they held prior to their grandchild becoming unwell. These included the eager anticipation of 'normal' grandchild-grandparent activates:

> *'had Oliver been a normal child and lived, he would probably be down here now for the half term and we would be taking him out and doing what other grandparents do with their child, so I suppose there's a a- it's a sense of loss for yourself really'* (Gary)

Participants highlighted their role in providing love. When asked about his role, John simply stated *'well, it was to pass some love over, wasn't it?'* Continuing to express his thoughts on the perceived fragility of his family, Robert shared the following advice: *'give as much as you can because [pause] whatever comes back to you is wonderful.'*

Participants acknowledged a love of being a grandparent. For some, the sick child was their first grandchild. Olive spoke of her delight on her Hannah's birth, and her becoming a grandparent:

> *'I'd just had my 60th birthday when Hannah were born, ah God, it was the best birthday present, and all my friends have all these grandchildren and they've - it wasn't just shared - all my friends who were grandparents shared the thrill of us finally being grandparents [laughs] you know.'* (Olive)

The love of being a grandparent extended beyond simply the status, including the differences between parenting and being a grandparent, and the benefits of having the time, focus, experience and patience to devote to grandchildren. The strong affinity for their grandchildren provided a drive for the role. Olive spoke of her love of Hannah, sharing some intimate memories of their time together before her death.

> *'Kate said do you want to nurse her? And she laid in my arms for 6 and a half hours, and that was a very precious moment to me [sobs]. So I spent all these days, as much as I could.* [...] *I could just have time for Hannah and myself'* (Olive)

5.2.4.5 Summary

Participants highlighted a number of emotional drivers that both motivated and sustained their involvement and engagement within the family. Like the other superordinate themes, emotional drivers could be divided between two primary motivations, namely those that relate to the drivers associated with parenting, the others relating to the traditional roles and expectations of grandparenting.

Participants discussed a strong sense of responsibility, which mostly surrounded their need to parent. Other participants discussed their perception of being head of the family, and the responsibility that such a position demands. Usually the sense of responsibility was implied rather than being discussed overtly, where participants used terms such as *'obviously...'* or *'we had to...'*, suggesting there was no option in the action taken, or that their role came naturally.

The relatively objective position of participants within the family unit afforded them to take a holistic overview of their family. Most commonly, the definition of *'family'* in this context was used to describe the grandchild's immediate family unit, comprising the deceased child's parents, siblings and grandparents. *'Family'* was less commonly used to describe the participant's immediate family, including all of their children, including those with well children, where the challenge of balancing the needs of all of their children and grandchildren was discussed, specifically those challenges associated with determining priorities between the sick and well grandchildren, and the needs of their child with a sick child against those with well children. The impact of balancing and managing the needs and wishes of the whole family created a stressor within participants, contributing to their experience of emotional pain.

The need to maintain hope was a frequently cited motivating factor amongst participants. The perception of hope appeared to be a continuum – participants did not discuss a loss of hope, but a change in what was being hoped for, which was relevant to the context of the family at any given time, which progressed in correlation with the prognosis and morbidity of their grandchild. It appeared that a central drive was a need to maintain an overall sense of hope, rather than hoping for any single element of hope. The subject of hope oscillated most frequently between the participant's grandchild and child. Where hope related to the participants themselves, it surrounded a hope that they had been perceived as being useful and fulfilling the expectations of the grandchild's parents.

Finally, love was discussed throughout the interviews; the implications and effects of love are woven throughout the themes explored. Overwhelmingly, it appeared that participants were motivated by love. Participants discussed the love of their child most prominently, followed by their love of their family as a collective, and their grandchildren. Participants who were either new grandparents, or those with fewer grandchildren discussed the love of being a grandparent, highlighting the status and lifestyle of grandparenting, and the special relationship between a grandparent and their grandchildren.

5.3 Chapter summary

This chapter has presented the findings of seven interviews with bereaved grandparents, following the death of a grandchild with a LLC. Each semi-structured interview began with the question *'can you tell me the story of your grandchild?'*. The findings have been structured thematically; a total of 17 themes were identified from the transcripts, which were arranged into four superordinate themes: the experience of emotional pain, the roles of a grandparent, transition from before to after the death of a grandchild, and finally, drive and motivation.

The experience of emotional pain was the most frequently cited experience and rarely discussed in isolation, but in conjunction with other facets of experience, including the perception of helplessness and witnessing the grief and experience of their children. Disenfranchised grief was highlighted by participants, where the intensity of their grief was not recognised by their family or social support networks, which led to the exacerbation of emotional pain. Participants predominantly shared their stories from a parental perspective, discussing their role, pain and drive in the context of their role as a parent. Conflict in the role of grandparents was discussed, including the confusion and friction created by the changing demands placed on the participants by their family, and the simultaneous dual roles occupied by them of both parent and grandparent. A number of phenomena endured the pre and post bereavement experience of participants, namely love, which was referred to recurrently throughout individual stories, and helplessness, where participants discussed their distress at being unable to make the family better both before or after the death of their grandchild. There were a number of features that appeared to drive grandparents; these were love – of their child, grandchild and their role as a grandparent, a sense of responsibility as the self-perceived elder or 'head of the family' and the protection and maintenance of hope. Hope appeared to be discussed as a continuum, despite discussing the deterioration and death of their grandchild and the experience of their child's family. Hope was never talked of as being lost, but rather as something that changed to fit the context of the particular experience, providing a focus for and drive for participants.

The following chapter discusses these findings and subsequent interpretations with the aim of answering the research question '*how do grandparents experience the death of a grandchild who had a life limiting condition?*'

Chapter 6: Discussion

6.1 Introduction

This chapter starts by summarising the research process to this point, before discussing the findings of this study in relation to existing research literature and theory. The relevance and congruence of these findings are then explored, using current theories of grief to increase the understanding of the phenomena under investigation. The opportunities for further research and the implications for policy and practice are stated. Finally, the discussions from within this chapter are brought together into some general conclusions of the study.

6.1.1 Summary of the thesis

Chapter 1 discussed how existing literature concerning grandparental bereavement is largely extrapolated from research conducted with parents and siblings, or is explored in isolation, without the context of family. Chapter 2 is a meta-ethnographic literature review, which led to the identification of eight common themes, which were arranged into three superordinate themes that encapsulated the grandparenting experience: the intergenerational relationship between grandchild and grandparent, the influence of the family and emotional pain. There were a number of gaps found in the existing literature, specifically a need to explore the effect of social context on the experience of grandparents, and the association between children with profound and complex health needs, and those children who require palliative care.

This study addresses the question *'how do grandparents experience the death of a grandchild who had a life limiting condition?'* Chapter 3 focused on the methodology of the study, and chapter 4 the research method, namely interpretative phenomenological analysis. The findings of the study were presented in chapter 5, where four superordinate themes were identified: the experience of emotional pain, the roles of a grandparent, transitions from before to after the death of a grandchild, and motivation and drive. These findings are discussed below.

6.2 Grandparental grief

Grief is the multifaceted human response to separation and loss, including death (Buglass, 2010), explored in some detail in chapter one. As discussed in chapter 2, grandparental grief is similar to the grief experiences of parents (Alam *et al.*, 2012; Arnold and Gemma, 2008; Forrester, 2008) or siblings (Foster *et al.*, 2011; Jenkins and Merry, 2005; Packman *et al.*, 2006) of children with LLCs. The experiences of grandparents who have experienced the death of a grandchild with a LLC have some similarities to the experiences of grandparents who have experienced perinatal deaths (O'Leary, Warland and Parker, 2011; Roose and Blanford, 2011; Schmid, 2001), describing confusion in role and expectation of the family and losses other than death, including incarceration (Grinstead *et al.*, 2003), family breakdown (Doyle, O'Dywer and Timonen, 2010) or emigration (Coall and Hertwig, 2010), where grandparents express feelings of isolation, disenfranchisement and a lack of recognition or appreciation of their experience of loss.

It is not surprising that the grandparents within this study experienced loss; what is remarkable, is the breadth of the losses experienced, and the number of extrinsic factors, beyond the control of participants that affect the experience. Grief was a continual and evolving element of the stories shared by grandparents. The individual elements of grief experienced by grandparents are not unique to grandparents, nor are they individually novel or remarkable. Grandparents are not the only grievers to experience disenfranchisement, duality of roles, changing identity, bearing witness, survivor guilt – these elements are reported widely in a broad range of fields, including surviving veterans, cancer survivors (Hutson, Hall and Pack, 2015), those who survived the holocaust (Ayalon *et al.*, 2007) or natural disasters (Viswanath *et al.*, 2012), parents, and those whose grief is not socially sanctioned, openly acknowledged or publically mourned (Baum and Negbi, 2013; Mizota *et al.*, 2006). However, what is remarkable is that grandparents experience all of these elements, creating a footprint of grandparental grief that is different to other grievers. What sets grandparental grief apart from the experiences of other family members is not only their grief footprint, but the breadth of the emotional pain experienced by grandparents, and the lack of control they have over their position within the family, which has a direct impact on their experience.

6.2.1 When do grandparents grieve?

The findings of this study suggest that grandparental grieving starts at the time of diagnosis or recognition of the LLC. The losses experienced by grandparents include multiple losses in relation to their grandchild, beginning at a much earlier stage than the death of their grandchild, owing to the trajectory of LLCs in children (Mellor, Heckford and Frost, 2012). What is clear from the interviews is that the participants have faced multiple losses, as illustrated in figure 4, In addition to those listed in figure 4, grandparents faced the loss of function, of their established role within a family, and on occasions, their loss of purpose, which were often renegotiated as the child's condition progressed. Grandparental experiences of loss were peppered throughout all four of the superordinate themes identified in the findings.

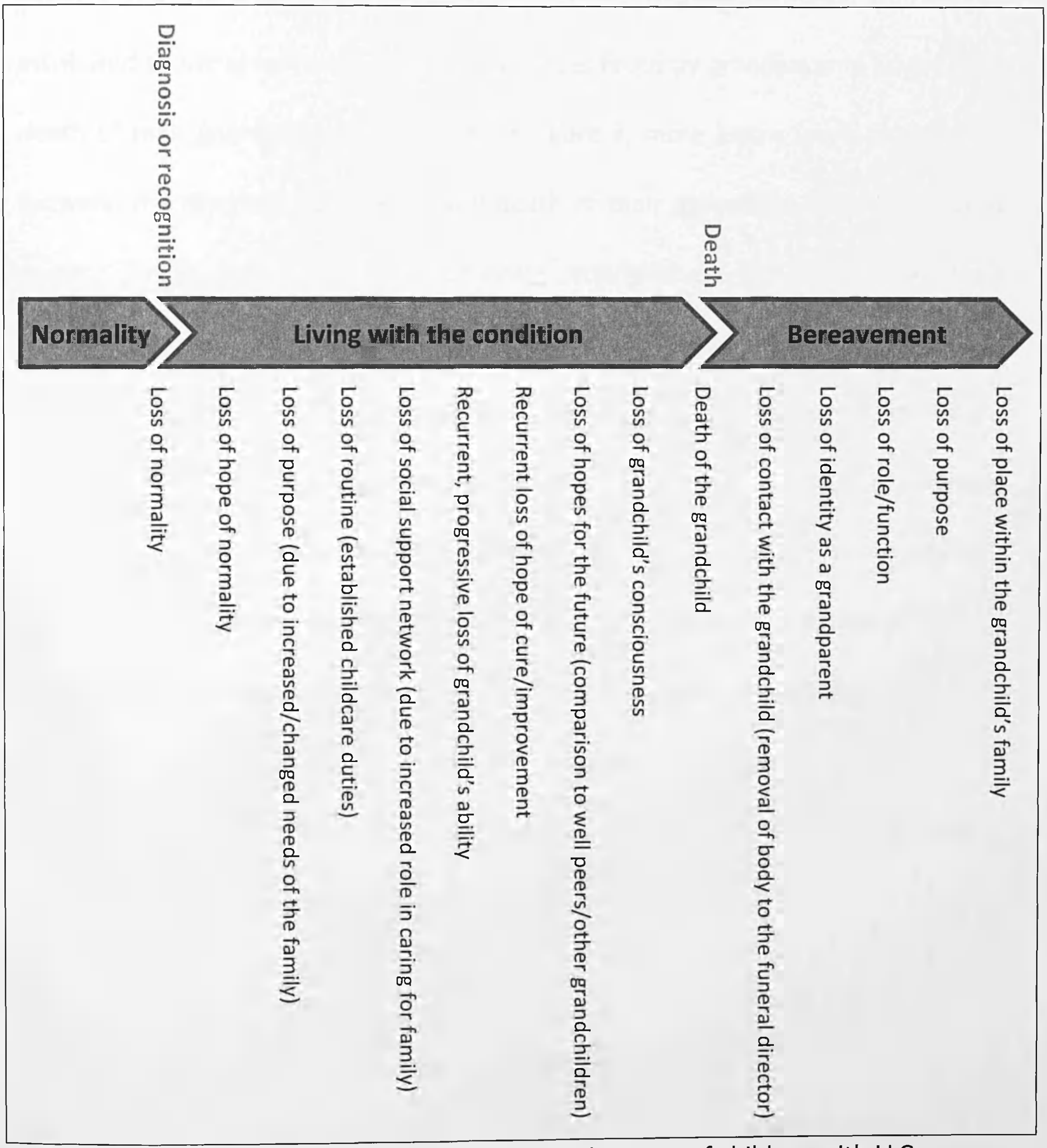

Figure 4: Examples of losses experienced by grandparents of children with LLCs included in this study

