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The grief-related experiences of grandparents
when a child has died or is terminally ill / severely disabled

A study exploring the experiences of 11 grandparents who have experienced, or are experiencing, the illness, death or severe disability of a grandchild.

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Part II of a Research Portfolio submitted in fulfillment of the requirements for the degree Master of Counselling

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This research project is dedicated to my beloved grandmother

Anita Leveson
(1904 – 1980)
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I would like to acknowledge my research supervisors Dr Margaret Agee and Dr Jan Wilson from the University of Auckland’s Counsellor Education programme. They were unstinting in giving their support, time and energy without which I could not have completed this study. When my motivation flagged or when I thought that I just couldn’t do it, they were there to encourage and show me that they had faith that indeed I could and would complete. Their thoughtfulness, expertise and guidance were invaluable.

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ABSTRACT

This exploratory, qualitative study aimed to describe the grief-related experiences and support needs of grandparents when dealing with the death, disability or terminal illness of grandchildren. Three focus groups were held: the participants in two were grandparents who had been bereaved by the death of a grandchild, and the participants in the other were grandparents who had a grandchild with a disability or terminal illness. One participant who was unable to attend a focus group was interviewed individually. This small study found that when a child is seriously disabled, ill or dies, often grandparents are seen as part of the support system for the parents and siblings of the child, but their grief and disempowerment in the situation in which they are not usually the decision makers can be hard to bear. It was found that the grief experienced by grandparents can be complex and multi-dimensional as it can be complicated by a number of factors, including: having to support their children and other grandchildren in their grief; grieving for them, while grieving for themselves; and the loss of their dream of a future where their grandchild could have a full and healthy life. Recommendations for further research and what can be done to help these disenfranchised or forgotten grievers are discussed.
CHAPTER 1

Introduction
My decision to undertake the research presented in this report emerged from my own personal and professional experience. When I was a child growing up in a dysfunctional family, my grandmother was a constant source of unconditional love and care in my world. She was the one I’d go to for comfort, laughter, hugs and encouragement. I always had a sense of how important her role was in my life, and I attribute a lot of my well being and achievement as an adult to her—and yet as a child I was also aware of her loneliness and disconnection from the outside world.

The nuclear family was mostly a closed unit and my grandmother was only allowed in at certain times, by invitation. She and my mother (her daughter-in-law) did not get along, something that made things very difficult for her.

The feeling that we failed to honour and recognise my grandmother enough during her lifetime has always been a great sadness for me. As an adult, I’ve heard grandparents describe their difficulty with belonging but not belonging—of often having to do a dance with their child or child’s partner to get access to their grandchildren. Yet in my counselling practice, when clients have described the dysfunction and pain in their childhoods and I ask “Who was there for you? Who could you rely on? Was there someone who gave you unconditional love?” invariably the answer would be “my grandparents” and a smile would come across their face.

So when it came time to decide on what to do for my research project for my Master’s of Counselling research portfolio, I naturally thought of grandparents. I wanted to do research that hadn’t been done over and over again: to look at a group who were largely not considered but who were extremely important, and to do something that could build some awareness and appreciation of the importance of grandparents.

A big area of my counselling work is in the field of loss and grief, and I’ve been interested to hear my clients who have lost their child refer to their parents and parents-in-law. Most of the stories I’ve heard have been of unstinting support for their child, grandchild and family, and I’ve wondered who was supporting them.
I could only imagine what it felt like for them to have been the main decision maker for their child, and now to have to take a backseat and allow that adult child to make the decisions for their child, but still be unendingly supportive (even if they disagree with the choices made). It would take a lot of wisdom, patience and trust.

My research project therefore grew out of my wanting to honour grandparents in my research, as well as my grief and loss work. To narrow it down into something specific and reasonably tangible, I decided that the research should be on the bereavement-related experiences of grandparents when a grandchild has died, is terminally ill or severely disabled.

This ticked a few boxes for me: I was focusing on a group on which there has been little research, looking at grief and loss and how it manifested for them, and examining both the pain and gifts that come with helping the family involved. I was aware that a limitation of the research would be that since participation would be purely voluntary, it would probably attract grandparents who were “hands-on” and present for their children and grandchild, rather than those who chose not to be involved. However, I felt this would still enable the study to contribute to the field, as a reflection on the importance of grandparents, and on the contribution and needs of those grandparents who are there for their families.
CHAPTER 2

Literature review

In recent years there has been a great growth of insight into how we grieve and many old myths have been turned on their head. There has also been more understanding in the field of unsupported, or disenfranchised grief, which can be particularly difficult for the griever. In this literature review, these contemporary understandings in the fields of loss and grief, and disenfranchised grief, will be explored, with a concise overview of what has changed and been discounted. In particular, the focus will be on how the new insights can be used to better understand the grief-related experiences of grandparents who have lost a grandchild, or whose grandchild is severely disabled.

To do this, the review will begin by looking at grandparents and their role in their family and society as a whole, then at general grief and loss research. Finally, I will look at the existing research that relates specifically to the grief-related experiences of grandparents.

The role of grandparents:

Evolutionarily research shows that people becoming old enough to be grandparents (living beyond 30 years old) is something that has happened relatively recently in human pre-history, occurring concurrently with the development of symbols underpinning the evolution of language and art. This would suggest that growing to older ages was one of the things that gave human beings advantages over other groups such as Neanderthals (Caspari, 2011).

Lewis (1999) suggested that the big change that came with people living longer was the effective transmission of knowledge through the generations. “Success in human society is uniquely dependent on knowledge, and older individuals are repositories of useful information.” (Lewis, 1999) He suggested that living longer meant effective transmission of information from older people to their grandchildren. Grandparents often embrace the role of educator and storyteller, recounting events from the past, information that could have a bearing on survival for the whole family group.

The evolutionary approach, which focuses strongly on the biological role of grandparents, also claims that grandparents’ ties to a grandchild may depend on the genealogical relationship to that grandchild, with the mother’s mother being the most involved and the father’s father being the least. The theory claims that this is
particularly the case if there are few, rather than many, grandchildren (Coall, 2010). The reason for this, Coall has suggested, is that the mother’s mother knows for certain that the grandchild is biologically connected to her. Using data collected in the United Kingdom, Pollet, Nelissen and Nettle (2009) found that maternal grandparents are in fact more likely to invest time and resources in their grandchild than the paternal grandparents.

A study by Fingerman (2004), however, shows that the relationship of grandparent to grandchild is more contingent on the relationship with the middle generation, and often in particular with the son- or daughter-in-law. “This study did not find that grandparents feel closer to the daughters’ or sons’ children per se, but rather the quality of ties to the parents mattered” (p. 1044).

In 2009, research carried out though the University of Hertfordshire’s Family Matters Institute (Brooks & Hill, 2009) found that grandparents were extremely valuable to their grandchildren. It found the relationship, most often categorised by love and trust, enabled children to use grandparents as confidantes, playmates and instructors. They could get non-critical support, advice and unconditional love and time, something that was often lacking for their busy parents who needed to concentrate on their careers. This report pointed out that with the prevalence of divorce and various family breakdowns and dysfunction, it was not uncommon for grandparents to provide the only much-needed stable relationship with an adult family member. The researchers also found that the benefits are mutual: grandchildren can bring a sense of fulfillment and happiness to their grandparents’ lives.

Many in our culture see becoming a grandparent as gaining a special status and it can give people a new energy and lease on life (Seligman & Darling, 1997). Coall and Hertwig (2010) concluded in their research that the roles and functions of grandparents are complex and in need of multi-disciplinary research to encapsulate their full meaning. They suggested that much of the study into the role of grandparents is focused on the benefits experienced by the younger generations, but concluded the limited studies that have focused on the grandparents show that there are definite benefits from grandparent involvement to grandparents alone. They even cited Tinsley and Parke (1987) as suggesting that “grandparents reported significantly greater satisfaction with their contact with children and grandchildren than the parents did” (p48).
In fact, Powdthavee (2011) has suggested that there is a possible life-satisfaction payoff to being a grandparent. Using a survey in the United Kingdom focusing on more than 5000 grandparents and 6000 non-grandparents, the findings were that having at least one grandchild had a significant statistical correlation with overall life satisfaction. This was found to be not necessarily the case for parents, meaning that the payoff for having children may in fact come later in life, as long as the children have children.

Conversely, Muller and Litwin (2011) found in their research of European grandparents 50 years and older, that there was little correlation between psychological well being and the grandparents’ role. This was attributed to perhaps being connected to the changing modern world where grandparents are healthier and rely more on networks outside of the family than inside. This study found that the more activities the grandparent had outside the family, the more psychological wellbeing they experienced, no matter what age or gender.

Perhaps the significant issue may not be about having grandchildren or not, but about having involvement with grandchildren if one does have them. An earlier study, by Drew and Silverman (2007), concluded that loss of all contact with existing grandchildren can be seen to increase the depressive symptoms experienced by grandparents, especially as they get older. Thus the researchers concluded that loss of contact with grandchildren did have a negative effect on mental health.

Erber (2005) suggested that considering increasing longevity, particularly in industrialised societies, it is likely that people will spend more and more years holding the role of grandparent, and even great-grandparent. Younger grandparents may still have children at home and therefore have primary parental roles and work, while older ones may have more time for their grandchildren. Factors such as economic status, ethnicity, gender, age of grandchild and more can also affect role and relationship.

Dunifon and Bajracharya (2012) found that the key factors that influence the relationship between a grandparent and grandchild were geographical distance, the relationship with the middle generation, the parents’ relationship with the child, and the ages of the child, parent and grandparent.

Geographical distance from grandchildren can have a big effect on how close—or otherwise—the relationship between grandchild and grandparent is. Erber (2005) has
cited Kivnick and Sinclair (1996) as identifying the following styles of grandparenting: companionate, remote and involved. Remote grandparents may live a distance from their grandchildren, or be busy with other interests. Companionate grandparents tend to share pleasurable activities with their grandchildren, such as baking, going to movies or playing games. They tend not to be involved in the disciplining of grandchildren; while involved grandparents spend a lot of time with their grandchildren, often looking after them when parents are at work or otherwise occupied. Involved grandparents can go to the extreme end of being custodial grandparents (Eber, 2005).

Given the research findings about grandparents' relationships with their grandchildren and the significance of their roles and relationships, when those bonds are broken or threatened it would seem that significant loss and grief may occur.

**Loss and grief**

In recent years the established beliefs about loss and grief have been challenged. The experience of grief was framed narrowly in the 20th century. Sigmund Freud saw grief as being a gradual, solitary process of the griever detaching from the deceased person. Grief was necessary for the griever to release his/her bond with the deceased through re-examining the past with that person and then letting go and creating a new attachment (Buglass, 2010).

The later behaviourist approach suggested that behaviours get reinforced by others, so when someone one loved dies, certain behaviours are no longer rewarded (Dunn, 2004). As a consequence, the griever experiences a loss of a part of him/herself. This approach is empirically based, as according to this view, only what can be observed can be studied, because grieving involves complex inner process, this theory alone has been found to be inadequate for the investigation of the loss and grief experience.

More recent thinking, developed by Klass, Silverman and Nickman (2006), is that grievers tend to continue the bond with the deceased, rather than sever it. This is often expressed culturally through ideas of the presence of ancestors, spirits and ghost stories. Out of this idea has developed a “causality thesis” whereby continuing the bond has been seen as supporting good adjustment, something that the originators of the theory claim was never intended.
We (the authors of Continuing Bonds, 1996) wrote, 'As we develop a model of grief that includes continuing interactions with the dead, we need to be open to both the positive and negative consequences of this activity.' (Klass, 2006, p. 844)

The main change in thinking that occurred with the idea of continuing the bond with the deceased was that it was normal, rather than pathological, as Freud and other early theorists had claimed, however that does not mean it is always healthy (Klass, 2006).