Participants spent more time talking about their own and their family's experiences of living with their grandchild than on their experiences after death. This phenomenon may have been for a number of reasons; grandparents had a more clearly defined role within the family during the grandchild's life (Miller *et al.*, 2012), providing a metaphorical vehicle onto which they can pin the understanding of their experience. Such experiences include their responsibilities for childcare, practical support and the provision of financial assistance. This phenomenon can also be attributed to the progressive and multiple losses faced by grandparents prior to the death of their grandchild; as illustrated in figure 4, more losses were experienced between the diagnosis/recognition and death of their grandchild, than those after death. Finally, the focus of grandparents' attention on the time before their grandchild's death may provide a coping mechanism, where grandparents strive to preserve the memory of their grandchild. The focus on the time before death has been identified in studies of parental grief (Price *et al.* 2011), as discussed in section 5.2.4.3. It may also be attributed to the fact that the time spent 'living with the condition' is now a past experience, providing grandparents with a period of time on which they can reflect. At the time of the interviews, participants had been bereaved for less than two years. In addition, grandparents discussed the uncertainty of their position within the family, making their current (at the time of interview) situation unclear, making reflection more difficult.

6.2.2 Grief and identity: a parents' or grandparents' grief?

Although the dual role of grandparents is highlighted in existing literature (Gilrane-McGarry and O'Grady, 2012; Reitzes and Mutran, 2004), this study provides novel insight into the oscillation experienced by grandparents between the parenting and grandparenting role. The findings of this study add to current knowledge, suggesting that for grandparents, grief is complicated by their duality of roles within a family – simultaneously acting as parent and grandparent, each with the potential to affect the other. The predominant identity assumed by participants in this study was that of a parent, correlating with the findings of the literature review (Fry, 1997; Gilrane-McGarry and O'Grady, 2011; Moules *et al.*, 2012b). This appeared to originate internally, but was reinforced by the family, particularly the child's parents, who looked to the grandparent for emotional and practical support. This is supported by contemporary family systems theory, which suggests that concepts including family hierarchy, processes, roles, boundaries and belief systems are shared and agreed by the family (Crittenden and Dallos, 2009), and are related to, but different from individual conceptual processes. The participants presented two catalysts for occupying a parenting role, originating from a need to protect their offspring or to maintain control of a given situation (Fry, 1997; Gilrane-McGarry and O'Grady, 2011 and Moules, *et al.*,2012).

The uncertainty of the role of the participants, coupled with the grief associated with the progressive deterioration of the grandchild (Hubbard *et al.*, 2012; Munday, 2012; Mellor *et al.*, 2012; Rallison and Moules, 2004; Wood *et al.*, 2010) added to the experience of emotional pain. The experience of participants was characterised by fluctuating experiences over a sustained period of time, which relate to interactional experiences both within and outside the family unit (Syrén, Saveman, and Benzein, 2006). Grandparents within the study fulfilled prominent roles within their family, discussing changes within the family unit, occurring continuously throughout their story. Family systems theory suggests that a family consists of interrelated parts that are constantly changing and adapting in response to others within their family unit. The perpetual change in the grandchild's condition influenced the rest of the family (labelled as the *'child effect'* in family systems theory), which in turn affected others within the family unit (*'transactional effect'*).

6.2.3 The breadth of emotional pain: compounded grief

Emotional pain is well documented in current literature, as identified in chapters one and two, however it is the breadth of pain, both in terms of longevity and sources that the findings of this research adds to existing knowledge. The experience of emotional pain was a multifaceted theme in which participants discussed a range of sources of pain, including bearing witness, helplessness, a lack of recognition and a change in role.

Current literature describes the concept of *'double grief'* in grandparents, resulting from the loss of their grandchild and the experience of witnessing their son or daughter's grief (Drew and Goodenough, 2006; Moules *et al.*, 2012); a smaller body of literature alludes to *'triple grief'*, which includes the effects of survivor guilt on the grief experience (Ponzetti, 1992). This study supports these findings, and builds on them, providing further insights into the loss of a grandchild. This study found that a number of interrelated factors from the experience contributed to the perception of emotional pain – these extended beyond what was felt or observed by the participants to include the direct effects of the family. Participants were unable to separate one event or source of grief from another, which resulted in the compounding of their feelings of grief. The concept of compounded or cumulative loss has been identified in siblings (Packman *et al.,* 2006), where the effect of witnessing their parent's behaviours, distress and vulnerability, exacerbates the feelings in children. Gilrane-McGarry and O'Grady (2012) describe the cumulative pain that results from the death of a grandchild, where they suggest that five sources of pain contribute to the experience of grandparents. This study supports and adds to their findings, suggesting that in addition to the five sources identified, grandparental grief is also affected by the experiences that result from those sources of pain – such as the feelings of helplessness that result from bearing witness. The findings of this study suggest that the feelings of grief are not restricted to the deceased grandchild's family, but extend to include the families of the grandparent's other children and therefore, grandchildren. The complexities associated with managing their family as a whole, including involvement with other sets of grandchildren compounded the experience of grandparents. This novel insight has not been reported in existing studies.

6.2.4 Grief, resilience and drive

The final superordinate theme captures the drives and motivations for participants' involvement, although as was the case with loss, grandparents' motivation was discussed throughout the stories of participants. The overwhelming drive, as alluded to above, is that of parenting. Participants highlighted a desire to protect their child from the emotional pain and uncertainty arising from their awareness of the juxtaposition of cure or improvement and death of their grandchild. This need to protect is expressed in current literature (Gilrane-McGarry and O'Grady, 2011; Woodbridge, Buys and Miller, 2009; Youngblut,*et al.*, 2010). Participants discussed a strong sense of responsibility and duty. As the positions of parent and grandparent are not mutually exclusive (Reitzes and Mutran, 2004), it is not surprising that participants occupied both positions within the family. The dominant perspective of participants as parents may be explained by the participants' observation that the needs of their grandchild are being met by their parent, or that the needs of the child's parent are greater; both resulting in a focus on the child's parent. This serves to meet the needs of the family system (Kozlowska and Hanney, 2002) and the participant as a constituent member of that family, giving a role and sense of duty (van Ecke, Chope and Emmelkamp, 2006).

Described as being pragmatic, positive, responsive to current situations and used to anticipate future possibilities (Folkman, 2010), participants presented the concept of hope as a dynamic continuum. Loss of hope was not discussed at any stage but the context of hope changed as their grandchild's condition progressed during life, death and in bereavement. The evolution of hope has been described in existing literature as contextual and complex, providing goal-related motivations (Snyder, Irving and Anderson, 1991). Within this study, participants used hope to maintain stability and equilibrium within the family. These phenomena are seen in the literature, where hope provides a vehicle for motivation (Folkman, 2010), emotional resilience and coping (Eliott and Olver, 2007), however not from the perspective of grandparents. Findings from this study suggest that grandparental hope is experienced from multiple, multigenerational perspectives, often in the form of love. Love for individuals within the family and the family collectively were most frequently discussed, alongside the concept of hope.

The bereavement experiences of grandparents vary depending on the relationship with the grandchild before death (Fry 1997). Although all grandparents discussed a love of their grandchild, not all described a close grandparent-grandchild relationship. This appears to be for a number of reasons, including geographical proximity, frequency of contact with the grandchild, and the profound and complex needs of the grandchild, all of which affected the quality of the relationship. Neither the *'unique and special relationship'* described by Gilrane-McGarry and O'Grady (2011:170) and the concept of friendship, highlighted by Nehari, Grebler and Toren (2007), were found in this study, with the exception of Olive, who had a remarkably close relationship with her granddaughter prior to her death. This is perhaps owing to the age of the deceased children, or the LLC they had within this study, making friendship or *'special relationships'* difficult. Olive's experience was unique within the cohort of participants for this study – she was the only grandparent to provide regular, intense childcare, even before diagnosis and lived much closer to her daughter and family than other participants. Olive's understanding of childhood appeared in contrast to other grandparents, perhaps owing to her health professional background. The values of play, interaction and cognitive development were extremely important to Olive, as was the status of being a grandmother. This, coupled with the cognitive ability of her granddaughter, and the high level of access she was given to her granddaughter helped to enable the close and mutually-fulfilling relationship that existed between Hannah and Olive.

6.3 Grandparents, grief and family

Other studies have conceptualised grandparental grief to varying degrees (Gunn, 2011; Hayslip, 2004; Nehari *et al.*, 2007; D. White, 2002; Youngblut *et al.*, 2010). In addition to exploring the way in which grandparents experience the death of a grandchild, this study aimed to explore how the contextual factors in which the grandparents function affects those experiences. The following sections explore the ways in which the grandparent's family affect their experience, drawing on allied empirical research and theory, most prominently, family systems theory.

6.3.1 Grief, children with complex disability and grandparents: who is in control?

The role and expectations of grandparents within this study was fluid. The degenerative nature of the life limiting conditions experienced by the grandchildren, as described by their grandparents, were progressive in nature, resulting in dynamic needs of the grandchildren. This in turn affected the demands placed on the family by the child, either directly or implicitly, depending on the age, condition and ability of the affected child. Family systems theory suggests these demands, regardless of whether they are knowingly or consciously made, give the child a role within the family unit (Morgan, 1988). The needs of the child were predominantly met by their parent; participants described the increasing needs of the child and the evolution of the role of the parent in response, suggesting a dyadic relationship. Family systems theory incorporates numerous levels of analysis (Byng-Hall and Stevenson-Hinde, 1991) from the family as a whole and how it interacts as a unit with the world, to interactions and relationships between constituent members within the family. The interactions between the grandparent and others in the family were affected by the subsystems, which included the grandchild; a change in the demands of the child affected the parent, which in turn changed the demands the parent made on the grandparent. Both of these subsystems describe a dyadic parent-child relationship (Popov and Ilesanm, 2015), where it is the child's parent who is fulfilling a dual role of both parent and child, due to the presence of the child's grandparent and the interactions that occurred as a result.

The level of care children with profound and complex needs require results in the child playing a key role within the family system in which they exist (Morgan, 1988). Neimeyer (2001, 2004) suggests that in dealing with their grief, individuals must reconstruct meaning and purpose without the deceased. The findings of this study suggest that the reconstruction of purpose of the grandparenting role within a family is often outside the control of grandparents – participants described the moving on and regrouping of the child's parents and remaining siblings into a tighter family unit, resulting in their perceived exclusion.

Control is a multifaceted concept; participants discussed their frustrations in their inability to make the situation better, describing that as a fundamental element of '*being a parent*'. Others described the lack of control of the family as a whole, with male participants particularly describing their vexation in their position as an elder within the family and an expectation and self-appointment of the position of '*head of the family*', which did not correlate with the views within the family. Conflict resulting from shifting power dynamics has been reported in response to a stressor

(Haefner, 2014; Long and Marsland, 2011). Within this study, control was most frequently perceived as being held by the child's father.

6.3.2 Grandparents and family: responding to the dynamic needs

Grandparents discussed the uncertainty created in meeting the dynamic expressed and observed needs of the family. The perception of almost-simultaneous dichotomy of being pulled into the family, then pushed away by the participant's children caused the most emotional pain related specifically to helplessness. Syrén, Saveman, and Benzein (2006:26) describe a serious illness as an *'uninvited guest that must be incorporated into families' lives'*, recognising that the onset of such a condition forcibly challenges both the physical and emotional barriers within a family unit.

The role of participants included in this study was not a passive one; participants played active and important roles within the family, which evolved to reflect the needs of the family throughout their grandchild's deterioration and death, and the family's needs which followed, as perceived by the participants, or expressed by their families. Changes within the child's immediate family, (usually comprising parents and siblings) which followed their death resulted in a sudden change in the demands of grandparents, perceived as unexpected by participants; the effect of this appears to be two-fold – grandparents struggle with the change in demands placed on them by their family, expressing feelings of helplessness and loss of a defined role. In addition, the reduced demand means that grandparents are less distracted from their grief, creating space to reconstruct meaning and purpose (Neimeyer, 2001;

2004), both following the loss of their grandchild, and as a member of a family in which they had a defined role.

6.3.3 *Grandparenting after the death of a grandchild: where do they fit?*

Following the death of their grandchild, grandparents discussed the change in the needs, demands and expectations of their family, and a distinct move away from the nucleus of the family unit. This is described concisely by Welford (2014) who suggests that individual boundaries within a family system become confused on the death of a family member. The perceived exclusion from their grandchild's family exacerbated participants' feelings of isolation and disenfranchisement, contributing to their experience of emotional pain, as outlined in section 5.2.1 above. Altered family dynamics resulting from a change in the family system following the death of a constituent member of the family is recognised in contemporary literature (Delalibera *et al.*, 2015). Within this study, all participants discussed changes within their individual role and the family as a whole following the death of their grandchild; however those grandparents who portrayed more secure intergenerational relationships with their children coped more ably. This may be attributed to the recognition that open communication, cohesion among family members and expression of feelings facilitates adaptive adjustment following a death of a family member (Delalibera *et al.*, 2015), which is more attainable in families where secure intergenerational bonds have been established and maintained. Within this sample, more secure relationships were seen most frequently in mother-daughter relationships. There also appeared to be a direct correlation between the geographical distance between home addresses, where those living closer to their families discussed a more functional, active relationship. That said, the sample size included in this study is insufficient to make claims that can be applied beyond what was observed.

Ng (2006:430) suggests that *'fear and uncertainty activate attachment needs'*; those participants with less secure intergenerational attachments articulated their emotional insecurities and sought reassurances more frequently from their family. This is supported by Welford (2014), who reports a direct link between attachment and the ability to grieve effectively. Conversely, those participants who expressed a more secure parent-child relationship appeared to adapt to the changes to both their role, and the family as a whole following the death of their grandchild. Within this study, the most secure relationships presented by the participants were those between mothers and daughters, notably between Anne and her daughter and Olive and her daughter.

Contrary to the changes experienced in transition, there were a number of experiences that were sustained following the death of their grandchild, namely a love of their child, grandchild and their family and of the status of being a grandparent. Although these elements endured transition, some contributed to a sense of loss, further exacerbating the participants' experience of emotional pain.

6.4 Grandparents, grief and society

The systems within which humans exist extend beyond family, into society. Societies vary depending on the culture, dynamics, values and beliefs of its constituent members (O'Gorman, 1998). Within this study, grandparental experiences were exacerbated by a number of extrinsic factors, including the expectations of others, a lack of recognition and support for their own grief (disenfranchisement), and their identity of being a grandparent.

6.4.1 Lonely sadness: disenfranchised grief

The findings of this study support those in the meta-ethnography regarding disenfranchisement (Fry, 1997; Gilrane-McGarry and O'Grady, 2011; Moules *et al.*, 2012), where grandparents' initial reluctance to acknowledge their own grief leads to those around them failing to offer support that the grandparents anticipate. Disenfranchised grief is not a phenomenon exclusive to grandparents, arising when the loss or relationship to the deceased is not acknowledged, such as homosexuality (Oerlemans-Bunn, 1988) and where the death is not recognised or valued, such as suicide (Gaffney and Hannigan, 2010) or HIV/AIDS (Mizota *et al.*, 2006), or where the death is devalued by society, including the deaths of the very old, or where the deceased has disabilities (Todd, 2007).

Failure to acknowledge grief in grandparents was highlighted by participants, and appeared to correlate to the quality of the intergenerational attachment between themselves and the child's parent. Attachment insecurities have been shown to affect bereavement outcomes (Zech and Arnold, 2011); insecure attachment is associated with individuals who describe a lack of trust in themselves, a sense of abandonment, a lack of love and support, and express anxiety in separation (Delespaux *et al.*, 2013). The findings of Delespaux *et al.* (2013) are echoed in this study. Recognition of these characteristics in grandparents will enable practitioners to identify support individuals at risk (Parkes, 2006; Zech and Arnold, 2011; Zech, Ryckebosch-Dayez, and Delespaux, 2010), thus improving the support offered to grandparents.

6.5 Reflection on the methodology and method

6.5.1 Reflections on the use of IPA

The structured process of IPA allowed the common themes that bound the experiences together to be emphasised, while simultaneously highlighting where there are variations in individual experiences. The IPA framework has been vital in defining the research findings and in identifying both the clinical implications and areas for future research.

The context and experience of grandparenting varied widely, as discussed throughout this study. The use of IPA enabled participants to discuss their experiences without being led, and for their understanding of that experience to be captured and explored further. The initial expectation was that the research would focus on experiences post-death, however though the use of semi-structured interviews, individual stories began at a much earlier stage in their experience than was first anticipated. This in turn provided context for their post-death experience, enabling more detailed analysis of conceptualisation, and how this effects the presentation of experience and grief reactions. Biggerstaff and Thompson (2008) echo similar benefits of IPA noting the possible difference between the researcher's expectation and the interview data. Specific reflections on the design, research process and rigour, and limitations follow.

6.5.2 Reflections on the design

As a novice researcher, elements of this study were designed following a review of practices from current, peer-reviewed allied research in the clinical fields of palliative care and bereavement support. The inclusion criteria (as outlined in section 4.2.2.2) were based on current practices in bereavement research, designed to identify participants who were able to vividly recall their experience without including those recently bereaved who may not have had sufficient time to process their bereavement. The window of being bereaved for six – 24 months correlates with similar research on bereavement experiences (Davies, 2005; Hynson *et al.*, 2006; Price *et al.*, 2011), however it is acknowledged that there are examples of research with bereaved participants that have successfully employed a much larger bereavement window (Gaffney and Hannigan, 2010; Todd, 2007). It is fortunate that the narrower recruitment window was sufficient to identify an appropriate number of participants in the first stage of recruitment. Had this not been the case following the two approved recruitment stages, then a broader recruitment window would have been considered, enabling a greater number of participants.

The methodological approach taken enabled participants to direct the interviews in ways that reflected their experience. Interviews opened with the open question *'tell me the story of your grandchild'*, which allowed participants to begin at the most relevant point of their story for them. Initially, it was anticipated that this study would focus on the bereavement experiences following the death of a grandchild, however all participants demonstrated the significance and intensity of their role during the child's illness, starting their stories at or around the time of the diagnosis of their grandchild's LLC.

The opening of the interviews is perhaps more closely associated with other methods of qualitative enquiry, such as a narrative approach, owing to the word *'story'* within the question (Brocki and Wearden, 2006). The initial question was deliberate; as highlighted in the earlier parts of this thesis, existing studies suggest that grandparental experience is affected by the context of the family in which they exist, which resonates with my clinical experiences as a children's nurse. To enable participants to begin by focusing on elements of their experience which were important to them, a broad opening question was designed. More specific questions were considered, such as *'tell me about the experience of your grandchild being ill and dying'*, however it was felt that a broader initial question would allow participants to shape the beginning of the interview, thus beginning to identify the constructs, understandings and interpretations of their individual experiences which were subsequently questioned as each interview progressed. Whilst practicing as a children's nurse I have supported families where there is great variation in elements of an experience which individuals find most important, which was reflected across the participants of this study. I was conscious of not placing too much emphasis on the death of the grandchild, as I was aware that for some, it was likely that there were more important elements of their experiences that they may wish to share before discussing the death of the grandchild, which was an implied topic of enquiry based on the letters sent to parents and grandparents, and the participant information sheet (see appendix 4).

On reflection immediately after the fifth and sixth interviews, there were some anxieties surrounding labelling of the participants as *'grandparents'*, as they appeared to identify almost exclusively as parents. Whilst the dual occupancy of parent/grandparent positions was accepted from the outset, as reflected in the introduction and literature reviews, it was during the interviews of Jon and Jenny that the labelling of participants as grandparents felt presumptuous and I was concerned that I may have led participants to discuss certain aspects of their experiences which they associated with that of a grandparent. On the transcribing, verification and analysis of the interview however, this was not the case, and although during the interview it felt like the focus was more on their role as a parent, it appears this was due to their less significant relationship with their sick grandchild due to their limited regular contact and focus on other grandchildren who lived closer.

The design of the study correlates strongly with my epistemological position as a practising children's nurse within a children's hospice setting. Pringle *et al.* (2011) note the importance of individual accounts, which chimes with the nurses' desire to offer holistic care. The approach taken to the interviews enabled participants to explore their experiences in their own terms, which served to highlight the most significant elements of those experiences to the individuals, without making assumptions on the roles assumed by individuals within the family, or the values placed on them. The small number of participants meant that the context of individual experience was preserved; this would have been difficult in studies with a larger number of participants.

In keeping with IPA the sample was *'fairly homogenous'* (Smith and Osborn, 2007) in terms of ethnicity and role at the point of recruitment. Following the interviews and subsequent analysis, it could be argued that there was variation in the sample, making it appear less homogenous that expected. The issue here surrounds the point at which homogeneity is assessed: the sample is homogeneous, based on the inclusion criteria. The role played by the grandparents was unclear initially – it was only following the research that the impact of diversity became clear. To have pre-empted the effect would have been premature. While it is believed that the sample was entirely appropriate for this study, understanding would be enhanced further by conducting further IPA studies with variant homogenous samples, in terms of culture, religion and levels of involvement.

6.5.3 Reflections on the process, as a novice researcher

Undertaking this research has been simultaneously the most difficult and most rewarding study I have been involved in. It has challenged my perspective on familial coping, and the events that are considered the most significant by families along their journey with a child affected by a life limiting condition. Through the completion of this study, I have also been given the opportunity to explore and discuss, first-hand how grandparents cope with a range of conflicting elements of their experience, and how these are affected and compounded by the family in which they exist. As a clinician who values family centred care, I was surprised by how much of the experiences shared by grandparents were 'new'. The different approach taken whilst wearing a 'researcher hat' (to use Olive's metaphor) led to a different relationship with grandparents, within which disclosures, thoughts and feelings were declared that would be difficult to obtain at the bedside; these insights have been invaluable in seeing the full and complex experiences of grandparents.

Regular academic supervision was instrumental throughout this process. At times, I have struggled to maintain the stance of a researcher, veering too regularly towards my *'comfort zone'* of nursing! As a clinician, I have provided bereavement support to families following the death of children for the past 17 years. Enabling individuals to identify priorities and features of their grief is something I am used to as a practitioner, where my role is to provide reassurance and to normalise the grief. As a researcher, my role felt initially vastly different – my role was no longer to provide support, but to explore the experience and to develop understanding of the phenomena. Aspects of the interviews within this study that I found particularly challenging, were the inability to provide reassurance throughout the interview, the lack of touch (such as hand holding) and not knowing details of the child before meeting the grandparent. This impersonal approach, while entirely appropriate for the context of research, was in conflict with my usual role in similar situations as a nurse. It was due to the richness of the data collected following the first two interviews, and the openness and positive feedback from Olive and Robert that enabled me to continue with the research process.

6.5.4 Reflections on quality

There has been debate surrounding the validity and rigour of qualitative studies (Pringle *et al.*, 2011), due in part to ongoing dissatisfaction with the persistent application of measures designed to assess quantitative research being applied to qualitative studies (Smith *et al.*, 2009). A number of tools have been created to appraise the quality of qualitative research, including Dixon-Woods *et al.* (2004), Popay, Rogers, and Williams (1998) and Spencer *et al.* (2003), however the principles of Yardley's (2000) assessment guidelines have been used. Yardley's (2008) principles occupy a pluralistic stance, therefore enabling application in IPA studies. Yardley (2000) describes four principles of quality assurance, namely sensitivity to context, commitment to rigour, transparency and coherence, and impact and importance. The application of each of these principles is discussed in section 4.2.7.

6.5.5 Limitations of the study

There is criticism regarding the representational validity of the experience presented by participants, rather than capturing the actual experience itself (Willig, 2008). That noted, the subjective accounts presented by participants are how participants made sense of their experiences, which is a key focus for this study.

Children with oncological conditions represent a greater than anticipated percentage of the grandchildren within this study. The trajectory of oncology conditions differs from the majority of LLCs due to the period of good health prior to the diagnosis, creating a different context and reference points for families.

The approach to sampling meant that only grandparents of children who used children's hospice services were invited to partake. The most recent figures suggest that only 20.2% of children with palliative care need are supported by hospices (Devanney, Bradley, and Together for Short Lives, 2012). Families without the support of hospices often have less access to the ongoing, holistic support that such services offer, including short breaks, perhaps impacting on the context of the family unit as a whole. Recruitment was restricted to hospices in the North of England; this too may have affected the findings, as palliative care services for children differ across regions of the UK, which again, may impact on the context in which the family exists.