Klass (2006) argued that if we want to look at causality between adjustment and continuing bonds, it needs to be seen in a complex, dynamic way – and to consider that causality can happen from many directions simultaneously. He suggested using Attig’s (1991) grief model which looks at how people relearn the world, and Rubin’s (1991) two-track model incorporating Neimeyer’s (2000) theory meaning making as central to processes of grieving.

The two-track model conceptualises the process of loss through bereavement along two “separate but interactive axes” that look to the covert and overt responses to loss (Rubin, 1999). The first track looks at biopsychosocial functioning after loss and track two focuses on continued emotional attachment and the relationship with the person who has died.

Rubin (1999) argued that his model enables researchers to look at grief both mutually —what’s common in the grief/trauma/change area—and at individual differences: how there can be preoccupation with the deceased rather than with trauma/change? The purpose of his model is to incorporate the behavioral-empirical perspective with the perspective of the individual’s relationship with the deceased. He suggests that with a death, the person dies, but the relationship continues. Contemporary grief research also shows that it’s important to see grieving as an active, rather than passive process, and part of grieving is relearning one’s understanding of a world without the deceased and finding one’s way to cope and restore a sense of meaning and purpose as well as learning to function within it (Attig, 1991).

Attachment theory, which originated from psychodynamic theory, deals with the lasting bond between human beings. Theorists and researchers began by looking at the temporary separations of parents and child, but the field evolved to also focus on the
“profound biopsychosocial transitions occasioned by the permanent separation from a loved one through death” (Neimeyer, Scott & Gillies, 2006, p. 716).

Nelson (2010) suggested that attachment and separation work as two sides of the same coin. Walsh and McGoldrick (2004) have observed that “the way that the members of the family normally manage their separations also influences the way that the distress of grieving is handled” (p. 86). They also noted that Bowlby's (1980) attachment theory looks at how the grieving process typically progresses, and how the implications of the death are eventually accepted. Once this occurs, the bereaved can begin to act with full knowledge of what is truly facing them. The future they assumed would occur in which the dead person had a role becomes one where it is accepted that life has inexorably changed and what was expected, their original vision of the future, would not occur.

Still there are many myths in the community about loss and grief, particularly around Elisabeth Kübler Ross’s stages of grief model, which claims people go from denial to anger, bargaining to depression to acceptance when they grieve (Bolden, 2007). Konigsberg (2011) has suggested Kubler Ross’s five stages of grief are nothing more than myth, and a potentially destructive myth at that, because sometimes if people are not going through the “stages” they start thinking that there’s something wrong with them. In fact, more recent research suggests that grief is much more of an individual phenomenon, and that some people get through it quickly, whereas others need more time (Neimeyer, Harris, Winokuer & Thornton, 2011).

Personal histories, personality and expectations all come in the mix. The stages models seem to claim that grief is something passive that we go through (Attig, 1991), but while a loved one dying is not our choice, the way we grieve can and should be chosen (Neimeyer, Harris, Winokuer & Thornton, 2011).

For grief not to remain debilitating, Attig (1991) says grievers “must let go of the debilitating desire to have the dead restored to life, which lies at the heart of grief, and engage actively in the coping processes of relearning the world to secure for those now absent the new place ongoing and meaningful life” (Attig, 1991, p. 393).
Neimeyer's (2008) approach to grief and loss, meaning making, is grounded in constructivism. This is a post-modern psychology approach that focuses on the personal and social ways that people create meaning and orientation to their lives. According to this approach, grief can be seen as “a struggle to reaffirm or reconstruct a world of meaning that has been challenged by the loss” (Neimeyer, 2002, as cited in Neimeyer, Holland, Currier & Mehta, 2008, p. 270). Again there is an emphasis that grief is active, not passive.

In this vein, making sense of the bereavement, or grief associated with significant non-mortal loss, and creating meaning around it, is vital. It is suggested that looking at grief through the lens of Bowlby’s (1980) attachment theory and Neimeyer’s meaning reconstruction can help people both with complicated grief, and examining coping and resilience (Neimeyer, 2008).

Stroebe (2010) has found that most people dealing with grief can initially suffer health effects and interpersonal difficulties, but manage to find resilience and come to terms with the bereavement, and psychological treatment or intervention is not necessary or particularly useful. She has suggested that “Intervention should rather be planned for high-risk groups and those who have complicated grief manifestations” (p. 149). This researcher suggests that further research needs to be done into situations when grief becomes “maladaptive” and that that research should consider perspectives from family relations research, as when there is a bereavement, it’s usual that at least four family members are deeply affected.

Most often grief is a natural process that does not need to be treated by professionals – but for some, help is needed. Complicated grief may occur when the griever becomes stuck in his/her bereavement and the successful reorganisation of his/her life becomes near impossible. This outcome is more likely when the grief is traumatic, when the death is out of the expected life cycle (i.e., when a child dies) or when there is “bereavement overload”, that is when the griever is dealing with many significant deaths simultaneously (Neimeyer, 2000).

Interestingly, whether or not grief should be treated has recently become a hot topic in the media. The January 2013 edition of Scientific American has reported that the American Psychiatry Association’s (APA) guidebook on mental illness, the Diagnostic and Statistical Manual of Mental Disorders (DSM), has in its next incarnation, the DSM 5,
eliminated the exclusion of grief as a mental illness, and added footnotes describing the differences between grief and depression. This step has been controversial, but does give grievers insurance cover for help that may be needed. (Internet, http://www.scientificamerican.com/article.cfm?id=dsms-5-update&page=4)

Disenfranchised grief:
When a child is seriously disabled, ill or dies, often grandparents are seen as part of the support system for the parents and siblings of the child, but their grief and disempowerment in the situation in which they are not usually the decision makers can be hard to bear. Speaking about grandparents of children with disabilities, Johnson (1995) observed they were: “Often expected to provide emotional and practical support to help their adult child adjust to the demands and stresses of having a child with a disability, grandparents may be struggling with their own uncertainty and grief” (p. 30). Because their focus is often on the family, their grief can often be “disenfranchised” (Doka, 2002).

As Lenhardt (1997) suggested, with disenfranchised grief, the individual often does not recognise the right to grieve or acknowledge a loss—in this case, particularly when the loss seems to be someone else’s (their children’s loss)—and social acknowledgment and support are often lacking as well. Often grandparents are expected, and expect themselves, to be able to simply deal with their loss because they have more experience of loss than others in the family, when actually the reverse may be true: other losses may make the loss of a grandchild even harder for a grandparent (Lee & Gardner, 2010).

In the foreword to his book Disenfranchised Grief, Doka (2002) outlined the importance of having a loss both recognised and validated, and made the point that there is no hierarchy of grief or grievers. There may also be a generational aspect in play where people who are grandparents now were taught as children to “get over it”, “harden up” or “put it behind them” when distressing or painful events occurred. These sorts of messages do not aid constructive mourning (Corr, 2002).

Grandparents’ grief when a grandchild has died
In her nursing PhD thesis, written in Wellington, New Zealand entitled "When an Infant Grandchild Dies", Steward (2008) said that there was an increasing awareness of the needs of parents and siblings when a small baby dies, but that there's been little attention paid to grandparents, and that a large part of what attention there is on grandparents has been on how they grieve, rather than how they see their bereavement and how that is contextualised within the family. In her research, she saw the constructivist approach as a way of looking at how the participants saw their relationships, and how they created stories around their loss (Stewart, 2008). This research highlights the importance of the grandparent role, which can bring both pain and the need to be involved as the parent of the adult who is suffering through their child's illness. Steward suggested that nursing staff be more aware of the role and needs of grandparents.

Moules, Laing, McCaffrey, Tapp and Strother (2012) in their research with 16 grandparents with grandchildren with cancer in Alberta, Canada, found that grandparents are often silenced by their will to protect their adult children from being concerned about them. They hold what the researchers call a double worry for the child and the child's parent. The study found that grandparents, like other subsystems of the family, are greatly affected by their grandchild's illness.

In another piece of research (Galinsky, 2001), based in Canada, which comprised interviews with grandparents after the death of their grandchild, it was found that many felt a dual loss. In addition to grieving for themselves the loss of the child, the grandparent was also grieving for the loss experienced by their adult child. Also, although these grandparents often wanted to jump in and solve things for their child, they had to consider the other parent (their child's partner – who may see things quite differently), and found that trying to solve things in ways they were used to was not always the best response.

These researchers also found that many of these grandparents also experienced physical symptoms such as shortness of breath, and chest pain, which could have been due to the grief, or a serious physical condition. The conclusion was that grandparents often need
care and support through their grief, and that further research was needed to help counsellors respond to the dynamics of grandparents’ grief (Galinsky, 2001).

Ponzetti and Johnson (1991) suggested that there was a large amount of research that focused on the grief of parents, but little on that of grandparents. They suggested that when there is any death in the family, the family system as a whole is impacted. These researchers suggested that grandparents’ role in the family, being of a voluntary nature, was unique, however there is a vested or generational interest in their grandchildren. Ponzetti and Johnson (1991) argued that grandparents often played an important role in families, and their grieving process should not be ignored. Part of this grief is that grandparents expect to die before their grandchildren, even more than parents do. “When a grandchild dies before a grandparent, the order of nature seems to be blatantly violated” (Ponzetti and Johnson, 1991, p. 158).

Grandparents’ grief is three-fold, they suggested: they grieve for the grandchild, for their child and for themselves (Ponzetti & Johnson, 1991). These researchers also found that in addition, grandparents grieve about their loss of hopes and dreams for what the grandchild might have become.

Many years later Nehari, Grebler and Toren (2007) embarked on a qualitative study on the grief experiences of grandparents of children who have died of cancer at a palliative care centre in Israel. These researchers found that common in grandparents’ grief was the questioning of the legitimacy of their grieving, difficult relationships with their children and the meaning of such a loss in their old age. They suggested that in Western culture the expression “bereaved grandparent” is rare, while that is not the case for “bereaved parent”. They also concluded that the cultural understanding of bereavement is that it is limited to the nuclear family.

“It appears, therefore, that the absence of a clear social position and social role for bereaved grandparents, within the culture and the family framework, causes vagueness concerning what they are expected to be and how they should cope.

(Nehari, Grebler & Toren, 2007, p75)
They found that bereaved grandparents often experience a great sense of isolation which can be extremely painful. Often the place in the family for a mourning grandparent is not clear. Also, in commenting on their study, Nehari, Grebler and Toren (2009) observed that as many grandparents are fit and healthy and in their 50s, they may still have employment responsibilities, and while there are allowances made for parents in this situation, grandparents are often not given the same understanding.

Many of the grandparents interviewed said the loss of their grandchild was far more difficult than any of the other losses that they had experienced in their lifetimes. These researchers created a three-circle model of grandparents' grief, looking at culture (social role, support systems, rituals, code of behaviour, mores and memorials), family (dynamics, closeness, resources, role, communication, boundaries, multi-generation) and personal (other losses, age, health, gender, support systems).

Yet another study, this time from Ireland, agreed that more research was needed into grandparent grief. In “Forgotten grievers: an exploration of the grief experiences of bereaved grandparents”, the authors commented that while a lot of research has been done investigating the grief experiences of parents, children and spouses, very little has been done about grandparents (Gilrane-McGarry, 2011).

Gilrane-McGarry (2011) undertook qualitative research, doing in-depth interviews with 17 people. The finding was that although a lot of the previous research that was found on the topic focused on the dual loss—grief for themselves and their adult child—grandparents’ grief seemed to often be far more multi-faceted and complex. Although dual loss was part of the experience, the grief of their participants was often complex and cumulative. The sources of pain discovered in this study included the losses experienced through the aging process, such as the loss of spouse, parents and friends in their life. The researcher suggested that it was the experience of these losses that often made the community believe that grandparents were experienced and could deal with the pain better than younger family members, when in fact this could actually exacerbate the loss (Gilrane-McGarry, 2011).