6.6 Research strengths and summary of theoretic contribution

This study has brought together empirical research findings and concepts from existing theories relating to grief, family and identity to explore the role of grandparents within contemporary families affected by the death of a grandchild from a life limiting condition. The use of an IPA approach, particularly the idiographic nature of the analysis (Phillips *et al.*, 2014; Pringle *et al.*, 2011) enabled a whole and unique picture of the individual grandparents to be presented. The small sample size enabled rich, in-depth analysis of individual stories, as well as identifying commonalities across accounts. IPA literature discussed the transferability of findings across groups, rather than generalisability – the result of studies with much larger participant numbers, such as grounded theory approaches (Hefferon and Gil-Rodriguez, 2011). That noted, Smith *et al.* (2009: 4) discuss theoretical generalisability, where readers can *'assess the evidence in relation to their existing* *professional and experiential knowledge.'* As discussed in the introduction, much of the work of children's hospices is based on little more than anecdote and good intention. This study provides qualitative empirical data, which can be used to underpin practice. This study has provided novel insight into the experience of bereaved grandparents, which have theoretical transferability to policy and practice surrounding contemporary family-centred children's palliative care. The conclusions of both the meta-ethnography and grandparent interviews have been brought together to enhance the understanding of the bereavement experiences of grandparents where their grandchild had a LLC.

During the synthesis of existing evidence in the meta-ethnography a number of theoretical connections were assumed across studies. *'Reciprocal'*, direct translations and *'lines of argument'* connections between studies were constructed. These connections have been tested explicitly with grandparents of children with LLCs. The meta-ethnographic approach to reviewing existing literature, and the use of IPA to conduct empirical research preserves the context of individual accounts. IPA enabled novel insight to grandparental grief through the detailed idiographic analysis of participants' experiences, and their understanding of those experiences, to develop the understanding of grandparent identity and the associated motivations, role perception and emotional pain during their experience of being part of a family with a dying grandchild.

6.7 Recommendations for future research

To build on the findings of this study, the following recommendations would enhance the understanding of grandparental experiences:

- How grandparents experience the death of a grandchild who did not have a diagnosis. These children are often affected by profound disability; the experiences of Christine and Gary were notably different from the other grandparents in the study, owing to the underlying condition affecting their grandson.
- How religious and cultural beliefs affect the experience of bereaved grandparents; by interviewing grandparents from specific cultural groups, as well as those in non-Western societies, which is likely to differ significantly to those grandparents included in this study, who were, by chance, all white British.
- Interviewing grandparents of grandchildren living with LLCs to identify whether the understanding of experience changes following grandchild death.

The following avenues of research would develop understanding of the context of grandparenting within families of children with LLCs:

- The use of dyadic parent/grandparent interviews to gain multi-generational, dual-perspective understanding of the role of grandparents to explore correlations in the experiences across the generations, and how intergenerational relationships affect this.

- Longitudinal studies, to explore how the understanding of experience of grandparental grief changes over time.

6.8 Clinical implications

Family centred care is a fundamental principle on which children's nursing is based in the UK. This study highlights the extent of the multiple, cross-generational roles played by grandparents of children with life limiting conditions and their families and brings into focus the impact of the conflicting roles and expectations of grandparents by their family and the extent to which these contribute to their experience.

In British paediatric nursing practice, relationships are considered from the perspectives of the child, and efforts are made to enable those relatives to fulfil these assumed roles. To that end, a child's grandparents are usually exclusively regarded as a grandparent. The findings of this study suggest that this is not always appropriate; participants within this study focused largely on the needs of their children, discussing their experiences through the eyes of a parent. This suggests that in order to meet the needs of grandparents, we must acknowledge and enable their dual, simultaneous multigenerational roles of both a parent and grandparent. Family-centred care planning can be improved to accommodate the perspectives of family members, which identified the contributions and roles of individuals within the family, in addition to their support needs. Most children's hospices boast integrated care and emotional support services (Blackburn, 2010), resulting in blended, holistic approach to care through illness, death and bereavement. Suggested enhancements to practice are achievable, with only a small shift in scope required to address the needs of grandparents. Offering targeted services to grandparents, perhaps through facilitated peer group support would enable the identification of issues that matter to grandparents and for the hospice to subsequently address them.

To assist in raising the profile and awareness of grandparents within families, it may be helpful for practitioners to consider them as a resource on which the family can draw on as a source of support. The findings of this research suggest that the care and support provided by those in a grandparenting role is considered by families as an integral part of the day-to-day lives; for some families, care provided within the family means that they do not require or desire any additional support outside of their own family networks. However, circumstances can arise which impact on the ability of grandparents to continue to provide such support. Framing grandparental input as a resource will help to focus on the contributions made by grandparents, recognising and valuing the impact of their involvement, and focusing on preserving and maintaining the role.

6.9 Policy implications

There are currently no policies relating specifically to grandparents of children with LLCs in the UK. References are made in some third sector guidelines, such as those published by Together for Short Lives (Bennett and Ilic, 2011; Cottrell *et al.*, 2011; McNamara-Goodger, 2009; Widdas *et al.*, 2013), but specific policy is lacking. This study adds to the evidence surrounding grandparent need, developing understanding of both the roles, and needs of grandparents, which can inform the development of policies including the family centred elements of the Together for Short Lives Charter (2012) and the Trieste Charter (Benini *et al.*, 2013). National guidelines should be developed that reflect the diverse and multifaceted roles of grandparent; this would have the greatest impact if published by high profile and highly regarded organisations such as Together for Short Lives, or Child Bereavement UK. The contributions made by grandparents in terms of enabling family functioning have been discussed throughout this thesis; contemporary policy need to reflect this, making grandparents more visible within families, and ensuing that the model of family centred care being used is relevant to those who rely on palliative nursing care services.

The findings of this study suggest that grandparents need to be supported during their grandchild's illness in a similar way to parents and siblings pre-bereavement (Blackburn, 2010). The data suggests that this support should focus on the definition and negotiation of role, particularly the challenges of meeting the needs of themselves and their family, simultaneously fulfilling the roles of a parent and grandparent.

6.10 Conclusions and final remarks

This study began with the unvoiced assumption that grandparents identified as grandparents – a point so obvious that it did not need to be expressed. Using a robust, scientific process, the study has ended with the conclusions that grandparents' identity fluctuates between parent and grandparent, with a primary drive of parenting. Grandparents of grandchildren with LLCs experience multiple, progressive losses associated with the deterioration and death of the grandchild. These losses, when combined with the effects they have on the grandchild's family system and the resulting experiences of bearing witness, survivor guilt and disenfranchisement create a footprint of grief that is unique to grandparents. These new perspectives into grandparental experience can help to develop policy and practice, improving the care and support available to better meet their needs as a parent, grandparent and individual who has experienced the child death.

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Appendix 1: *Faculty of Health and Medicine research ethics application*

Application for Ethical Approval for Research

1. Title of Project:

How do grandparents experience the death of a grandchild following a life limiting or life threatening illness?

2. If this is a student project, please indicate what type of project by ticking the relevant box:

☐ PG Diploma ☐Masters dissertation ☐MRes ☐MSc ☐ DClinPsy SRP
☐ PhD Thesis ☒PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being ☐MD
☐DClinPsy Thesis
☐ Special Study Module (3rd year medical student)

3. Type of study

☒ Involves direct involvement by human subjects
☐ Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information

4. Name of applicant/researcher:

Michael J Tatterton

5. Appointment/position held by applicant and Division within FHM

PhD Palliative Care student, International Observatory on End of Life Care

6. Contact information for applicant:

E-mail: *M.Tatterton@lancaster.ac.uk* ***Telephone:*** [redacted]

Address: [redacted]

7. Project supervisor(s), if different from applicant:

Name(s): *Dr Sara Morris* *Dr Catherine Walshe*

E-mail(s): S.M.Morris@lancaster.ac.uk C.Walshe@Lancaster.ac.uk

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):

Dr Sara Morris
Senior Research Associate and Public Involvement Specialist, Lancaster University

Dr Catherine Walshe
Senior Lecturer in Palliative Care, International Observatory on End of Life Care, Lancaster University

9. Names and appointments of all members of the research team (including degree where applicable)

None, other than those listed above.

The Project

NOTE*: In addition to completing this form you must submit a detailed research protocol and all supporting materials.*

10. Summary of research protocol in lay terms (maximum length 150 words).

Grandparents play an important and increasing part in the lives of children affected by LL/LT conditions and their family. This study aims to develop knowledge of how grandparents experience the death of a grandchild with a life limiting or life threatening condition, and how their social background affects those experiences. Using qualitative research methods, it will explore how grandparents make sense of their experiences, and the meanings that those experiences hold for them.

Participants will be recruited via parents that are known to children's hospices. Those eligible for inclusion will identify themselves as fulfilling a 'grandparenting role'; this is not restricted to biological grandparents. Participants will have been bereaved for between six and 24 months. Participants will be recruited from children's hospices in the north of England.

Research will predominantly be carried out in participants' homes. Semi-structured interviews will be used to explore the experiences of grandparents, focusing on the *impact of the child's death on themselves and how this affects their position in the family. To enable understanding of the participant's individual circumstances, some specific questions relating to the participant, their grandchild and family will be included.*

11. Anticipated project dates

Data collection: December 2013 - July 2014

Coding, analysis and writing: from January 2014

Aim for submission: June 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

To enable the depth of analysis required, I plan to have a sample of up to 15 participants.

Participants eligible for inclusion will:
- *identify themselves as fulfilling a grandparenting role. This is not restricted to biological grandparents, and may include, for example step grandparents, or those in a relationship with biological grandparents.*
- *be bereaved for between six to 24 months of a child that they supported in a grandparenting role that:*
    - *had a life limiting or life threatening condition (ACT/RCPCH, 1997),*
    - *used a children's hospice.*

Due to the limitations of funding, only that can speak and understand English are eligible for inclusion.

Grandparents who are the principal carers for a child (i.e. occupying the parenting role) are ***not*** *eligible for inclusion. This includes grandparents who are subject to a legal or children's services order with delegated full or shared parental responsibility, including interim care orders (section 38 of Children's Act, 1989) or special guardianships (section 31 of Children's Act, 1989 (amended) Children and Adoption Act, 2002).*

13. How will participants be recruited and from where? Be as specific as possible.

Purposeful sampling techniques will be utilised in this study.

Participants will be recruited via children's hospices in up to three rounds of recruitment, as required.

Phase one will seek grandparents from children's hospices in the former Yorkshire and the Humber SHA boundary, namely Forget Me Not Children's Hospice (Huddersfield), Martin House Children's Hospice (Leeds), Bluebell Wood Children's Hospice (Doncaster/Sheffield) and St Andrews Hospice (Grimsby/East Coast).

If insufficient grandparents are recruited during phase one, phase two will include recruitment from children's hospices that neighbour the former Yorkshire and the Humber SHA boundary, namely Derian House Children's Hospice (Chorley), Francis House Children's Hospice (Manchester), St Oswald's Hospice for Children (Newcastle-upon-Tyne) and Butterwick House Children's Hospice (Stockton on Tees).

Following discussions with the Directors of Care and Family Support Managers (or equivalent role) in each children's hospice, and after their agreement to participate, information packs will be sent to each children's hospice, who will distribute them to bereaved parents of children that are known to their services. There will be a covering letter explaining the study and asking parents to pass the information pack onto grandparents. The covering letter will also provide details of sources of support for parents, should they find that the invitation emotionally distressing.

Should this method of sampling prove ineffective, a third round of recruitment will be undertaken at a grandparent's group based in a group of children's hospices based in the midlands (Acorns Children's Hospices), enabling direct recruitment of grandparents.

It is important to note that following provisional discussions with local children's hospices, it seems unlikely that the second and third rounds of recruitment will be required.

14. What procedure is proposed for obtaining consent?

Expression of interest forms will be included within the information packs sent to grandparents, which will be returned to the researcher using a prepaid envelope provided. At the time of the interview, written formal consent will be obtained and documented. It will be explained that interview transcripts can be withdrawn within two weeks following the interview, as detailed in the consent form.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

The research will include discussions surrounding the care of participants' deceased grandchild, which may include both their personal experiences, and those of their *family. Due to the sensitive and emotive subject, it is acknowledged that some psychological discomfort may be caused during the interviews. There are no other risks associated with this study.*

A topic guide is attached. The interviews will not include set questions, allowing participants to share within the limits of their comfort. It will be made clear at the commencement of the interview that the participant can stop the interview at any time, and that breaks can be taken as often as required. The researcher has extensive experience of working with bereaved children and families within the context of children's palliative care. In addition to support at the time of the interview, participants will be anticipatorily signposted to a number of bereavement support organisations, one of which will be the children's hospice used by their grandchild.

A distress protocol is attached.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

It is likely that interviews will be conducted in participant's homes, therefore risks associated with lone working have been considered. The researcher is experienced in lone working, gaining experience through community nursing.