It was also found that the participants often experienced great distress in witnessing the distress of their son or daughter, as they were powerless to rescue their child from the pain of loss. The study suggested that grandparents’ relationship with their child can change, as the parent of the deceased child may be negatively changed by the experience
of loss, and that can affect the relationship. The study also found that grandparents experience the grief that is common to most bereavement, and in fact often grandparents suffer a similar intense reaction to the death of a child as do parents.

In another study from Florida in the United States that looked at health and functioning after a grandchild’s death, it was found that grandparents often experience depression, anxiety, suicidal thoughts, increased drug or alcohol use and pain for their adult child. However, it was acknowledged again that research on grandparents’ health and functioning after the death of a child is limited (Youngblut, Brooten, Blais, Hannan & Niyonsenga, 2010). Thus a consensus emerged from these researchers and the others cited here, that there is a need for more research into the bereavement experiences of grandparents.

There could also be a generational aspect to the way grandparents grieve, as there was a cultural shift in the baby-boomer generation (born from 1946), where people became more comfortable with talking about their emotions, although that was a slow progression. The previous generation who tended to be stoic and felt that they should not “grumble”, were called the Silent Generation (Brownlie, 2009). Grandparents of today would probably span the Silent Generation (1925-1945), and Baby Boomers, with some younger ones being of Generation X (1965-1979).

As with most experiences of loss, grief and bereavement, it is important for grandparents to find meaning in the death of a grandchild. Some may use religion or spiritual belief, which conversely can also be threatened by the bereavement (Dent & Stewart, 2004). For some grandparents caring for the family is a way of coping, as is keeping busy and having the opportunity to talk about their experience, but the terms recovery, getting over it and accepting are not helpful, as Dent and Stewart (2004 as cited in Stewart, 2000) suggested.

Creating ritual, and a place to remember the child within and without the family, are important. Many grandparents find acknowledgement of their bereavement in the community is quite often not offered. Sometimes grandparents may be asked: “how are the parents” and not “how are you” (Dent & Stewart, 2004). All this contributes to the disenfranchisement of grandparent grief.
The bereavement experiences of a grandparent when a child is terminally ill or severely disabled

The birth of any child, never mind a disabled one, has a profound effect on a family system (Seligman & Darling, 1997). As reflected on previously, in modern times grandparents often take on a role in helping with childcare, acting as playmates and generally helping the family out. However, in many cases when there is a grandchild with a disability, the role of grandparent often changes from what Erber (2005, as cited in Kivnick & Sinclair, 1996) has called companionate to involved.

While grandparents are often expected to be of emotional and practical support to the parents and family of a disabled child, they themselves may be struggling with their own grief and confusion. They also often lack access to information and resources that are made available to the parents of the child (Johnson, 1995).

In a study conducted through the University of Oklahoma in the United States, with 32 grandparents of disabled grandchildren, it was found that only a small number knew of the disability in advance of the birth (Scherman, Gardner, Brown & Schutter, 1995). It was found that initially, on learning about the disability, the grandparents experienced grief feelings similar to those experienced by parents. Subsequently many became more involved with the family, providing both emotional and financial support. Many of these grandparents expressed fears around the future of the grandchild, and whether they would ever be able to live independently, and the ability of his/her parents to sustain the stress of having a disabled child. Few accessed community services or support groups, but said they got their support from family and spouses.

There are many services available in the Western world to help children with disabilities and the parents, but as Johnson (1995) suggested there is very little that caters to the “special needs” of grandparents. There is also the unique grief that they hold: grief for themselves, for their adult child and for their grandchild who is unlikely to have a “normal” life.

Sherman et al. (1995) found that while many of the grandparents they interviewed expressed a willingness to help the family in any way possible, many were wary of interfering with their child’s family. This caused internal conflict and limited direct involvement in some cases. The researchers argued that grandparents can be active partners with the family in aiding their own, and the family’s adjustment to the situation.
Other aspects that were concerning to the grandparents in this study were: dealing with the constraints imposed by the grandchild’s disability, such as: needing to ensure wheelchair access and foresee difficulties in taking the child into the community; worry about the child outliving his/her caregivers—who would look after him/her in adulthood?; concern about the stigmatisation of their grandchild in the community; and the stress that having a disabled child would have on their child’s marriage. The study found that many of the grandparents realised the family would need extra time from them, but were unsure about how to go about giving it.

Grandparents with a disabled or ill grandchild often find their role expands, but a lot depends on the grandchild’s family system and the grandparents’ acceptance within it (Lee & Gardner, 2010). Lee and Gardner noted that there has not been a lot of research done on the role of grandparents when a grandchild is disabled, even though they often assume “additional roles that include unique involvement as support for their grandchild and his/her extended family” (p. 468).

In their analysis of what modern literature there is on this topic, Lee and Gardner (2010) suggested that grandparents’ support depends on geographical proximity to the family, their depth of understanding of the disability, their relationship with their child, and the level of solidarity between them. These researchers found that the grandparents’ attitude to the disability and possible prejudice towards the disabled as a group could come into play and affect their involvement. They cited Gabel and Kotsch, (1981), Hastings, Thomas, and Delwiche (2002) and Hornby and Ashworth (1994) as saying: ”Grandparents can add stress or emotional burden to the family of the child with a disability if the grandparents cannot adjust well to their situation” (Lee & Gardner, 2010, p. 482)

In fact, Shakespeare (2007) observed that people with disabilities are further disabled by societal prejudice, not only interpersonal prejudice, but in cultural representation and stereotyping. Dovidio, Pagotto and Hebl (2011) found that although people often express support for people with disabilities and say they feel positive about companies that employ them, they often ”spontaneously exhibit negative emotional reactions to people with disabilities, discriminate against them in subtle ways, avoid interactions …” (p. 173).

Lee and Gardner (2010), suggested that:
...there are a variety of variables and contextual factors that can impede or promote grandparents' involvement and support. Providing grandparents with access to accurate information regarding their grandchild's disability, maintaining and improving communication between grandparents and their adult children, and creating support groups or workshops specifically tailored to grandparents’ perspectives, seem to be promising contemporary themes. (p. 484).

In a survey of mothers of children with disability concerning support from grandparents done through the University of West Virginia, it was found that the mother’s mother was the most likely to be the most helpful – but there was a level of solidarity found from all the grandparents (Baranowski & Schilmoeller, 1999).

This study found that perhaps the most important thing for the mother was unconditional acceptance and love of the child by its grandparents, regardless of how the child behaved. The researchers found that grandparents can be an important and powerful resource for the child with disabilities and his/her parent, especially when it comes to emotional support, skill development and simply in allowing the parent to have a break. The researchers suggested that bringing the grandparents into the loop—providing them with information and education—could be beneficial for the whole family.

Seligman and Darling’s (1997) view was consistent with that of more recent researchers in noting that one of the parents’ major concerns is how their parents will react to the disabled child. For grandparents, a future that often seems assured by a healthy baby, can be made uncertain by a challenged one. Often grandparents have been known to deny the problem, or have unrealistic fantasies that the child will "grow out of" the disability. Some grandparents have also been known to avoid having contact with the child. Responses are individual and both depend on and affect the family system (Seligman & Darling,).

Seligman and Darling (1997) cited George (1988) as suggesting that grandparents have a role in enhancing coping in the entire family. They ran a pilot support group in New York successfully where grandparents could exchange information and discuss how they dealt with the various crises that can occur with a child that is disabled. Research
shows that grandparents want to be better informed about the disability of their grandchild, workshops and extended family programmes have also been tried in the United States with some success (Seligman & Darling, 1997).

Miller, Buys and Woodbridge (2011) noted that there has been a lot of research on mothers coping with a disabled child, but very little on her support system (fathers, other children and of course grandparents). They also observed that there has been very little research done on the grandparents’ role in the family when there is a disabled child, a fact that was cited as the reason for their research, which was based in Australia. These researchers also suggested that only a very few studies have looked directly at the viewpoints of grandparents. They concluded that grandparents are important resources for the family, providing emotional and other support, but that little is known about the impact that this support has on the grandparents lives.

This research was with 22 Australian grandparents who were 55 to 75 years old (Miller, Buys, & Woodbridge, 2011). Four general themes were found, they were firstly that grandparents struggled with their emotions, but generally chose to focus on what was in front of them and trying to remain emotionally tough and positive; secondly there was plenty of self-sacrifice where grandparents did things such as reducing work hours, moving house and changing their retirement plans to accommodate the family. Thirdly, they maintained communication with members of the extended family and often worked as a “go between”. And finally they showed a lot of concern for the future of the family when they grew too old to be a big help.

Interestingly, none of the research on grandparents with disabled grandchildren seemed to focus on the “gifts” that could ensure. In a study which explored the experiences of parents with disabled children by Kearney and Griffin (2001), it was found that indeed there were joys and gifts in the experience. In their findings, they suggested that “although they [the parents studied] experienced much anguish and sorrow, the parents also spoke of hope, love, strength and joy” (p 582). It will be interesting to find if this pertains for grandparents too.

**Conclusion**

In view of the importance of the grandparents’ role in the family and the minimal amount of research into their experiences, it seemed worthwhile to embark on this current study. The study aims to talk to grandparents who have either experienced the
death of a grandchild or who have had a grandchild who was severely disabled. The overriding purpose would be to do a descriptive study on their experiences to see whether they correspond with the general modern theories of grief and loss, and also in order to ascertain their support needs.
CHAPTER THREE

METHODOLOGY

This is a small, exploratory qualitative study using a thematic analysis approach. Participants were divided into two groups – one for those with grandparents of children who have died, and the other for grandparents of children who are terminally ill or severely disabled. The reason for dividing the groups was because hearing about experiences from the contrasting stages in the grandparenting relationship being with the former could have been too distressing for members of either group. Each group attended one focus group and one follow-up meeting. The follow-up meeting was explained to group members as a way for them to share thoughts about their experiences that may have come up after the focus group. It was explained that it was not compulsory to attend this meeting, and if a participant couldn't attend they could share their thoughts via email or phone.

Methodology

To gain some understanding of the bereavement experiences of grandparents, and how they are supported, or not, by the community led me to choose a qualitative methodology approach for this study, where participants could share their individual experiences without the constraints of a fixed survey, this would create a fluidity where a wider investigation could be made. Qualitative research is art and science, it’s a way for a researcher to investigate real-world social phenomena – to ask questions and be open to getting complex and unexpected answers (Rossman & Rallis, 2012).

According to Rossman and Rallis (2012), there are two unique features to qualitative research: Firstly, the study is conducted through the researcher, which is why the positioning of the researcher is important in understanding the research – it allows for any biases or expectations of the researcher to be noted, and the purpose is to understand something about the social world and how it operates.
McLeod (2003), suggests that qualitative research allows participants to share their experiences, perspectives and views in their own words. I chose focus groups as a way to collect my data as according to research (Krueger, 1994) focus groups are carefully planned discussions that are specifically designed in order to study an area of interest in an environment that is both permissive and non-threatening “a focus group is a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment” (Krueger, 1994). It was a way for the grandparents to discuss their experiences with me, the researcher, and each other in a safe environment where they and I could gauge commonality and individuality of their processes around the death/disability of their grandchild. I could also gauge whether it was helpful for them to share their experiences with myself and the others who had gone through the same kind of experience, with a view of finding whether this kind of sharing had helped them cope with their grief.

The questions
As a grief and loss counsellor, I thought about what aspects of the grandparents’ experiences I was most interested in and what questions would help gain an understanding of the grandparents’ experiences and needs. When a child is seriously disabled, ill or dies, often grandparents are seen as part of the support system for the parents and siblings of the child, but it seemed their grief and disempowerment in the situation in which they were not usually the decision makers could be hard to bear. I was interested in the factors that could complicate their grieving experience – particularly if they were dealing with what’s called disenfranchised grief (Doka, 2002). As suggested by Onwuegbuzie, Dickinson, Leech and Zoran (2009), firstly I identified the type of data that could be collected in the focus groups – and set questions accordingly. Because I wanted the grandparents to share their experiences in an organic way, and not to impose things on to them, I saw the questions I collated (Appendix A) as a loose blueprint that I could refer to in the focus groups rather than prescribed questions I would ask one after the other.
Participants in the qualitative study

Participation was completely voluntary, and participants, as a consequence to that, were grandparents who were very involved with their grandchildren, rather than ones who were more distant (Erber, 2005). I contacted various organisations, including Child Cancer, Age Concern, a bereaved parents support group and a major children’s hospital. The hospital were particularly helpful and recruited a number of the participants, who then got into contact with me. All the grandparents who wanted to take part were accepted.

Recruitment of grandparents with severely disabled or terminally ill grandchildren proved more difficult to recruit as there was a resistance to the idea that these grandparents should be told that they were grieving, as can be seen by the following email received from an Auckland music therapy Centre:

Thank you for sending through these documents. I’ve taken a look at them and have also discussed your request with the management team here at the Centre. Following this discussion, I’m emailing to let you know that we have decided not to participate in recruiting participants for your research study. There are several reasons for this:

- the children we work with are not ill or dying, but do have disabilities and special needs
- we felt uncomfortable with the assumption that grandparents of children with disabilities are grieving. While this may be the case, we felt uncomfortable approaching people with this as the specific topic of the research project. Perhaps it is more appropriate to look at the experiences of having a grandchild with a severe disability, rather than specify ‘grief-related experiences’.
- our approach at the Centre is strengths-based and, as such, we are cautious about labelling anyone’s experiences, whether those of the children, young people and adults with whom we work, or members of their families.

I am sorry that we are unable to help you further with your research project and would like to wish you all the best with it. I am presuming...
you have already been in touch with the organisation 'Grandparents raising grandchildren' who I am sure would be able to help you out. Again, please accept my apologies for not being able to help at this stage.

In the end, the participants in this group came from people I knew asking people they knew in that situation if they wished to participate. Finally, I had seven participants in the one group and four in the other. Because some of the grandparents in the bereaved grandparents group had different schedules – some worked, had arrangements on certain days, lived elsewhere and were going to be in Auckland at a certain time etc, in order to include them all, I decided to divide them into two different groups so they had a choice of times. Because the follow-up meeting was not compulsory for the research and some of the grandparents would be unable to attend as they lived elsewhere, I followed up with one such meeting where all participants were invited. Four participants attended that meeting, and others sent thoughts via email. One of the grandmothers, who was keen to be a part of the research, was heading overseas and couldn’t make either of the focus group times, so I did a one-to-one interview with her.

Of the four participants in the “disabled” group – three attended the follow-up meeting.

As far as conflict of interest was concerned, there was none – as although I am a counsellor at the Grief Centre I was in the role of researcher for this project, and did not take any of the participants on as clients. I did not recruit any of my clients as participants, clearly differentiating between the roles of counsellor and researcher.

**Sample size and demographics:**
In all there were 11 participants, nationalities ranged from New Zealand, South African, British and Australian – all live in Auckland, except for one who lives in
Christchurch. All the New Zealanders were Pakeha, bar one, who was Māori. Eight of the participants were women and three were men.

**Data collection method**

The data was collected through taping the focus groups and follow-up meetings using a digital voice recorder (DVR). There was one individual face-to-face interview with a grandmother, which was also recorded using the DVR. The recordings of the focus groups were then transcribed by a university transcriber who had signed a confidentiality agreement. Permission for the transcription from participants was received through the consent form they signed (Appendix B).

I made the decision not to have the follow-up meetings transcribed in full, but listen to them carefully and reflect any new information in the research report. Having focus groups allowed participants to describe their experiences in their own words, so the richness and depth of their emotions and thoughts could be captured. McLeod (2003) suggests that a weakness of this type of research is that the researcher’s interpersonal style or personal way of being could influence the data that is collected. Realising this, the researcher kept out of the discussion as much as possible and only guided things when deemed necessary. The facilitator’s/researcher’s response style was mainly reflective, this was to allow participants to explore their experiences deeper (Denzin & Lincoln, 2000).

The richness of the data collected and the feedback from participants may indicate that they were truly able to share their experiences, and benefited from the way the group was structured.

**Procedure**

The participants contacted the researcher via email expressing interest after being informed of the research project by people in the community that I had requested to publicise it. They were emailed back with the project advertisement and participant information sheet (Appendix C). Once they replied, saying they definitely wanted to take part, I asked them about their availability, and timed the focus groups according to what suited the majority of participants.
At the focus groups, I explained to the participants that the follow-up meetings were not a prerequisite, but rather an opportunity for sharing things that they may have thought of after the group had met. I said if it was not possible to attend the follow-up meeting, they could email or phone me with thoughts they wished to share. There were four participants who could not attend the follow-up meetings – one because of living in Christchurch, one because of a trip overseas, one because of ill health and the last for no disclosed reason.

**Data Analysis**

I chose to take a thematic analysis approach in analysing my data. It is widely used for qualitative analysis and is an accessible and flexible approach (Braun & Clarke, 2006).

According to Braun and Clarke (2006), “thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data” (p 79). These authors suggest that although it is broadly used, there are no set agreed ways of how to go about it. Finding the themes is concerned with finding patterns within the data – something that is either directly observable, or could be picked up as a subtext or something implicitly referred to by the grandparents (Marks & Yardley, 2004). “Even when the manifest theme is the focus, the aim is to understand the latent meaning of the manifest themes observable within the data, which requires interpretation” (p.57).

McLeod (1999) suggests that anyone undertaking qualitative research should firstly immerse themselves in the data by listening carefully to recorded material, taking notes and reading the transcripts a few times. Secondly, they should identify various meanings – looking at categories and themes that come out of the research. Thirdly, the researcher needs to move back and forward from the text, noticing where the themes become apparent, and checking their validity – attending to detail is vital here, and it’s important also to be open to new and different meanings than the researcher had thought would be found.
Fourthly, there is the task of writing up the understandings that have been reached in the process.

I followed all these steps ---- I listened carefully to the focus groups with the transcripts to ensure they were accurate and listened again with the transcript and wrote down themes as I heard them. I made broad notes clustering them, then I went through the transcripts and grouped what the participants said in the themes that I had identified through cutting and pasting from the transcript. I then read through what I had put together, to make sure that what was being said was accurately put into the themes chosen – there were times when I switched things around as they seemed more applicable within a different theme. My supervisor checked how the data was organised and made some suggestions in order to confirm that the themes and subsections were valid.

**Possible researcher bias**

Since I am not a grandparent I didn’t need to be too concerned about imposing my experiences of this role on to the participants. I was aware that I came in with a bias towards the importance of grandparents and an appreciation of their role in the family, but in the context of this research, this bias and unconditional positive regard for the participants did not seem to be a problem.

I was conscious as a grief and loss counsellor not to impose my personal understandings and knowledge of bereavement on the participants, as I wanted them to speak freely within their understandings and not have other understandings imposed on them.

**ETHICAL CONSIDERATIONS**

This research project was approved by the University of Auckland Human Participants Ethics Committee (UAHPEC) on September 19, 2011.

**Confidentiality**

Since this is research into a sensitive topic and information for this research was gathered by means of focus groups, matters of confidentiality and privacy of
information were particularly important. There was a clear agreement between myself and focus group members regarding confidentially of information within each focus group and within the consent form (Appendix B) is a confidentiality clause.

I explained to each group that if they wanted to share information about their own individual experience in the focus group, that was ok, but they needed to agree not to share anybody else’s story, comments or identity.

As far as the research data are concerned, I explained to the participants that the names and identifiable personal information pertaining to the individuals taking part would be kept confidential. Protocols included asking participants to choose pseudonyms for use in the research report; my undertaking to omit or disguise potentially identifiable personal information; and offering participants the opportunity of withholding or withdrawing any sensitive personal information from the data gathered – nobody requested this. ‘

In conducting this research, as well as adhering to the expectations of the University of Auckland Human Participants Ethics Committee I was also bound by the ethical standards of the New Zealand Association of Counsellors, of which I am a Provisional Member, and my research supervisor is a Member.

**Informed Consent**

The principles and practices associated with informed consent were observed. Prospective participants were recruited through Starship Hospital, Age Concern, the Grief Centre, and other organisations. The managers of these organisations were provided with an information sheet that described the purpose of the research in detail, as were participants (Appendix D). Participants were also told of the purpose of the research at the beginning of their focus group and informed again that they each had a right to withdraw from the group at any point if they wished, and to have the data they provided withdrawn at any point up to the completion of the analysis of the data. No participant made this request.
Possible harm
There was a slight possibility that participants could experience some emotional distress. As far as safety was concerned, the researcher made sure there would be availability of ongoing support for participants as needed through the University of Auckland counselling programme – particularly if they found things that were said in the group were disturbing to them. Also, at the time the focus groups were running, there was a counsellor on the premises that could immediately be of aid to anyone who was so distressed as they had to leave the room while it was being held. Participants were told of this access at the beginning of the focus groups.

Possible benefits
It was hoped that the focus groups would in fact be beneficial to participants as they would give them opportunity to name things that perhaps they hadn’t felt able to express before. In creating a safe, warm environment for the participants it was hoped that they would find sharing their experiences to be cathartic and rewarding.

Findings
The findings would be presented under the themes and sub-themes marked out through the analysis. There would be different sections for the bereaved grandparents and the group dealing with the disability of their grandchild as it seemed likely that they would put different emphasis on their experiences.
CHAPTER 4

RESULTS:
The grief-related experiences of grandparents when a child has died

The seven grandparents who participated in this part of the research ranged in age from their 50s to their 80s. All except one whose grandson was stillborn so she didn’t have the opportunity, were what can be called “involved grandparents,” as they gave up their time, and some left work, in order to help in the care of the child. Some seemed to have moved from being “companionate grandparents” who tend to share pleasurable activities with their grandchildren such as baking, going to movies or playing, to taking on an “involved” role because of the circumstances and medical needs of the child. Most expressed a degree of disempowerment, feelings of isolation, and frustration at the lack of information provided to them. In addition, as grief research would show, unique factors influenced the grief experience of each participant.

The grandparents were:

H (61-year-old female) and J (69-year-old male), a couple who lost their four-year-old grandson to neuroblastoma. They have one other grandchild. They were in Focus Group 1.

M (75-year-old male) who lost his four-year-old grandson to leukaemia. He has eight other grandchildren. He was in Focus Group 1.

SH (54-year-old female) who lost her 14-month-old granddaughter to cancer. She has no other grandchildren. She was unable to attend the focus groups at the times scheduled due to an overseas trip, so was interviewed one-to-one.

Jo (64-year-old female) who lost her 14-month-old granddaughter to cancer (same child as above). She has three other grandchildren. She was in Focus Group 2.

Ma (84-year-old female) who lost her 15-year-old grandson. She has seven other grandchildren. She was in Focus Group 1.

C (67-year-old female) whose grandson was born stillborn. She has three other grandchildren. She was in Focus Group 2.
Involvement with the grandchildren

Most the grandparents spoke of their care of their grandchild and being both pleased and privileged to have been involved.

*I used to spend two or three nights a week up there, she was never left alone. We [family – including SH] just used to be with her all the time... I wanted to be involved and I wanted to help as much as I could and I used to make them meals that they could put in the freezer and, my son and his partner. (Jo)*

At the same time, they also spoke of their deep sadness at having witnessed what the child went through.