The researcher's employer has agreed that data collection can be done within working hours, therefore the employer will be aware of the whereabouts of the researcher at all times (following the organisation's lone worker policy); this will include the address and the expected finishing time of the interview. The researcher will contact the employer at the end of the interview. Should the researcher not contact the hospice within one hour of the expected end time, the hospice will attempt to contact the researcher. If contact is not achieved, the hospice will escalate the policy, and attempt to contact the researcher using the telephone number of the participant. Should contact still not be achieved, the police will be notified. The researcher will carry a mobile telephone, used only for professional purposes.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

No direct benefits are anticipated from taking part in this study, however some participants may find it helpful to be able to share their story.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

There will be no financial incentives or payments made to participants. Out of pocket expenses are not anticipated, as research will normally be conducted in the participant's home.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

Following consent, qualitative data will be collected using semi-structured interviews, using a suitably encrypted voice recorder. This will then be transcribed by the researcher. Structured questioning will be used towards the end of the interview to gather biographic details, enabling contextualisation. This will include the completion of a genogram to identify familial relationships considered as important by the participant.

Data will be analysed using interpretative phenomenological analysis (IPA). Qualitative thematic analysis will be undertaken, enabling the development of rich idiographic descriptions, contextualised in the lived experiences of individual participants. Coding will be generated directly from the data (verbatim interview transcripts).

IPA enables the analysis from a first person perspective, allowing the researcher to explore not only the experience, but the participants' understanding of that experience and what has shaped that understanding and meaning.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

Service users have not been involved in the design of this study. This is due to the relatively small numbers of eligible participants. There was intention to discuss this proposal with a bereaved grandparents' group at a children's hospice, however this was not possible due to the cancellation of the group due to a lack of attendance.

In light of this, consultation has been sought from professionals involved in providing emotional and psychological support to bereaved families, including grandparents.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Participants will be made aware of the following prior to the interview.

Lancaster University's Policy on Confidentiality and Data Protection Act Terms and Conditions will be followed.

The contact details of participants will be known only to the researcher; confidential information will be kept securely; paper copies of contact sheets will be kept in a locked filing cabinet, and electronic records will be encrypted and stored on password protected computers. Personal details of participants will only be used to contact them to arrange an interview.

Digital recordings will be transferred to a password-protected drive on an encrypted computer, after which the file on the recorder will be deleted. Field notes will be made on paper; these will be identified by date only – no biographical data will recorded.

Biographic data (to allow contextualisation), collected on paper, will be stored separately to transcriptions in a locked filing cabinet within a secured office.

Each transcript will be anonymised by being given a unique code number, and all names and identifying features will be disguised or removed.

Transcriptions will be anonymised using gender appropriate pseudonyms. Place names will be changed to generic terms such as 'children's hospice' or 'district general hospital'. Transcripts will be stored in a password-protected drive on an encrypted computer, backed up on an encrypted external hard drive.

Personal details and audio recordings will be destroyed following the assessment of the PhD thesis. Transcripts of raw data will be destroyed five years after thesis assessment. Following the completion of the PhD, the researcher accepts all responsibility for the safe and appropriate storage of data.

22. Will audio or video recording take place? ☐ *no* ☒ *audio* ☐*video*

If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Interviews will be digitally recorded using a portable voice recorder. Digital recordings will be transferred to a password-protected drive on an encrypted computer as soon as possible, after which the file on the portable recorder will be deleted.

Computer-stored audio recordings will be destroyed once the thesis has been assessed.

23. What are the plans for dissemination of findings from the research?

A general summary of the findings will be shared with participants who indicated they wish to receive such information.

In addition to using the findings for a PhD thesis, results will be disseminated by submitting to relevant academic journals for publication and conference presentation.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study?

i. ***The exclusion of grandparents in a principal caring role***

There is a potential that grandparents in a principal care role may feel excluded by this study. The exclusion criteria will be explained comprehensively to children's hospices before they assist by sending out packs. As hospices are aware of the relationships within families, they will be asked to follow the inclusion and exclusion criteria strictly. My interest surrounds the experience of grandparents as allied carers. It is their role as a secondary carer, and the effect of that on their grief experiences that I'm interested in.

ii. ***Recruitment strategy***

Although seemingly convoluted, the proposed recruitment strategy has been devised following much consideration and discussion with children's hospice professionals throughout the UK. Due to the lack of existing support available for bereaved grandparents, and the associated databases, very few opportunities exist that would enable direct recruitment. As highlighted in section 13, provisional discussions with hospices throughout the region have been positive. I am therefore confident that despite the potential for both hospices and parents to 'gate keep' that an adequate sample will be achieved during the first and second rounds of recruitment.
The third round of recruitment, although enabling more direct recruitment, will create practical complications surrounding traveling time and distance, which may prove problematic, particularly as this PhD is being undertaken in addition to full time work.

iii. ***Limitations of confidentiality***

The limitations of confidentiality are outlined comprehensively in the attached distress protocol. Participants will be made aware of this via the participant information sheet and prior to the interview. Confidentiality will be broken should the researcher feel that the participant has indicated that they may cause harm to themselves or others. This will always be discussed with the research supervisors.

Signatures: Applicant:

....

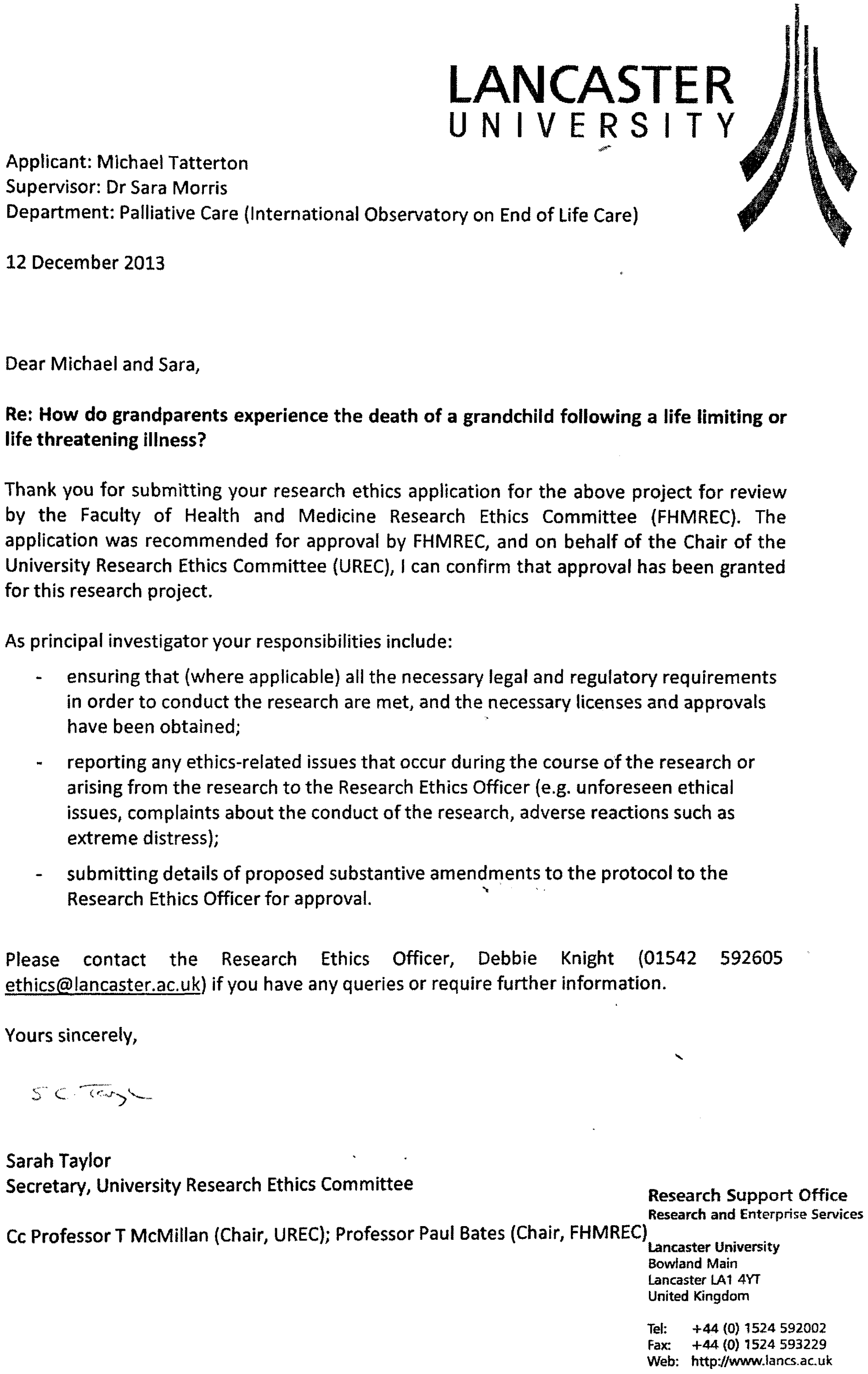
Date: ....

Project Supervisor (if applicable):* ....

Date: ....

**I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.*

Appendix 2: *Faculty of Health and Medicine research ethics confirmation*



LANCASTER
UNIVERSITY

Applicant: Michael Tatterton
Supervisor: Dr Sara Morris
Department: Palliative Care (International Observatory on End of Life Care)

12 December 2013

Dear Michael and Sara,

Re: How do grandparents experience the death of a grandchild following a life limiting or life threatening illness?

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Professor T McMillan (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

Research Support Office
Research and Enterprise Services
Lancaster University
Bowland Main
Lancaster LA1 4YT
United Kingdom

Tel: +44 (0) 1524 592002
Fax: +44 (0) 1524 593229
Web: http://www.lancs.ac.uk

Appendix 3: *Email trail regarding NHS ethical approval*

From: *"nrescommittee.yorkandhumber-leedswest@nhs.net"*
<nrescommittee.yorkandhumber-leedswest@nhs.net>
Date: *Thursday, 4 July 2013 09:14*
To: *Michael Tatterton <michael.tatterton@forgetmenotchild.co.uk>*
Subject: *FW: Ethical approval query _ PhD research involving bereaved grandparents*

Dear Michael,

Thank you for your email below.

We have now received a response from the ***Chair of the Leeds West REC*** *and I have detailed her response below:*

I think this is clearly research but the participants, the grandparents are not those in receipt of treatment/care nor or they (usually) the immediate carers of the child.
In that sense the grandparents are not in receipt of NHS services and so this would come under the heading research but not NHS research.

Based on this it would NOT need to go to an NHS REC but I think one of the Inclusion/exclusion criteria should be that the grandparents are NOT the principle carers of the child.

I hope this answers your query.

Kind Regards,

Neil.

Neil McCaffery
REC Coordinator
NRES Committee Yorkshire and the Humber – Leeds West
Health Research Authority
Jarrow REC Centre
TEDCO Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Tel. 0191 428 3578
Email: nrescommittee.yorkandhumber-leedswest@nhs.net
Web: www.nres.nhs.uk

LAS Line: 0191 428 3305
CAS Line: 0845 270 4400

If your email is regarding a formal request for information under the Freedom of Information Act, please resend to HRA.FOI@nhs.net *to ensure it is dealt with promptly*
Streamline your research application process with IRAS (Integrated Research Application System): www.myresearchproject.org.uk

From: *"LeedsWest NRESCommittee.YorkandHumber- (HEALTH RESEARCH AUTHORITY)"* <nrescommittee.yorkandhumber-leedswest@nhs.net>
Subject: Ethical approval query _ PhD research involving bereaved grandparents
Date: *27 June 2013 14:15:02 GMT+01:00*
To: *"'rhona.bratt@btinternet.com'"* <rhona.bratt@btinternet.com>

Dear Rhona,

I have just received the email below from a PHD student who would like to know if he will be required to gain NHS approval to go ahead with his study.

The PIS and Lancaster University ethics submission form are attached. Could you please advise me on whether he would require approval or not.

Kind regards,
Sarah

Miss Sarah Dunn | Assistant Committee Co-ordinator
Health Research Authority
NRES Committee Yorkshire & The Humber – Leeds West

North-East REC Centre,
Room 002, TEDCO Business Centre,
Rolling Mill Road,
Jarrow,
Tyne and Wear.
NE32 3DT

Tel: 0191 428 3548
Fax: 0191 428 3432
Email: sarah.dunn7@nhs.net
Web: www.hra.nhs.uk; www.nres.nhs.uk

LAS Line: 0191 428 3305
CAS Line: 0845 270 4400

If your email is regarding a formal request for information under the Freedom of Information Act, please resend to HRA.FOI@nhs.net *to ensure it is dealt with promptly*
Streamline your research application process with IRAS (Integrated Research Application System): www.myresearchproject.org.uk
P Help save paper - do you need to print this email?