*He went on a trial programme which really gave him from diagnosis until he died about 11 months with us. That was really precious time and we did a lot, but we also went through a lot of I guess medical procedures, chemotherapy, radiotherapy during that time, which was quite harrowing at times. (H)*

*You know, looking back, you know, I’m very pleased I had because I really got to know her which, although in some ways it made it even sadder but at least we had that time. (Jo)*

Most saw their involvement as a privilege.

*And looking back on it I can see that my daughter actually did place me in a special position because she decided that I was the only one, apart from herself and her husband, that she was going to allow to visit Starship. (M)*

*She [baby’s mother who suffered mastitis] left R... with me to bottle feed, she’d pump and bring milk around and I was with R... I bonded with her earlier than J [the mother] as it turned out. (SH)*

SH also realised however that her involvement was sometimes at the expense of herself, and had resulted in depression that she understood as related to “depression” of her own feelings:
I think I’m a bit of a battler and so, like, when no-one else could sort of go into the hospital, I’m there. When J and J [daughter and son-in-law] can’t be there, I’m there. When things are really hard, I’m there and so there’s a part of my nature that that’s part of the job, is to do that. But also because I’m such a battler I don’t actually have another mode that I go into ... so I would say at the moment that I’m really just owning up to the point of realising that I’m actually depressed. And I think what that is just a depression of feelings. (SH)

**Seeing their grandchild suffer**

Some grandparents spoke of seeing their grandchild’s suffering as particularly hard to bear.

*He had a dreadful [time]. And I’ve been with a lot of people that have passed away so peacefully in their sleep. And in people’s arms, ours was dreadful. (H)*

*I think the worst thing is, when I think about her, is some of the bad days that she had, you know, and she was such a tiny little thing who had to go through all these procedures as they call them all the time, you know. (Jo)*

*My, my quarrel with God was not, not over death as such. It was over taking a child so early I suppose. And, and with so much extended pain. (M)*

This participant however was relieved that his grandchild’s death was very peaceful.

*The actual point of death was very peaceful, extremely peaceful. And he, he just passed away in his father’s arms while they were watching his favourite Nemo DVD – that felt good. (M)*

**Cultural Influences**

Interesting conversation arose in both focus groups about the influence of culture on grief processes. The grandparents felt that their culture greatly
affected how they grieved. Most felt that Māori were far more accommodating to extended family and have better structures for grieving than Pākehā.

_I lost my grandchild, grandson a year ago and I find it hard for me to talk about it because we have a different way of looking at whānau death. (Ma)_

When questioned whether her culture (Māori) was making it difficult to grieve or just difficult to talk about in our company, her reply was:

_It’s not hard for us at all because we have a place for that, we have the marae. That’s where we talk about it. That’s where we grieve. (M)_

J reflected on this:

_It’s a better cultural support than we have because as we talk you are going to find out that we didn’t have any support. (J)_

C wished her daughter had decided to have a funeral for her stillborn baby boy, as that would have had the effect of allowing friends and family to be involved:

... _because if you’re not in the sort of culture, which a lot of us aren’t these days, which has sort of services which are the sort of part of your culture, you know, that you do, a lot of funeral services, you know, if you’re Māori and have tangis and various things like this, and it’s all expected of you isn’t it? ... In some cultures the parents wouldn’t have an option. It would just be an expectation that if you’re not strongly religious or something like that, you don’t have an expectation, you know what I mean? And so I thought afterwards, well perhaps that’s the purpose of funerals and things, is actually to allow people to all come together and recognise that. But I don’t know. (C)_

Jo agreed that the funeral was important:

_We had a funeral but I think, and my daughter-in-law, she just spent days organising it. I think it was quite good for her to keep, it was something that she could do for her baby. And it was great, you know? (Jo)_
The grandparents commented about how much money went into trying to save their grandchild, something they were ambivalent about as it also prolonged the suffering.

*It’s just amazing, amazing how much money is put into these children .... thousands of dollars to save one life. Incredible. I’m not sure what I even think about that. (J)*

*It’s something I feel grateful – and sad about ... the amount of effort, the money ... it kept L here suffering for longer. (H)*

**Relationships with the parents of the child**

The participants’ accounts indicated that dealing with a sick child and subsequently the death of a child can both strengthen and strain relationships:

*When I read your brief, the thing that struck me was not really my own grief so much as my relationship with my daughter. Which I will describe as like walking on eggshells. Because she had ... I was rehearsing this my wife last night. I said it was something like she had poured so much emotional energy into, into the boy that there just wasn’t any left. (M)*

However, looking back, M said:

*I think it’s [relationship with daughter] probably better than it was before it happened. (M)*

Indeed, relationships could get stronger.

*I’ve definitely got closer with my family and my son’s in-laws, I think, you know, we’re all very close now. . . .Well I think I’m probably closer with my son now. He’s quite a private person in a way but now I just, I just don’t care. I can say anything I like to him now because we’ve been through so much, you know, and I know he’ll tell me if he doesn’t want to go there or he doesn’t want to talk about it today or, you know, just mind your business or something (laughter), you know? Which is lovely. (Jo)*

However, the participants also felt that as grandparents they needed to be careful in their involvement
I'm filling in for her but only when she wants, only as she wants, and I have to really shut up for the rest. And I get that and I think that's what mothers and mother-in-laws have to do, I do get that you have to do that otherwise you'd create some massive schisms with your family and lose them. So I wasn't going to do that. (SH)

When relationships were strained already, the experience could be made more difficult:

We don't get on very well with our daughter-in-law. That's part of the problem. We have a serious relationship problem there. (J)

My son turns to me when there's a crisis. When he needs, when there's a crisis. And there were a lot of crises through that time. But my daughter-in-law can't talk to me. And she wanted to exclude me. (H)

It helped when the relationship was good.

She's, you know, she's a real gift to me and she's a wonderful daughter and I love her and I'm deeply grateful for her. And she, J's actually quite demanding. She's got a, has a natural, if she's with me, people will say, oh she has you around her finger. She does really. I don't mind. (SH)

**Layers of grief**

Grandparents' grief was often not only for themselves, but also for their adult children. This came out strongly in the focus groups.

Well it's really feeling for myself. I'm thinking, okay, I've lost R, she's lost R, how would it be if I lost my daughter? And so I've sort of, it's sort of like I kind of get into a double whammy... It's like there's two, there's two women below me if you like, I mean not below me but in my line, that's like J and R. And I suppose where I get to is feeling intense gratitude that I still have my daughter, and then I sort of like, I go into sort of like real, another level of grief thinking, okay, well I'm lucky, I
have my daughter. And then I think, oh my God, how would it be if I lost my daughter? So I kind of, like, drop into this sort of, like this exacerbation, I can't think of the right word, exasperation about pondering how that would be. (SH)

It’s nearly two years now (crying) and I still find it hard, you know, that he’s [son] had to cope with that. And yet they’ve done so well, you know, they put on such a brave face in front of everybody else but I’m sure behind closed doors that, you know, they have very bad days sometimes. . . .I think I’m not grieving so much for R now but it’s more for my son. You know, they’re doing their best, they’re trying so hard and all this sort of thing and yet you know it must be hard for them. (Jo)

There are really three arenas that grandparents get caught up in – one is for the person who’s going through it and what’s being done to them, we found that almost as bad as what what the prospect was for him. There’s you’re trying to be a support person to your children – and the third is your own self, things about your loss and what it might be. So you have these three areas that you have to face with your feelings and grief process … (J)

Care came in layers too.

And we were the ones that were really supporting L through his illness. And we were supporting my son and daughter-in-law – With meals. With going up to the hospital. With giving them time. Because it was a 24-hour job that they had. And so would relieve them a lot. We did a lot for them. (H)

The grandparents reflected on the idea that they had had a life, but their grandchild was denied one.

You know, when her and I were together, it’s just like, I just played music and dance and it just broke my heart wanting to do more. Because I don’t care about myself, I’ve had a life, you know what I mean? (SH)

You feel that the child has not had their turn – even as a Christian, you know, I think that was really hard to cope with. You know, why would God want to cut off a life at four? (M)

Another grandparent reflected on the loss of his grandchild’s future.
I think the hardest thing to cope with is what might’ve been. I don’t know how you find it. But that’s the worst trap for your own mind is to go down the path of thinking what might’ve been. . . .

It’s not only the person not having a life – you would have been a part of, observing that life some reflected pleasure in that life that to me is the negative side of the expectation that someone has a good an meaningful life – it would have given you some pleasure to see a grandson grow up ... achieve some education thing – that’s what you resent having lost out on. (J)

Other grandchildren
One grandparent found that having other grandchildren helped.

I don’t grieve in quite the way that you’re probably grieving now [directed at J and H]... I have 2 other grandsons by that child. I have 6 other grandchildren, or 5 others by other children. So I feel I’m particularly blessed. (M)

Others felt however that their involvement with the sick child distanced them from their other grandchild/ren.

We, we found, we felt that we didn’t have time to develop a relationship [with her well granddaughter] was probably more the accurate. We feel it now that we have got time to work with her. So we’re working on that. But during the process, we didn’t, we didn’t feel in the space, the right space to perhaps. We tried to be normal as much as we could with her and that sort of stuff. So ... it was affected, it did affect our relationship with her. But now it’s much more important to establish a better relationship with her. Because we can give her the time. (H)

The eldest is 9. Yes, sometimes I used to think if I show too much joy about seeing them, you know, that it might hurt J and J, you know? But you know, my daughter who’s the mother of these children, I mean she was very supportive of R and she came, she was living overseas, well she still is, and she came home several times just to help out and to be there and everything, so. I still think it must be hard for J and J sometimes to see, to see those children but at the same time, you know, they love them as well, so. And yes, it’s tricky sometimes. (Jo)
Lack of many other grandchildren could hurt too.

“Because one son, one grandson. We haven’t got a sort of a larger, larger family to dissipate some of those sort of emotions amongst.” (J)

**The effect on other relationships**

Going through the illness and death of a child, as experiencing any death, can affect all relationships.

*I tell you what my advice might be and that’s to the expectation that some people that perhaps you don’t know so well are going to be very useful and helpful. And other people you thought were your friends are going to disappear over the horizon. So expect change in your relationships outside your family as well as within your family. (J)*

Many grandparents spoke of feelings of isolation from others. This related to the size of the immediate family and lack of an extended family, lack of real understanding by others, geographical isolation and a sense of emotional loneliness:

*We only have one son. We don’t have an extended family. This is what I’m saying, you’re very isolated. Our experience was quite isolated. We don’t have an extended family that was able to relate to that was very empathetic. (J)*

*I mean people are lovely and they send you a card and things but I just felt that sometimes people didn’t quite get the enormity of it for me. But it’s a bit hard to comprehend sometimes anyway. (Jo)*

*I probably should say that I’m in a second marriage and so. And my first wife, the mother of my daughter is in [other city]. So really I was a unit of one this time, and my wife was obviously very supportive, my present wife. But she really wasn’t an invited part of it. (M)*
I do want I want to do ... It sounds awful doesn’t it, but yeah, I mean I'm lucky that I've got a lovely partner, he's very supportive and he's not someone that would ever talk about it a lot but I just know that I can to him if I want to. But after a while I decided he wasn’t very useful (laughter). Because people, they’re happy to be kind and sort of, what's the word, they let you get away with anything for a wee while but then they think, oh it’s time you got over it now and get on with it, you know? And yet you’re not and deep inside, you know, you still have days where you just want to cry (Jo)

Clashes in family belief/culture could also complicate things:

That with the two grandmothers involved, from two quite different families, I know every family is so different in what their expectations are and how they deal with things, and I felt occasionally that the other grandmother, who's ten years younger than me and into all sorts of spiritual stuff, you know, I can’t relate to it at all, and I used to feel sometimes that she thought I wasn’t trying hard enough or, I don’t know, just I wasn’t dealing with it the way she wanted me to in a way. Do you know what I mean? (Jo)

Waves of grief

People who are grieving often find that outside stimuli can bring sudden waves of grief from their inner most selves. The grandparents expressed how these come up for them.