From: *Michael Tatterton [mailto:michael.tatterton@forgetmenotchild.co.uk]*
Sent: *27 June 2013 13:52*
To: *LeedsWest NRESCommittee.YorkandHumber- (HEALTH RESEARCH AUTHORITY)*
Subject: *PhD research involving bereaved grandparents*

Dear Team,

I am undertaking a PhD in palliative care at Lancaster University; for my thesis I plan to explore how grandparents experience the illness and death of a grandchild following a life shortening condition.

I have consulted the NHS Health Research Authority decision tool, which suggests I do not require NHS approval, however IRAS advice seems a little unclear. I have had a number of discussions with my supervisors regarding ethical approval and the requirements of NHS ethics. My proposal seems to fall into a grey area, and I would welcome your advice as to whether NHS s approval is required.

I have attached the ethics form competed for Lancaster University, which I hope provides you with sufficient information. I am in the process of writing the research protocol and can forward this to you, should you require more details.

I'd really welcome your advice.

Thank you for your assistance. I look forward to hearing from you soon.

With best wishes.

Yours sincerely,

Michael

Michael Tatterton
MSc; PGDip; RSCN; RHV: Queen's Nurse
Consultant Nurse in Children's Palliative Care

Forget Me Not Children's Hospice
Russell House, Fell Greave Road
Huddersfield
HD2 1NH

Office: 01484 411042
Mobile: [redacted]

michael.tatterton@forgetmenotchild.co.uk
www.forgetmenotchild.co.uk

Registered Charity No. 1110457

Appendix 4: *Research participant recruitment pack*

<DATE> Accompanying material one: covering letter to assisting children's hospices
NB: This letter will be sent out following a discussion/meeting with the Director of Care

Dear <DIRECTOR OF CARE NAME>,

On the death of a grandchild: grandparents and their grieving.

Following our <telephone conversation/meeting> a few days ago, I would like to thank you for agreeing to help in the recruitment of bereaved grandparents for inclusion in the above study.

*Research studies are done to answer a question. The question I'm asking is **'how do grandparents experience the death of a grandchild following a life limiting or life threatening illness?'** The study aims to explore experiences of being a grandparent of a child who has died following a life limiting or life threatening condition.*

I hope to recruit a small sample, as my interest surrounds the experience of individuals, rather than that of the grandparent population as a whole. I hope to recruit between six and 10 participants, who must meet the following criteria. Those eligible for inclusion will:

- *Identify themselves as fulfilling a 'grandparenting role'*
- *Be bereaved for between six to 24 months*
- *Speak and understand English.*

*Please note that grandparents who are the principal carers for a child (i.e. occupying the parenting role are **not** eligible for inclusion.)*

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee at Lancaster University. It has also been presented to the NHS National Research Ethics Service (Leeds West), and has been deemed not to require NHS ethical approval. Copies of these documents, along with the detailed research protocol are available should you wish to review them.

*The packs have been designed to be sent to bereaved parents, with instructions of how to pass them on to grandparents. I have enclosed a number of packs in stamped envelopes. I would be grateful if you could add family addresses and send out over the next week. The envelopes have been left open should you wish to review the pack, or to add a covering letter from your hospice. **It is important that you do not remove anything from the pack.***

Please do not hesitate to contact me if you have any questions. I am happy to explain any details to you and to answer any questions you may have. Thank you again for your help and support. I really appreciate your assistance.

Yours sincerely,

Michael Tatterton
PhD Student

<DATE> *Accompanying material two: letter of invitation to parents*

Dear Parent,

I am writing you to let you know about a research study that aims to explore the experiences of bereaved grandparents. You have been contacted because you have used <HOSPICE NAME>, who have agreed to support me in this study.

Firstly, I would like to assure you that your personal details have not been shared with me. This letter and information pack has been sent to you by <HOSPICE NAME>.

*Research studies are done to answer a question. The question I am asking is **'how do grandparents experience the death of a grandchild following a life limiting or life threatening illness?'***

The research study is being conducted through Lancaster University as part of a PhD in palliative care. More details about the study are provided in the enclosed participant information sheet.

I am looking for people who want to take part in this research study and who consider themselves to be grandparents. This is not restricted to just biological (related or natural) grandparents, but can include any person, whether related or not, who acts as a grandparent to your child and family, for example step grandparents, and partners of grandparents. I'd be very grateful if you can pass this pack on to anyone in your family who might like to take part in this study. If you have more than one family member who may like to take part, please let me know and I will send you more information packs.

The enclosed participation information sheet provides you with more details about the study. The information sheet includes advice on who to contact should you find this invitation or any of the information within the pack upsetting.

Please do not hesitate to contact me if you have any questions. I am happy to explain any details to you and to answer any questions you may have.

***Taking part in research is voluntary. You may choose not to take part.** If you decide not to take part in this study, your decision will have no effect on any care you or your family members will continue to receive from <HOSPICE NAME>. The hospice will not be made aware of whether or not you decide to take part in this study.*

Thank you for your time.

Yours sincerely,

Michael Tatterton
PhD Student

<DATE>

Dear Grandparent,

I am writing you to let you know about a research study that you have the option to take part in. You are being invited to take part because you have had a grandchild that used <HOSPICE NAME>.

Firstly, I'd like to assure you that your personal details have not been shared with me. This letter and information pack has been sent to you by <HOSPICE NAME>.

I am exploring ***'how do grandparents experience the death of a grandchild following a life limiting or life threatening illness?'*** *The research study is being conducted through Lancaster University as part of a PhD in palliative care. More details about the study are provided in the enclosed participant information sheet.*

To answer the question, I would like to interview people who provide care and support within a family as a grandparent. This is not restricted to biological or 'natural' grandparents, and may include step grandparents, or partners of grandparents.

The enclosed participation information sheet provides you with more details about the study. The information sheet includes advice on who to contact should you find this invitation or any of the information within the pack upsetting.

If you'd like to take part, please complete and return the enclosed form using the prepaid envelope provided to:

Michael Tatterton, Deputy Director of Clinical Services, Martin House Children's Hospice,
Grove Road, Clifford, Wetherby, LS23 6TX.

Please do not hesitate to contact me if you have any questions. I am happy to explain any details to you and to answer any questions you may have.

Taking part in research is voluntary. You may choose not to take part. *If you do not wish to take part in this study, you do not need to take any action; simply ignore this letter. If you decide not to take part in this study, your decision will have no effect on any care you or your family members will continue to receive from <HOSPICE NAME>. The hospice will not be made aware of whether or not you decide to take part in this study.*

Thank you for your time.

Yours sincerely,

Michael Tatterton
PhD Student

Participant Information Sheet

How do grandparents experience the death of a grandchild following a life limiting or life threatening illness?

My name is Michael Tatterton. I am a children's nurse that works in a children's hospice and I am conducting this research as a PhD student in the International Observatory on End of Life Care at Lancaster University, Lancaster.

What is the study about?

The study is about bereavement. The purpose of this study is to explore the experiences of grandparents who have had a grandchild who has died. The study will help to develop understanding about the needs of grandparents and help organisations to improve the services they provide specifically for grandparents.

Why have I been approached?

You have been approached because the study requires information from grandparents who have had a grandchild who used a children's hospice in England.

Please be assured that your details have not been sent to me. This information pack has been sent to you by the children's hospice your grandchild used. I have not been passed any contact details of any potential participants.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you do not wish to take part, simply ignore this letter. If you would like more information before you decide whether or not you take part, please see the contact details below.

What will I be asked to do if I take part?

If you decide you would like to take part, I will arrange to meet you in your own home or a place of your choosing for a tape recorded interview lasting about an hour. During the interview we will discuss your experiences of being a grandparent of a child who has died. You will also be asked to complete a short genogram, or 'family tree' that will show family relationships.

Will my data be confidential?

The information you provide will be anonymised. The data collected for this study will be stored securely and will be password protected. Only the researcher conducting this study and the two supervisors will have access to the data. Your contact details will be known only to the researcher; confidential information will be kept securely. In addition:

- *Audio recordings will destroyed after the thesis (research) has been assessed.*
- *The typed version of your interview will be made anonymous by removing any identifying information including your name and the names of family, friends and services we may discuss. Anonymised direct quotations from your interview may be used in the reports or publications from the study; this means your name, the names of your family or services you mention will not be attached to them.*

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my academic supervisor about this. If possible, I will tell you if I have to do this.

What will happen to the results?
The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal, and presented at conferences. Those taking part in the study will be sent a summary of the study.

If you wish, you can be sent a copy of the transcribed (written) interview. We can discuss this during the interview.

Are there any risks?
There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?
This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the principal investigator:

Michael Tatterton
Tel: 01937 845045 or [redacted] *(note: these are professional contact numbers)*
Email: m.tatterton@lancaster.ac.uk

You can also contact the research supervisors:

Dr Sara Morris
Senior Research Associate and Public Involvement Specialist
Tel: 01524 592656
Email: s.m.morris@lancaster.ac.uk

Dr Catherine Walshe
Senior Lecturer in Palliative Care, the International Observatory on End of Life Care
Tel: 01524 510124
Email: c.walshe@lancaster.ac.uk

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study you can contact the researcher directly, or one of the research supervisors above. Alternatively, if you do not want to speak to the researcher, you can contact the head of department:

Professor Susan Cartwright
Head of Division of Health Research
Tel: 01524 592430
Email: s.cartwright@lancaster.ac.uk
Division of Health Research
Faculty of Health and Medicine

Furness College
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the palliative care doctorate programme, you may also contact:

Professor Paul Bates
Associate Dean for Research
Tel: 01524 593718
Email: p.bates@lancaster.ac.uk
Faculty of Health and Medicine
Division of Biomedical and Life Sciences
Lancaster University
Lancaster
LA1 4YD

Thank you for taking the time to read this information sheet.

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Together for Short Lives
0845 108 2210

Your local children's hospice
(note: this will be tailored to recruits to reflect the source hospice. Contact details of one hospice will be given per letter).

Forget Me Not Children's Hospice
01484 411042

Bluebell Wood Children's Hospice
01909 517369

Derian House Children's Hospice
01257 271271

St Oswald's Children's Hospice
0191 285 0063

Martin House Children's Hospice
01937 844836

St Andrews Children's Hospice
01472 350908

Francis House Children's Hospice
0161 434 4118

Butterwick House Hospice for Children
01642 607748

The Compassionate Friends
0845 123 2304

Cruse Bereavement Care
0844 477 9400

Winston's Wish
08452 03 04 05

Grandparents Association
0845 434 9585

Appendix 5: *Response form*

Response Form

How do grandparents experience the death of a grandchild following a life limiting or life threatening illness?

If you are interested in taking part in this research, please complete the following and return to Michael Tatterton in the envelope provided.

Name: ______________________________

	Yes
I am happy to take part in the research	☐
I would like to know more about the study	☐

If you ***do not*** *wish to take part, you do not need to complete this form, simply ignore the letter.*

If you have selected ***yes*** *to either of the above questions, please provide your contact details below so that the researcher can contact you.*

Address: ______________________________
____
____
____

Telephone: ______________________________

Email: ______________________________

Preferred contact: **Phone** ☐

Email ☐

If you require further information before completing this form, please contact Michael Tatterton on 07921 694 548 or email M.Tatterton@lancaster.ac.uk

Appendix 6: *Consent form*

Consent Form

Study Title: How do grandparents experience the death of a grandchild following a life limiting or life threatening illness?

You have been invited to take part in a research project that will explore the experiences of grandparents who have had grandchildren with a life limiting or a life threatening condition, through a face to face discussion, or interview.

Before you consent to participating in the study please read the ***participant information sheet*** *and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Michael Tatterton. Michael's details can be found on the participant information sheet.*

Thank you for taking part in this study.

	Please initial box after each statement
I confirm that I have read the information sheet and fully understand what is expected of me within this study.	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
I understand that audio recordings will be kept until the research project has been examined.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand I can withdraw the data collected from my interview up to tow weeks after the interview has taken place.	
I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of analysis.	
I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.	
I consent to information and quotations from my interview being used in reports, conferences and training events.	
I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with his research supervisor.	
I consent to Lancaster University keeping written transcriptions of the interview for five years after the study has finished.	
I consent to take part in the above study.	

Name of participant:	***Signature:***	***Date:***

Appendix 7: *Interview guide*

How do grandparents experience the death of a grandchild following a life limiting or life threatening illness?

*Following introductions and a discussion about the aims of the research, the **'family information sheet'** will be completed, including a genogram.*

The interview will commence with a very open question, with the intention of eliciting a narrative account. All interviews will begin with the same initial question.

'Can you tell me the story of what happened to <your grandchild>?'

Note: their grandchild will be referred to by name, gathered during the completion of the family information sheet.