We have some bad moments, we call them L moments, when memories come flooding back. And you get emotion that there’s no apparent trigger for it just comes upon you. You know you could be doing something or someone will say something or my little grandson with his parents or with his grandparents, those little moments get you. (J)

I can’t walk past a little boys clothing shop without a big gut wrench. Because I used to buy ... I used to buy really nice clothes for him, Pumpkin Patch and that sort of stuff. So that really gives your heart a tug. (H)
I was in a church somewhere in England I think. And there was some lines in the song that, and I suddenly found myself weeping for L. (M)

Meaning Making
Grief can be seen as “a struggle to reaffirm or reconstruct a world of meaning that has been challenged by the loss” (Neimeyer, 2002, as cited by Neimeyer et al, 2008, p270). There are various. Participants described the ways in which they found or made meaning of the loss of the grandchild. Influential in these processes were spiritual beliefs, general world views and decisions around remembering the deceased and making the death “count”.

Faith/spirituality
Some participants found that their faith was an important part of the grief process, while some found that it was challenged.

But for me I have a Christian faith and I found this very, a very rocky period for me. There didn’t seem to be any logic, any logic at all... And it was difficult for me to hold on to my faith but I did. (M)

No religion or spiritual path has the answers, so on one hand for a while it’s like, it seems like any real religious or spiritual foundations you have are really gone and I can see how that would be for just about everybody unless they really cling tight and you just have to re-question everything. So I’ve dismantled and questioned everything as I’ve gone through it, but at least I had something to question. (SH)

Some found it a comfort.

I was brought up in, in, in a very very strong faith, whatever religion was and we were brought up in was very powerful, we grew up in it... Of course [faith helped through the process of losing my grandson]. There’s gotta be somebody bigger than you ... And you definitely gotta believe it. If you don’t, don’t worry, don’t even think about it. ...Losing him or losing the hundreds out in the cemetery there, it’s all, it’s
how you look at it I guess. It’s how you look at life and death. How you look at your universe. How you look at your, around you. And connect. (Ma)

I research a lot and I’ve kind of always been a spiritual seeker which makes this whole, this whole kind of equation with R interesting, that you know, for the part of me that wants her back, like we all do, I think no, it’s actually every day that I’m here it’s one day closer to being wherever she is. And because I’ve always been interested in the afterlife, then I’m, and I realise she’s so pure, that I really do focus to quite a degree on purifying myself, whatever that means. That’s a tricky area. (SH)

It’s another dose of reality, perhaps. That these things happens. There’s no rhyme or reason, there’s no justice. All the things that make people with a faith, with a belief type faith as opposed to a question thing. I mean Christianity has got a lot of mechanisms to work around that that you can go on somewhere else and you’re perhaps going to meet up with them again. It contains a lot of those components that are comforting to people as a Christian faith. (J)

One grandfather felt he could not reconcile his faith with the loss, but that he could still hold to other aspects of his belief.

It was difficult to equate it with a God of love really. So it’s, I mean it was not only a death of a small child. But it was also, it was a horrible death in a sense. Although the actual point of death was very peaceful, extremely peaceful. And he, he just passed away in his father’s arms while they were watching his favourite Nemo DVD. ...And I ended up deciding that I couldn’t really reconcile it but that there were plenty of other features to my faith. (M)

A grandmother felt she had to hold on to her belief otherwise all would be lost.

Whereas before I would have hope for the planet, I would have hope for myself, I would have hope for children, I don’t really have that hope. I just think it’s a hit and miss and on one hand I’d like to think there is some kind of divine plan and this is where kind of my spiritual side comes in because I do think there is and part of it is that you cannot hang your hat and coat on the reality of everything you think and feel if you’re not into the part that is actually eternal. Which is a part that links me
with R because if I don’t actually believe that I am an eternal being then she’s not either and I’ll never see her again. And if I don’t actually think that that is true for this world and everyone in it then this is the sickest most f–ked up place that I can ever imagine. And if there was a hell, this is it. (SH)

For some it was about feeling the child’s short life had purpose:

I consider her to be, it’s so pure, you know, like she never got to the point of speaking. You could tell she didn’t have a bad thought, you know, she was so present so she’s quite inspirational in so many ways and quite a little angel. (SH)

It’s acceptance isn’t it really of what you know, you might’ve had him for a short time, but they were 4 fantastic years. We put a lot in to do things with him. And I was involved quite a bit with his care. (H)

… [I learned from other people] that you have to accept what came out of that life were inspirational and I talked at L’s funeral about legacy and the idea that you have had to live a long life to have to inspire a lot of people or … have had a lot of pleasure or done a lot of good for the world … is actually a human failing … if you can extend yourself to finding the marvellous things that happened for five months or something [speaking to Jo] you spoke of your son saying he wouldn’t have traded that for anything – how’s that for a life? (J)

They [the parents] had this gift for a time, and it was worth having. Even if it was for a time – I see that too. It’s a good way of looking at it. (M)

It’s a celebration. People said to us you should celebrate all the, every time we have a drink we clink our glasses and say here’s to L. Almost every, we don’t drink every day. Even if it’s soft drink, here’s to L. (J)

It’s a transition from the raw grief – to going thank goodness we had her for a short time anyway. (Jo)

…and there were lessons in the death.

One lesson, and it’s a spiritual lesson but it’s very strongly exemplified in the Christian faith but you’ve gotta understand the word, my understanding of the word and that’s forgiveness. Forgiveness isn’t saying that what somebody did was
all right. And I'm not going to kick you in the backside because you did it. It's letting go of your grudge, it's a letting go, I call forgiveness. And that's the big lesson for me in getting through something like that is not to hang on to what might've been. (J)

I think that was where my Christian faith probably, probably was more helpful to me inasmuch as I, you know I felt L had gone into eternity. (M)

Because I feel she was just so pure that if she did come in as a catalyst and a learning for all of us to kind of, like, wake up and be a bit more connected to what's real and what's important rather than all the trivialities of life and illusions, she's done a pretty good job on me. (SH)

Some found meaning in charitable work.

I always help the Child Cancer Foundation. I always collect on the street every year. (M)

We give to many charities – Canteen and all that. (H)

It's a bit too early for us though – I know some people start trusts when kids are in road accidents, something like that. But we haven't gone there yet – maybe in future. (J)

But that did not mean that the struggle was not a continuous one.

God made these bodies for a span – not 18 months ... it kind of seems like a waste of the delicate organism that the body is that hasn't been allowed to reach fruition – I kind of resent that ... (M)

What matters
Participants spoke about the way in which with grief, one's whole world was shattered, and it was necessary to relearn what truly matters, developing greater compassion for those who are suffering, realising the unpredictability of life and the importance of coping, and the realisation of how many people suffer losses and the preciousness of life.

What matters is the people that I love and who love me and that's about it. And of course I'm, I'm deeply compassionate for all others who have that interaction with
the people that they love and I’m very compassionate about people who are suffering because I feel as if I really, I can relate to that. (SH)

Well I suppose you realise that there’s a lot of sadness that a lot of people have to put up with and it’s sort of your turn really. Yes, but it just seems so unfair too, you know, what on earth did they do to deserve it? Just a young, happy little couple and they had to go through all that trauma and just, I suppose it makes you realise you’ve just got to cope with whatever life throws up at you and you don’t know what’s going to happen. (Jo)

I think it’s just one of those things, you know, sometimes when you’re talking to people you find out that they’ve lost children and those sorts of thing and it’s a lifetime thing I think, isn’t it? You know, I don’t think people get over it. And yes, I think that it’s just something that’s part of life really. Makes you realise how precious life is, too, when you lose something like that. (Jo)

**Finding resilience**

Continuing to do things they loved helped.

I turn back to gardening, which I always love gardening, right. Vegetables and all those things … I do it for the connection with mother earth … (Ma)

Well I try to do something positive and something enjoyable, something that I like doing. I might think about L at times and go and do something enjoyable. (H)

Knowing others who were going through the same experience – the sense of community and social support associated with a shared experience – was also helpful.

What helps … is just some of the parents in the ward you just because you’re all, in that ward, in that oncology ward everybody is equal. It doesn’t matter how much money you’re social background or how poor you are, they’re all equal they’re all facing. And it’s a very great leveller. And those people are much more supportive. (J)

**Beliefs around the role of grandparents**
However, the meaning making around the nature of the role a grandparent should take and how limited their involvement should be, and reconciling that with how much they cared, was difficult for the grandparents. SH’s “double-whammy” metaphor expressed the complexity of a grandmother’s role:

I don’t know entirely what the set-up is but I think it’s an expectation that your mother should be able to deal with it and that a grandmother is just a token kind of heart, you know, take her and she’ll make some cookies and she’ll play that, but that’s her, she has a role, there’s a role to play. But more than that she is a, she’s a mother herself plus she’s a grandmother and that makes, like, a double-whammy on the mothering kind of end of things, and as a double-whammy mother she probably needs double-whammy attention. (SH)

When I’m needed I’m here. (Ma)

**Disempowerment**

Many of the participants felt disempowered and isolated through their experience of loss. SH, for example, felt frustrated because she didn’t agree with her daughter’s choices.

And, you know, a part of it is I felt, I felt a level of frustration at the time because I wasn’t the mother and so some of the decisions I, I just kind of traumatised over at the time and felt that some of the decisions were wrong. And yet, you know, obviously it’s not my thing so, so I think as a parent you can also be sort of like indulgent in some way that you kind of have the right, well you do, it’s your right, but you’re sort of like indulgent with those rights. (SH)

Another felt excluded.

No, I don’t think that was even discussed or even thought of [needs of grandparents]. And I think even in, you know, in our daughter’s case, I think they still think it’s their, part of their problem. It’s not anyone else’s, it’s unique to them and it’s their sort of experience to cope with and they sort of feel that even with the new baby coming on, I think they still feel that, they’re surprised that other people
might want to be involved because they sort of feel, well, it’s their child and it’s their experience and it’s their responsibility sort of thing, which is interesting. (C)

A third participant had difficulty showing her emotions around her son, leaving her feeling uncertain about how to “be” with him and her daughter-in-law and “different” because she was still expressive about her distress.

In the earlier months afterwards I, you know, I mean I wanted to talk about R but sometimes I think, and then I’d end up crying and I’d think, well is that any help or not, you know? I didn’t know. But in the end I thought well, you know, that’s how I feel and so it’ll be up to them if they don’t want to talk about it with me, because it upsets them that I’m still crying all the time about it. But in other ways I used to think, well at least they know that I care, you know, and that might help them, you know, knowing that other people are sad just like they are. There has to be a fine line I suppose, doesn’t there. (Jo)

As a grandmother, SH described feeling lost and powerless.

I feel quite lost. I really feel lost and I really feel that if it wasn’t for my children I just wouldn’t want to be here, ie that I wouldn’t want to inflict more hardship in my daughter and that she needs me to be around. And if she has other children I know that the rational part of me would say that, okay, I’ll pick up and we’ll do it all again. But if J wasn’t around, I wouldn’t want to be around. (SH)

She explained what she meant in terms of not knowing how to help and how to be.Lost and powerless and not wanting to be powerful because that’s kind of historically me, you know, I can do anything. You know, I’m strong, you know, if other people are struggling I can pick up the slack, what do you want? You know, so I’m kind of like a bit of a can-do kind of personality so when I then face ‘can’t do’, well then it cancels it out so I just don’t know how to be. (SH)

The hospital system: Their experiences with the hospital system was part of what made many of the grandparents feel isolated and disempowered.