Depending on the disclosures made when answering the initial question, clarification will be sought from a number of topic areas, below:

- *Their previous relationship with their grandchild*
- *Expectations and relationships with the child's parents before and after the death*
- *Expectations and relationships with the child's siblings before and after the death*
- *Their feelings*
- *Advice they would offer to others*
- *Their identity as a grandparent, particularly if the deceased child was their only grandchild*
- *Other experiences of childhood deaths, and their impact*

Experiences of other losses or serious illnesses, and their impact

Appendix 8: *Distress protocol*

Distress protocol

This distress protocol has been adapted from work by Draucker at al. (2009) and is designed to:

- *monitor participants' experience of distress, and*
- *guide the researcher's response to this distress.*

Due to the nature of this research, it is anticipated that the research may elicit a some psychological discomfort. The researcher will be aware of, and alert for indications of a high level of stress or emotional distress OR the exhibiting of behaviours suggestive that the interview is too stressful. Such behaviours include:

- *uncontrolled crying,*
- *incoherent speech,*
- *indications of flashbacks etc.*

If distress is detected, the interviewer will:

- *Stop the interview*
- *Offer support and allow the participant time*
- *Determine if the person is experiencing acute emotional distress beyond what would be normally expected in an interview about a sensitive topic. If detected, stop the interview completely.*

If distress reflective of what may be expected in an interview about a sensitive topic is evident, support and the following opportunities will be offered:

i. *stop the interview completely, OR*
ii. *stop and regroup and then make decision to stop, OR*
iii. *stop, regroup and continue.*

If distress of any level detected, at either stop point (as above) or end of interview (if continued), the interviewer will take the following actions:

i. *Encourage participant to contact their regular health provider (GP or consultant for example) for follow up.*
ii. *Provide the participant with details of local support groups and services they may wish to access. This will include the contact details of the referring children's hospice.*
iii. *Indicate that, with permission, you will contact them the following day to see if they are okay.*

Should severe or acute emotional distress be detected, either during or following the interview, the researcher will:

- *Request permission from the participant to contact the referring children's hospice to request emotional support. OR*
- ***If there are any concerns about their immediate safety dial 999 for assistance.***

Draucker, CB, Martsolf, DS, and Poole, C. (2009) Developing distress protocols for research on sensitive topics. Arch Psychiatr Nurs; 23(5):343-350.

Appendix 9: *Genogram template*

Family Information Sheet

Grandparent	
Name:	*Date of birth:*
How many grandchildren do you have?	
Grandchild	
Name:	*Date of Birth:*
Diagnosis or condition:	
Age at time of death:	*How long ago did your grandchild die?*
Where did your grandchild die?	*Hospital* ☐ *Hospice* ☐ *Home* ☐ *Somewhere else* ☐
Family genogram	

Appendix 10: *Example of initial transcript coding*

Emergent themes	**Original transcript** *I: Interviewer P: Participant*	**Exploratory comments**
	I: and do you think that's different? Do you think the support a grandparent provides would be different to an aunty or uncle, or even close family friends or something?	
Need for closeness	P: no, I think anyone could do it. If they're - they've got to have a closeness to it, but yeah, anyone could do it. erm, no, I don't think it's just grandparents, but it has to be somebody very very close to them, and, it also comes that people would - surprisingly, I think people who, would	
	just step in, who you don't realise would just step in, whether anybody's ill, if I'm if, if something ever happened to erm [touching wooden coffee table], ever happened to me, I know there'll be people that will come forward to that you never expected to be the support. People need people	'step in' suggests usually on the outside?
Love - family	don't we. so, it's the love of a bond, it's a love that gets you going, and I think whether it's an aunty and uncle, a best friends, I mean you must have met people that you, you've given support to [pause] you can't do anything about what's happening to them but the support's there because you want to give it. erm, [pause] but,	
Ability to offer financial support	erm, I - erm, out of the two grandparents, Bob and I were probably the more financially able to help them out, which Bob will go through that but, I -	Finances – unique contribution - identity
	erm, it comes down to you as a person. Because if I'd have lived away, this isn't going anywhere - don't put it on your records! [laughs] I'd have lived	Judgement of other grandparents – proximity and contact
Love - grandchild	away, I'd have been over here, living with my daughter or somebody to make sure I was on hand, not just coming once a fortnight and using a phone call, so it comes down to an individual	Humour to mask confrontation
Shading: cumulative effect of grief – bearing witness to GC and daughter	personality doesn't it? Comes down to that. Erm, they're - it was just love for Hannah - it was my only way, I could do that. The only way. Looking after the baby since, it's been a long, it's not just been the diagnosis of Hannah, it was the treatment year, it was the new baby coming, losing Hannah, the stress that I saw Kate go under,	Shading: cumulative effect of family events – listed as separate rather than one event. e.g. diagnosis, treatment, death... rather than H's journey.
Suggests removal or paramountcy – daughter's needs before own	the grieving plan from both, the pressure that it put on them two, then this ne - this third baby came along. The stress I saw Kate and their- , so for three years I have been s- strong, to keep her	*'levelling out'* – compare to GM2

Emergent themes	**Original transcript** *I: Interviewer P: Participant*	**Exploratory comments**
	going, but the pain of losing Hannah will never go away, er, she's in our hearts, but I can see Kate's levelling out now, and I'm backing off. I'm not	
Practical examples of support	having the need to support, because it, it, when you, you're so active looking after, bring at the hospital looking after them, and when she came home and the staff were fantastic, constantly	
Change in kind of support offered, however remains practical	looking, you sort of become tunnel visioned you know, [holding hands up to side of face, indicating narrowed vision] - my priority is Kate, the baby, and Ben and then they'll g- and now I think washing, ironing, getting all that in together.	Demonstrating need of daughter
'explosion': suggests chaos	Then when this happened, there's all that big [pause] [long sigh] e- explosion of everything working, timing, church services, grieving	Grieving seen as a task?
	I: when Hannah died?	
	P: yeah yes. I don't know how to describe that. Because at the end you just think [pause] as much as I didn't want to lose her [pause] I was asking her to go. I was telling her who was there and who wasn't [became tearful] and who'll meet her [pause] because this little life is being ebbed	
Missed before death	away. And er, there's nothing for her anymore, and it's the same for anybody, but a child who's missed so much, but it goes on. it, it just goes on, and as I say it, its two years in May since she died and its coming up to three years of supporting, looking aft- keeping them going, but I can see now	Anticipatory grief or hindsight – probably the latter.
Positivity post death	that Kate's levelling an Bob and I are able to start living our little lives, you know. Do things without	Secure in own role
Acknowledgement of life outside the family	being there, thinking about them constantly. So as a grandparent [pause] and the type of grandparents that we are, and I think that depends, it depends on you as a grandparent what type of person you are. For whatever reason, you all do things in the way you're able to do don't you. Erm, some people might not have	
Paramountcy of family needs	been able to do - give them sort of - and I don't mean financial support, I mean that support of putting them first, and keeping them going, you know. Erm, so it comes down to personalities so, we just happened to be grandparents. if I'd had been a sister or an aunty I'd have probably closed to her cos I have a sister who I know would have done what I'd done you know, so erm [pause] does that answer your question or did I waffle on?	Sees herself as caring – not because she is a grandmother, but just 'her' – *'personality'*
	I: yes it does. So what do you think it is then that makes being a grandparent different or	

Emergent themes	**Original transcript** *I: Interviewer P: Participant*	**Exploratory comments**
	special? You know, why do grandparents matter do you think?	
Time Calmness Idea of catching up on missed experiences with own children 'so much to offer' as grandparents – flexibility Identity Love	P: Oh, they matter. Yeah. They're erm. Grandparents have time. Grandparents are calmer as we get older. erm, we haven't got, I mean I know Bob's only just retired, but when they step through the door, as they, a - your - as - a grandparent, everything goes, because you know they're either, if they're not staying the night, they'll go home, you can catch up with what you're going to do, erm, no. They are the ones that you want to share and mature shoulders, you just, because you've missed a lot with your own children cos you've been career minded. Well, Bob never saw his grand- his children because he was always working, erm, but you want to share them, in their experience. You'll go out of your way to go on little train rides, and train journeys. You have got so much to offer, which is, I think grandparents are calmer, and you've so much, yeah, so much to offer children when it comes down to being a personality again, because some grandparents don't want to do that. They think we've had our children and we want to move on. erm, I'm, Hannah- I'd just had my 60th birthday when Hannah were born, ah god, it was the best birthday present, and all my friends have all these grandchildren and they've - it wasn't just shared - all my friends who were grandparents shared the thrill of us finally being grandparents [laughs] you know.	Indicating that time with a GC is precious and paramount Belonging as a GP – being same as friends 'finally' - Much longed for GC
	I: mmm	
Gentle approach to GP role Time Importance of play Transient and intermittent involvement of others except Olive	P: erm, so being a grandparent, you have time, you're not giving them rules, er, well you are, to an extent, but you're the one that can share things and you've got time to sit on the floor and play and other things. They are the priority. When they step through the door you down tool everything. erm, and they, I think, with Hannah being in hospital, cos I was always there when mummy and daddy wasn't there, and her uncle'd come and see her or erm, th- Kate and Ben's friends would pop in, erm, my Bob would come straight from work, because there's a very	Importance of play linked to professional experience Emphasises her role and importance

Appendix 11: *List of codes*

So: Sources Ref: References

Code ('Node')	So	Ref
parental role	7	146
protect parents	7	26
supporting parents to 'cope'	5	21
pain in parents	4	15
hiding sadness emotion from parents	4	10
anxiety in parents	1	5
parental guidance	1	4
supporting OWN child (not both)	1	4
reassuring parents	1	2
telephone support	1	2
bearing witness	7	69
witnessing parental grief	4	8
helplessness	5	50
recognising own limitations	2	4
'inadequate'	1	3
inadequacy after death	1	1
hope	6	36
hope - loss of	5	10
hope - care after death	2	3
treatment options	1	3
hope created by subsequent children	1	1
effect of subsequent children	1	5
'we' considered as part of the grandchild's family unit	5	30
validated	4	30
'hardest' thing	5	25
diagnosis	3	6
tag question	4	23
identifies with partner	5	21
'they' considering themselves outside of the grandchild's family unit	4	19
Priority	4	18
important for gc not to be left alone	1	18
hiding own emotions-feelings	4	18
practical support	5	17
support FROM others	5	17
grateful for the support of others	2	2
sense of community	1	2
changes post death - the family	4	16
positive changes in the child's immediate family	3	4
changes post death - negative impact on GPs from +ve changes in the GCs family	2	4
sense of duty	4	15
referring to relatives by relation, not name	2	15

Code ('Node')	So	Ref
'we' togetherness in grief	6	15
internal conflict - living away from family	1	15
Justification/reasons to NOT move closer to family	1	9
justification for not visiting more frequently	1	5
loss of child's family post death	2	15
changes post death - loss of child's family	2	7
childcare - well siblings	3	14
cumulative pain-grief	6	14
disenfranchised grief	4	14
empathy	1	7
lack of understanding-support from others - post death	3	14
awareness of palliative nature of the condition	6	13
pain - in SELF	3	13
'anger'	5	13
'anger in the family'	1	5
anger, self	1	5
anger, partner	1	4
anger and closeness (family)	2	3
anger, M-GM	1	2
anger - focus not at each other	1	1
anger, GF-F	1	1
anger, M-F	1	1
anger, M-GF	1	1
apologies post anger	1	1
not recognised/acknowledged by parent	2	13
coping strategies	5	12
routine	1	12
play, importance and significance	3	12
photographs, importance of	6	12
'friction' (inc. tension, stress...)	3	12
traumatic	1	4
childcare - sick child	3	11
excusing behaviour	3	11
love of sick grandchild	3	11
being positive	2	11
suffering - gc	4	11
NOT acknowledged/recognised as grieving	2	11
things that assist coping	3	10
boundary between parenting and grandparenting role	1	10
belief in heaven-faith-afterlife	1	10
comparing sick grandchild to well peers	2	10

Code ('Node')	So	Ref
avoidance of voicing the diagnosis-death-difficult words	2	9
identification as a grandparent	3	9
closeness to family	3	9
crying - self	3	9
personality (outlook)	1	9
changes post death - value memory of deceased grandchild	5	9
effect-pressure on employment	1	9
family - inclusive	3	9
head of family	1	1
you are on the edge	2	9
compounded grief	3	9
implied friction with other grandparents	2	9
'left out' effect of other grandparents	1	2
'interfering' observations of other gp	1	1
waiting for gc to die	2	9
metaphor	2	8
idea of NOT being alone	2	8
kept out of the loop	1	8
trust in professionals	2	8
financial support	5	8
to the church	1	2
the other hat	2	8
recall of fine detail - interaction with grandchild	3	8
care of child after death - unease	1	8
sudden, unexpected - death of grandchild	3	8
'whole world changed' - global effect of gc death	3	8
change in priority following Dx	2	8
reflective-philosophical	2	8
transient and fragile - following the death	1	4
acceptance of reality - post death	2	8
'hole' left in the family by deceased grandchild	3	8
recognises the experience as belonging to the parents	2	8
impact of own ill health	1	8
lack of interaction with gc due to condition	3	8
balance - of other children	1	8
own role, not shared with partner	1	7
love	3	7
reluctance to shown OWN emotion	3	7
awareness of other children and families	2	7
2ndry grandparenting role	5	7
accepting of secondary carer role	5	27

Code ('Node')	So	Ref
knowledge acquired through work	2	7
comparing grandchild to YP cared for through work	2	5
vulnerability of grown up grandchild	1	3
not wanting GC to live due to suffering	3	7
judgements on quality of gc's life	2	7
repeated readiness-expectation of death	1	7
intensive visiting	3	6
expressed acknowledgement of palliation - death	4	6
passive aggression	2	6
comparing self to child's other grandparents	3	6
not wanting to add to parent's burden	2	6
concept of hierarchy	1	6
preserving, protecting and maintaining hope	2	6
trust	2	6
enduring role	5	6
enjoyment of grandchild	2	6
comparing self to peers	3	6
recognising own need	2	6
sense of responsibility for family	4	6
protect grandchild	3	6
time with grandchild (motive - to spend time with the child)	1	6
'snatched time' with grandchild due to work	1	1
pain - in grandchild	3	6
In the way	1	6
time for the family	2	6
changes post death - self	1	6
changes post death - ability to empathise	2	2
changes post death - intensity of feelings	2	4
aware of child's difficult future	1	6
grandchild's development-ability (developmental milestones)	3	6
conflict of managing well or sick grandchildren	2	6
aware of taboo	1	6
relief at being able to voice taboo thoughts	1	2
effect of GC on family life	2	6
effect of the illness on wider family	1	6
family split up due to illness	1	2
strength	1	5
empathy from professionals	2	5
acknowledged role of grandparent	2	5
dealing with own grief	3	5
change in priority due to hindsight	2	5

Code ('Node')	So	Ref
more family focused	1	3
resilience; motivation and drive for	2	5
humour	1	5
financial impact	1	5
support from the church	1	5
it made me think about religion	2	5
supporting the family	2	5
distance from family	3	5
unaware of detail of child's condition	3	5
affection for in-law	2	5
hospital and appointments - accompanying parents	4	5
poor quality of life	2	5
surprised by the impact of GCs death due to ltd. interaction	1	5
self assured in own role	3	5
'natural order' 'death out of sync' with family	3	5
changes post death - isolation of grandparents	1	5
funeral - struggling with,	1	5
praise for child and in law	1	5
emotion	1	5
empathy for - identification with clinical staff	1	4
normal expectations	3	4
changes in the grandchild	3	4
grandchild's deterioration	6	23
discussion of the grandchild's condition	5	15
awareness of distressing symptoms experienced by grandchild	2	5
conflict between in-laws	1	4
pain	1	3
Envy of other grandparents	1	2
grandparent blaming in-law	1	1
in-law blaming grandparent	1	1
auto-pilot	1	4
supporting others (strangers)	1	4
double grief	2	4
importance of relationship between staff and family	2	4
'closeness'	2	4
positive change in parent	3	4
share experiences with grandchild	1	4
grandchild 'missing out' on peer interaction - play 'normal'	3	4
grandparents - benefit of age	3	4
taking charge of the situation	3	4
NOT taking charge of the situation - not my role	2	2

Code ('Node')	So	Ref
taking charge	1	1
awareness of imminent death	3	4
identifying as a parent	2	4
reassuring grandchild during dying	1	4
own needs - with grandchild	1	4
not recognised as grandparent	2	4
changes post death - x taking things for granted	2	4
own needs - social	2	4
burden	2	4
questioning 'life'	2	4
life unfair	3	4
impact on plans for retirement-future plans	2	4
supporting partner	2	4
positive change in family	2	4
'move on' self-grandparents	2	4
support FROM professional colleagues	2	4
discussed from PARENT'S PERSPECTIVE	2	4
hope - after death	2	4
post death - talking about the deceased	2	4
survivor guilt	3	4
'sense of loss' hope of normality	3	4
objective, removed stance	1	4
discussing other grandchildren	2	4
implied friction within the family	2	4
control	1	4
sadness	3	3
meeting expectations of others	2	3
personal coping strategies	3	3
asking questions of professionals	2	3
reluctance to ask questions	1	3
needed practical information	2	3
protecting the family	2	3
role of wider family	1	3
post death -changed role	2	3
suggesting chaotic time	2	3
acceptance of death	1	3
time for grandchildren	1	3
'always there' consistency	1	3
reliance on partner	2	3
sharing pain with partner	2	3
reluctance to acknowledge own need for support	2	3

Code ('Node')	So	Ref
endurance of grief ('before or since')	3	3
parent - distraction of other children	2	3
being lost	2	3
morphine association with dying	1	3
sharing MEMORIES with the sick child	1	3
changes post death - more time-value surviving grandchildren	2	3
questioning ability to cope 'again'	1	3
partner's emotions	3	3
impact on grandparent relationship	2	3
'no time for us at all really'	1	3
overwhelmed	2	3
continuing bonds	2	3
subjective significance	1	3
'move on' parents-family	2	3
God - testing Him	2	3
emotions, welling up	1	3
changes post death - partner	1	3
changes noted in partner post death	3	4
sudden realisation	3	3
idea of being alone	1	3
love of being a grandparent	1	3
recognising importance of partner's role	2	3
grandchild central focus within the family	2	3
led by child's family - POST DEATH	1	3
ability of friends etc. to cope with loss	1	3
ostracised	1	3
wish for normality	2	3
role taken for granted by parents	2	3
'selfish' self	2	3
touch - GP-P	3	3
comforted by child not suffering post death	2	3
changes post death - benefits for family	1	3
'backseat' as a grandparent	2	3
'harder than expected' aspects of grief-experience	1	3
resentment of other children	2	3
'i felt sorry' - feeling for son	2	3
financial ability	1	3
previous experiences of death	3	3
difficult memories	2	3
closer relationship with other (M) gps)	1	3
accepting of that closer relationship	1	2

Code ('Node')	So	Ref
feeling useful	1	3
GP reassured by togetherness of parents	1	3
regards self as 'lucky' to be in the family	1	3
identification of home - hospital and hospice	1	3
understanding of [well] children	1	3
intuition	2	2
spoiling-indulging grandchildren	1	2
perspective	1	2
judging others	1	2
in-law referral	1	2
stigma	1	2
lack of exposure to peer group	1	2
needed	1	2
questioning unacceptable care	2	2
pain less than parents	2	2
suggesting frustration with 2ry care role	1	2
expressed modesty	1	2
impact of other changes in the family	1	2
gradual process	2	2
grandparent's own life	1	2
calm	1	2
'You have got so much to offer' as grandparents	1	2
financial cost of hospital-based caring	1	2
grateful for support FROM others	2	2
'going forward' restoration orientated behaviour	1	2
pray	1	2
go under,	1	2
grandparents - differences in coping (M vs. F)	2	2
identification AS grandchild's parent	2	2
showing emotions - OTHERS	2	2
'we just functioned in a cloud' lost, shock, unknown, numb	1	2
crying - sick grandchild	1	2
anecdote	1	2
precious	1	2
direct involvement with child at time of death	2	2
support FROM wider family	2	2
hiding own wants-needs	1	2
saying the wrong thing	1	2
'her favourite blanket' grandchild's possessions	2	2
Bargaining	2	2
love of surviving grandchildren	1	2

Code ('Node')	So	Ref
effort of staying positive	1	2
commitment to grandchild not shared by partner	2	2
impact on grandparent's social relationships	2	2
loss of interest outside of family	1	2
'responsibility'	2	2
change in values	1	2
finance - importance of	2	2
GF role in supporting the GM to care for family	2	2
'emptiness'	1	2
spiritual beliefs	1	2
spirituality - questioning beliefs	1	2
parental anxiety re health of subsequent children	2	2
effect of retirement	1	2
SEEKING REASSURANCE FROM RESEARCHER	2	2
changes due to retirement	1	2
dimensions of grandparenting	1	2
'total' support offered by grandparents	3	5
denial	1	2
feeling guilty	1	2
objective position of step-grandparent	2	2
frightened for grandchild's future as an adult	1	2
aware of parent's difficult time ahead in caring for grown up child	1	2
blaming state on drugs	1	2
'that had all been taken away' effect of condition	1	2
acceptance of condition - blame	1	2
acceptance of reality – illness/diagnosis	2	2
'horrendous' - 'whole thing'	2	2
'barriers' protecting self	2	2
family excluding people	2	2
friends with daughter-son	1	2
changes post death - relationship with child	1	2
conflict	2	2
reflective after death	1	2
limiting grief - 'wasting your life'	1	2
sharing memories OF grandchild when well	1	2
we don't talk about it a great deal	1	2
notion of modern vs. traditional grandparenting	1	2
grief - isolating self (withdrawn, shut out...)	1	2
anger at doctors	1	2
crying - not helpful	1	2
'normal, healthy baby'	1	2

Code ('Node')	So	Ref
given written details of gc's treatment	1	2
feeling valued by professionals	1	2
battle references re; condition and treatment	1	2
rollercoaster - emotions	1	2
friends that would take on practical roles of gp	1	2
secure attachment to child's family	1	2
child reassured by parents network of friends for support	1	2
aware of need of alone time for parents	1	2
unifying - togetherness of family after death	1	2
loyalty to hospital	1	2
hope of more grandchildren for child (rather than self)	1	2
unchanged - same as before (pre and post death)	1	2
ownership	1	1
parental aggression	1	1
stating role as primary grandparent	1	1
comparing to child's other grandparent	1	3
perceived limitations of grandparenting role	1	1
shared responsibility - family and professionals	1	1
comparing self to professionals, recognising limitations	1	1
faith in people	1	1
asking child to die	1	1
futility	1	1
missed before hear death - the child that was	1	1
'mistolerate' behaviour from in-laws	1	1
identifying with parents	1	1
'lash out' grandparents struggling with emotions	1	1
positive comments from others	1	1
I'm crumbling	1	1
reliance FROM partner	1	1
adding to burden of grandchild's sorrow	1	1
'try' suggesting professionals were unable to achieve aim	1	1
cancer	1	1
childcare - all children	1	1
benchmarks	1	1
stating needs of family before her own	1	1
time with grandchild AFTER DEATH	1	1
no changes in self - post death	1	1
understating role-part	1	1
Repetitive	1	1
impact on colleagues	1	1
suggesting shock	1	1

Code ('Node')	So	Ref
charitable, identification as being more	1	1
relating grief to business-career-work	1	1
events that strengthen belief in God	1	1
'the biggest thing'	1	1
'You've lost your granddaughter'	1	1
awareness of frequency of family breakup post death	1	1
impact on people of ill child	1	1
changes in feeling following Dx	1	1
'devastated' effect on family	1	1
frustration at lack of information	1	1
validated by grandchild	1	1
warm description of grandchild	1	1
comparing own experiences of pain to GCs	1	1
relieved by death of gc	1	1
expectations, failing to meet OWN	1	1
'walking on egg shells' worried about saying the wrong thing	1	1
suffering - self, post death	1	1
parent's thoughts - ability to influence	1	1
survivor guilt (by proxy)	1	1
putting family needs before own	1	1
'victim'	1	1
recognised by grandchild prior to illness progression	1	1
associating function with degree of loss	1	1
changes post death - loss of role	1	1
'you just feel forgotten'	1	1
gf - f support (male - male)	1	1
GF stepping in to role of F	1	1
protective of partner's honour-role	1	1
need to be recognised by parents	1	1
frustration	1	1
'injustice' of child death	1	1
reflecting on experience with own grandparents	1	1
instinct	1	1
implied friction with child in law	1	1
witnessing gc struggle when dying	1	1
'misery'	1	1
association of cancer with old people	1	1
careful not to give advice due to provoking anger	1	1
events that weaken belief in God	1	1
experiences of other deaths	1	1
change places with gc (to die before them)	1	1

Code ('Node')	So	Ref
control - of own emotions	1	1
'treadmill' - journey	1	1
embarrassed by cost	1	1
morality of NHS spending	1	1
justification to visit more frequently	1	1
practical tasks and distraction	1	1
own anxiety in meeting the gc's care needs	1	1
acceptance of hospice involvement	1	1
association of hospice with dying	1	1
uncertainty	1	1
resilience of gc	1	1
gc's acceptance of treatments	1	1
making memories	1	1
anticipation - anniversary of death	1	1
GP support from hospice	1	1
sympathy for others - cumulative grief	1	1
hurt by other children	1	1
parents 'deserving' of normality	1	1
time to grieve for parents	1	1