At the beginning we were and we wanted somebody to say this is what you should be doing for him. I mean you know you love them and you just want to care for them and shelter them from what’s happening. But it would’ve been nice for
somebody in the hospital situation which we were in at the beginning to have acknowledged us as the grandparents. We were very much a part of that family. And we were very much on our own. (H)

And I just felt no one took us aside and said he’s a little family unit, there was my son, daughter in law, we as grandparents. My brother who was very close to Lance too. They never took us aside and said how can we help? How are you guys going? … You wanted somebody to, to help you. (J)

Staff ignored them.

We would be in the room the nurses would come and go and do things, and they wouldn’t even acknowledge us. (J and H)

The nursing staff wouldn’t really acknowledge us, no. (Jo)

One had a different experience, which he appreciated.

Generally there was one nurse assigned to our case. So she got to know me and I got to know her. She was always very very welcoming. And always passed the time of day. (M)

However, he did think grandparents should be more included.

I mean I don’t think there is a culture in the hospitals at the moment to include the grandparents, particularly. And I contrast that with [Name] Primary School, I don’t know if it’s typical of schools. But in the [Name] Primary School every year, once or twice, there was a grandparent event. Either a school wide event or it was a classroom based event. And so we were invited one morning to C’s classroom and we saw their work and I was allowed a half an hour with him to read stories with him, and various things like that. And there was obviously a culture in that school to honour grandparents, or honour the relationship that grandparents have. And whether it could be introduced through the Child Cancer Foundation. I don’t remember that Foundation ever making any overtures to me. (M)

One grandparent thought it was good to not know the whole story.

And they were told that he was high risk … But they didn’t tell, my daughter didn’t tell me, which was probably a good thing. I’m quite glad she didn’t really. So I
always held up some hope. And the hospital never gave up hope. And they threw every, every ounce of knowledge and technology at L. (M)

Most the grandparents, however, felt they should have had more access to information.

_I think they were quite helpful with J but not me, no. In some ways I felt that they, you know, didn’t want to say anything because there was, you know, all the secrecy, the Privacy Act or something, you know. They didn’t think that we were the ones, you know, I or the other grandmother who was always there too, you know, that we weren’t allowed to know these things._ (Jo)

_One regret I do have though that I didn’t know, or I wasn’t told but maybe I should’ve been able to say that I had no experience of people dying and I didn’t know that she was going to die so soon. You know, and I got a heck of a shock and I wished I’d sort of said goodbye more completely, you know? (J)_

_But what we were really wanting all the time was how is, what are they doing now. What are they going to do? We didn’t get that first hand. It would have been good if we had been told even something literature-wise. Because you’re grasping at books from the library or anything. Just a little list of somewhere to go, who to talk to if you’ve got a problem._ (H)

_One grandmother agreed, but tried to understand._

_I think that is part of that privacy thing isn’t it, because we were questioned when we got the nurse to come in and talk to P and S about the baby going to Wellington for the autopsy and they questioned where it would be, and we just happened to be there at that time. And, you know, S and Pl said they were happy for us to stay so that was alright, but yeah, I guess it’s part of that isn’t it? (C)_

_Another grandparent felt the involvement with the hospital system was quite traumatising._

_I don’t like the way she died, I don’t like the fact that the hospital just stopped everything and they stopped giving her potassium, so you have a bitter, when they micro-manage care every degree her temperature goes up and every breath, while_
she's in the system they are all over. A drug for up, a drug for down, a drug for sideways, tests, everything. But when they decide that's it, that's it. They do nothing. Then it's that palliative care, they bring in that team, the team know, they've been called in when someone's going to die, and that's it. They don't have anything else to offer and it's a whole thought form. (SH)

One grandfather felt the hospital was trying to replace grandparents. Although he referred to them as “wiping out the grandparents, he also had high praise for a volunteer “grandma.”

And they kind of, they kind of wipe out the grandparents inasmuch as they will supply grandparents, a lady who comes in, a volunteer who comes in and reads to the children. And I think they’re encouraged to call her Grandma. And they’re very very helpful. Absolutely marvellous. (M)

One set of grandparents found the palliative care nurses included them more.

It really wasn’t until the palliative nurses were introduced to us with a social worker, and we asked our son could we talk to them about what, where we were going, or what sort of journey we could expect to go on. And they came into our house and talked to us... It was big for me because suddenly someone was telling us that they were there and if we had any questions they would do their best to answer them. (H)

One grandfather, who lost his grandson about seven years ago, remembered grandparents being included in the hospital during the follow-up meeting. None of the grandparents with more recent experiences had any memory of anything like this.

There was in fact a grandparents day that I do believe I went to during the course of L’s illness – we were given a tour around the hospital and I think had a light lunch, if I remember correctly. It was good. (M)

While the grandparents appreciated the hospital giving “beads of courage” to the child/child’s family, one felt left out in this too. There was no tangible
acknowledgment of their courage and resilience through their own painful journey.

As grandparents you don’t have those things [beads] ... those physical things. (H)

But photos helped.

We all value the photos – they seem to be a critical link. (M)

I’m still putting photos in frames, putting them in different rooms. (Jo)

Yes, photos are important. (H)

Unique Experiences
Unique circumstances influenced some participants’ experiences of the illness and death of their grandchild, and their associated with grief.

Professional background

Her professional background as a nurse made it particularly difficult for one of the grandparents, who was torn between holding onto hope as a grandparent, and her “insider” knowledge as a nurse of the realities of her grandson’s condition.

The nurse in me knew what the diagnosis was and we knew the outcome was not, as a nurse I knew the outcome was not good one. He had stage 4 cancer. ... High risk. And there was a little bit that we could grasp at hope, 50/50 they said. But you grasp a little bit of hope that he might be okay but the grandmother in me said, oh we will fight this. We will do anything we can. ... 

The nurse said why are you doing it? Don’t put us through this, please don’t put us through this. But the grandmother just does everything you can. (H)

Timing of the death
Concurrent loss: Another grandmother lost her father on the same day that her granddaughter died.

The same day R died, my father died as well and I had to race down to Waikato hospital and he died about ten minutes later and I’d been at the hospital all night with R and got home and my partner said ‘we have to get going, your dad’s in hospital’. So we zoomed down and yeah, and so dad died about quarter to twelve and R died about three o clock. (Jo)

Later she explained the way in which the timing of these deaths made it difficult to grieve adequately for each loved one she had lost.

But I did feel guilty though, because I felt I couldn’t grieve for my dad the way I would’ve wanted to and then I couldn’t grieve for R the way I would’ve wanted to if they both had sort of happened separately. You know, I mean I had to have two funerals and two speeches and, you know, we all got up and spoke and, which was good. I mean I’m glad I did it but it was quite hard, you know, it was quite draining. (Jo)

Effect of traumatic concurrent event: For one grandparent, the Christchurch earthquake was a complicating factor – as it happened on the day of the earthquake. She particularly felt for the other grandparents who didn’t get to see their grandson.

I think P, my daughter’s husband, I think his family felt very strongly that they hadn’t been included but the baby, we only just got into the hospital because a lot of the, the roads were closed in Christchurch at that particular time and we had a window of about 20 minutes we could go in and see him and get out. And they lived on the other side of town and they just didn’t have that opportunity. It’s probably all tied up with the circumstances at the time as much as anything else, yes. (C)

Accident of timing: One grandfather was traumatised by the fact that he had taken the sick child’s brother out on the day of the death – and had brought him home 20 minutes late, so he wasn’t there to say goodbye to his brother. His daughter and son-in-law were furious.
Well when we got to [the house] we, we were greeted by S and R holding the dead child. And he’d died like 10 minutes earlier and if we’d been right on time, B would’ve been there at the time L passed away. I don’t think this was too critical for B but it, it, it absolutely destroyed the parents for that moment. And of course they screamed at me for being late. And, and S shouted out, go, just go, get out. Just go. So it was quite a shocking way for them and for me. There was no perfect right in all of this. Although R… saw the difficulty and she came over to me and put her arm around me and said yeah we know you meant it all for the best. And I stayed a few minutes longer - So that’s what you might call a scar that has had to heal, one of the scars that has had to heal. But an hour earlier I couldn’t have anticipated that it’s still there … (M)

**Disagreement with treatment**

Another grandparent believes strongly that it was an inoculation that caused her grandchild’s cancer and felt extremely angry about this.

*I really feel as if it was the immunisation. Twenty minutes after she was having convulsions and, and I was there when J immunised … And that needle hit the bone. She, she went purple. (SH)*

She expressed her anger and frustration with ACC and the medical system.

*ACC gave her a carte blanche for any follow-up care she needed from that misadventure, they called it. So I wanted to scream, I wanted to be able to bash somebody and say 'You want to know how ill she is? You want to know what the follow-up is? One ward isn’t talking to the other, go and see her, she’s got leukaemia and she’s in ward 27, idiots. That’s how she is’. But nobody puts two and two together when they don’t want to. They seriously don’t want to do that. (SH)*

This left her feeling powerless.
Part of me's incredibly frustrated with the system and society and I know that other kids are arriving up in that ward every week and I don’t, I don’t know what to do about that. I don’t know if I can do anything about that, I don’t know if I want to do anything about that because it feels such a waste of time, such a complete waste of time.... It's just unbelievably frustrating, and disempowering is huge. Like I, yeah, I just hit the wall. I'm virtually banging the wall, I'm so frustrated. (SH)

Significance of anniversaries

Anniversaries are a particularly poignant time for grievers, as the participants in this study indicated, and they expressed a need to be included, although this was not always the case.

I don’t get invited to share those days. But I always send a card. They normally do something pleasant on the anniversaries of his death. And they may well release balloons something like that. Some sort of, I guess it’s kind of an act of reconnection of something like that. (M)

This participant described his own way of remembering however.

Well one thing we do do and I'm included in this so there's a kind of way of remembering is to L loved sunflowers. And he was interested in gardening and the last, the last winter he was home I think he helped his mother plant some flowers for the next summer. So they were coming into flower when he died, so R in whatever sense has harvested the seed of the sunflower and dried it out and then replanted it each year and also given, given me a supply of sunflower seeds. So I’ve been planting it in [suburb] and I took some to [country] 3 or 4 years ago and planted it in [region] when I have a small flat. (M)

Flowers were also significant for another participant and her family as a way of remembering.

Sometimes I think, oh she (daughter) might've got over it now, but she hasn’t. It’s like, it’s R’s birthday next week, she would've been three. It’s so funny, her birthday’s Anzac day, poppy day, so it’s like everybody wears a little rose, you know, a little rosette and it’s a day off for everybody commemorating those that we’ve lost. (SH)
Other participants described talking and consciously remembering on birthdays and at family gatherings.

*I suppose I’ve just tried to make an effort to get her (daughter) to talk about things as much as possible. I always mention him and we always sort of mark his birthday and those sorts of things. So it’s just not forgetting him really, I think, is what I’ve tried to do.* (C)

*In every family gathering we have, we will be thinking (crying) R should have been there.* (Jo)

However, some grandparents said they marked the anniversaries more for their children than themselves.

*I remember her all the time – I don’t need the anniversary, I do mark it for my son.* (Jo)

*It’s about holding their hand at that time – as the loss is more severe for them, I believe. We’re slightly at arm’s length – yet you don’t you don’t feel at arm’s length do you?* (M)

Rituals were important for both of these participants.

*Our family let up balloons on the anniversary – it’s quite beautiful.* (M)

*I got sunflowers at a Child Cancer family day that we were all invited to – I think I’ll be planting them every year in honour of R.* (Jo)

**Support for grandparents**

When asked what help and support they experienced, the grandparents showed appreciation of events and activities that they were included in. However they were not included in many.

**A helpful event for grandparents**

*You know when you were saying what, what help there is for grandparents, is it the Child Cancer or is it Bereaved Parents? They had a rally in the domain and the*
grandparents were all invited to that sort of thing and that was really good, and we went and we let go balloons, you know, for each child and then we were given these sunflower seeds and we all went home and planted them and you had this competition about who had the tallest sunflower. And we saved the seed from those ones and we'll plant them again next year but, you know, it's sort of a nice thing to be included in. (Jo)

Help needed
Help was provided readily to the children's parents, but not for the children's grandparents.

They [the parents] had counselling in the hospital all the way through. I didn’t think much of the counsellor because she wouldn’t even give you eye contact sometimes, but she would come in and get one of them to go away and talk. But she would never come over and say gosh, how are you guys doing? (J)

If I was in a ward where a child is, I would try as a charge nurse, bring the family together, just to have even one meeting and see the dynamics of the family. And perhaps the, bringing somebody in that could see the dynamics of the family and see where the help was needed. ... as grandparents, we, there was a place for us too. And if somebody just could've seen that we were on the fringe it would've been good. (H)

The parents’, parents’ counselling, whoever’s running that, needs to be told that those parents, mothers and fathers, need to tell, need to be told that their grandparents need counselling ... they need to help us get to counselling. So it needs to be within the fabric of the existing counselling system, that this should be so. Because there’s three that I know directly: myself, Jo and A’s grandmother. They’re the only ones that, yeah, that, they’re the ones that I know of and they need, I know they would benefit from some help. (SH)

Accessing professional help
Three of the seven grandparents who took part in the project accessed professional help only after realising they weren’t coping. At least one of these who didn’t think to get help because he believed in self-help, described feeling depressed and developing anxiety attacks.

_Trough the Christmas period, because I thought I’m doing okay here, I wasn’t dysfunctional or anything. I got into serious trouble with anxiety attacks out of nowhere. I’ve never had the problem, I’ve been a bit nervy I suppose, but never had a problem with anxiety attacks. To the point where I became fairly dysfunctional. Sleeping was a big problem. It got down to less than an hour a night sometimes. Eventually got some help, by way of medication and things. And that sort of got me through that period of anxiety ... I’ve always been a self-help person. So after I had my anxiety attacks I decided I needed some help which was a pretty big call for me. I went and saw a clinical psychologist. (J)_

_I became very angry, angry that we got put through what we did. And I went and spoke to a grief counsellor and he was very good ... He put it in perspective. He was a doctor and he could see where I was coming from as a nurse. That we didn’t need to get put through that, those trials. But he explained how to celebrate, everything you said you’ve done. How to celebrate the life that we had with [grandson]. And, and so that really was a turning point for me. I think it got rid of a lot of the anger. But he explained it from a medical point of view, that we do seem to be prolonging life. And that’s quite unethical. (H)_

_I did do some counselling though, that was good. My workplace arranged it. (Jo)_

_We just kind of expect it’s because we’re older and not sort of directly affected, just to cope. You know, it’s just like, that’s how I feel that I’ve been, I just needed to cope and that with it at the time and afterwards. And I think I’m only now beginning to see that that’s not quite true... So I would say at the moment that I’m really just owning up to the point of realising that I’m actually depressed. And I think what that is, is just a depression of feelings. (SH)_

This grandmother did not go for help for herself, but made sure her daughter got it.
I didn’t think [to get counselling help], I just didn’t even think about it. It’s really bizarre now because it just seemed so critical that they [the parents] did, you know what I mean? It was critical and so I was, it’s a little bit of, you know, the way that I am. And my to-do list is more what others should do. They’d probably love that if they heard it, oh yeah (laughter). They’d say, ‘great admission mum’, you know? (SH)

The following grandmother admitted that sometimes grandparents expect too much of themselves emotionally.

Yes, well sometimes you tell yourself, you know, buck up and get over it seems to be the sort of common phrase isn’t it? You’ve had enough of tears in the family but I’ve got a friend who’s my age and lost a baby in similar circumstances, you know, when she was young and she said she can still be in the shower and something will happen and she’ll just burst into tears. And it goes away and it’s just remembering something. So I just think we expect a bit too much of ourselves sometimes. You know, we want to be a bit too stoic. (C)

Supporting the family: Advice to others

Interestingly however, the grandparents’ advice to other grandparents seemed sometimes to be more about the family than themselves, and disempowering in itself. It was about making allowances for others’ behaviour and not engaging in conflict but being supportive.

Oh just try and love and support your family. I think the advice is to be there. (H)

When we were trying too hard we would back off and just say to A, we’re here if you need us and stop. And we had that several times during the course of things. (J)

I have one strong recommendation – with this walking on eggshells with my daughter … it was very hard to do the right thing, it was very hard to say the right things, so it was best to talk only when spoken too – she had a short fuse, she had a long fuse for the child – but for anyone else she snapped … My advice is don’t fight back – be a punching bag if that’s what they need. I had to be incredibly forgiving.
Be forgiving. Make incredible allowances. ... Not be judgemental no. Not to suggest remedies. (M)

The kind of situation, a baby with cancer, you have to, you can’t zone out. You know, you’ve actually got to show up and be present and that means present with what is, like R at a certain point didn’t want me to go and she got peeved slightly if she sort of, like this. I think it would be get your priorities right because in that situation priorities change. You can’t keep it together so you’ve got to adjust your priorities. And if that means that you drop everything, drop everything. Do it. Don’t regret. (SH)

However, when pushed they did talk about how they would suggest grandparents look after themselves.

I think we have to look after ourselves I guess, in that if you feel like we need counselling or, you know, we should do it. Because I don’t think our sons and daughters are in a position to help us, really, and why should they be? You know, I mean – ..... But I was lucky where I was working, I’ve worked there for quite a few years and they paid for the counselling. (Jo)

Talking, is important, yeah, and make sure they know that the person, the baby or the child they’ve lost, is still valued and precious and revered or, you know, all those words. That they’re [grandparents] never stuck on their own, you know, I think that’s very important. (Jo)

You have to do what you think you can do – without wearing yourselves out. Two years before I was dealing with breast cancer, chemotherapy and all that. I was just grateful that I was at a point where I could do what I could do. (Jo)

You need some out – you need something for you too ... (H)

My advice would be on how to deal with advice from other people – you don’t know what you’ll do or react – you will get through it even if there’s a time when you don’t think you will. Try exercise the idea of taking things one at a time – looking forward at the time. You also need a release in order to survive. You have to find
some level where you can sustain your own contribution. How to remain useful to the people who are actually going through it. You need to look after it yourself. (J)

One grandparent suggested a campaign to outline the importance of extended family.

Maybe we could have some television adverts about families and, you know, the extent of, well the broader family is important in those sort of circumstances or somebody dies. So it’s more an accepted thing, that all the family’s included. That all the family matters. …And maybe that’s just part of it, is recognising that, yeah, the wider family is important. But I don’t know about, yeah, and maybe yes, for counselling services to be available. I didn’t even know there were counselling services available for grandparents, are there? (C)

This participant also recommended the value of group support.

And I’m thinking one thing that would actually be very useful is groups, you know, like there are parents groups so that people can actually talk to each other and share their experiences. (C)

But other comments on a possible grandparents’ group expressed doubts:

I don’t know whether I’d do that ... (H)

It would have to be very informal, would it ... (Jo)

There is a gap out there, but maybe it’s about contacting people through that. Find the gaps and maybe existing organisations deal with them. (J)

Child Cancer does have some things that they include grandparents in, some days that are open to grandparents. Getting the information out is most important. Grandparents need to be seen as an entity – maybe get their personal magazine from Child Cancer. (M)

It would be good for grandparents to go to [groups] if they choose. I don’t know if a lot of people would take it up. (H)

**Effects of participation in research**

All the grandparents expressed appreciation for being in the study and said that talking with others in the same situation was helpful: it gave them permission to really process things and was a source of comfort.
I got a tremendous amount out of our meeting - especially ‘permission’
to feel as deeply in grief and mourning and healing as parents do. (SH)

I mean you can see it upsets me a little bit still, but I’m, it’s good. I mean I, I don’t
care about that. I think if it’s there it’s got to come out. I don’t know whether I’ve
been much use really, but ... Yeah, I think it’s useful for, getting people to talk about
these things. I think that’s the useful part of it. Something positive, yeah. (Jo)

It’s been really good being able to talk about these things – and to feel that our
doing it may help others. It’s been very helpful – because when I look at you
[addressing M], I can see that time does heal. (H)

It’s been very helpful – any session where there’s an exchange ... it’s helpful. (J)

I’ve never met anybody who’s lost a grandchild before – it’s been really a revelation,
and a comfort to know there are other people who have gone down the same road.
(M)

A sense of their participation as an act of “giving back” to benefit others was
expressed by the bereaved couple who took part.

We thought a research project was giving back. That’s what motivated us – to
contribute, rather than something we were doing for us. In helping others though
you help yourself too. (J and H)
CHAPTER 5

RESULTS:
The grief-related experiences of grandparents when a child is severely disabled or terminally ill

All four grandparents—three grandmothers and one grandfather—who took part in this focus group were highly involved in helping the family of the severely disabled child. The grandparents ranged in age from 68 to 80 years, while the ages of the grandchildren ranged from 20 months to 29 years old. All the grandchildren were both physically and mentally disabled. Their ages and ethnicities and their grandchildren’s ages and disabilities are listed below.

Grandparents and their grandchildren

H: (68 year old American Pākehā female) whose 6-year-old granddaughter is severely autistic.
T: (67 year old NZ European male) whose 10-year-old granddaughter has anoxic eucephylopathy and severe cerebral palsy.
M: (68 year old NZ European female) whose 20-month-old granddaughter has very little brain function and prenatal brain stem damage.
E: (80 year old South African female) whose 29-year-old granddaughter has Down’s syndrome.

Involvement with grandchildren

All the grandparents spoke of being involved in the care of their grandchildren—some by being available 24/7—and all said they found joy in their involvement.

I got into the habit of having the mobile phone by my bed every night, and I still do. I think for me, I feel like I’m on call any time. So if I’m doing something and my daughter needs me to fetch K from somewhere or take her or do something, I’ll drop everything and go and do it. I feel that she [daughter] really needs some respite because it’s 24 hourly constant worry over a long time. I mean it’s over 20 years she’s been on call 24 hours a day. So I’m very happy to do anything she wants.
at any time, you know. That’s the only way that I think it would affect me at this point anyhow. (E)

I’m exactly the same, exactly the same. I almost feel honoured when they ring and say could you come and look after E tonight. I don’t work on a Friday, so can you come round on Friday and do this or do that. I feel honoured that they ask me, they let her be in my care for a start. (M)

At the time we were living in Auckland and we decided to move down to Hamilton to be near them, to support them. (T)

H’s house is set up for the disabled grandchild:

In our house we still have the infant gates that were put up. It’s good for R to have those gates up otherwise she might walk out. It makes people be able to relax more. She’ll stay up in the second story, which is the living area of my house, because we have those infant gates. (H)

She also said she had slowed down at work so she could give her disabled grandchild time.

In some ways I really like this role, which I actually didn’t have time for. One reason I knew I would cut down to about a third of my work was wanting to have more time for R … to be available … (H)

The grandparents spoke of a special connection with their disabled grandchild.

She has brought so much joy, I absolutely adore her, absolutely adore her. And I can’t go past, you know, I work but I can’t go past too many days without I have to go around and have my cuddle and have my chat to her and tell her about everything. She has brought joy. (M)

It was evident that this participant holds her strong love for, and sense of connection with, her grandchild—a connection that is expressed in the grandchild’s recognition of her voice—alongside her knowledge of her lack of brain function.
She has no brain function, she can’t do anything for herself. She doesn’t even know she can lift her hand to her mouth, there’s nothing she can do. Her hearing’s very sharp. She’ll recognise my voice as soon as I walk in the door because she’ll freeze when she hears my voice. (M)

For another participant, her grandchild’s mention of a book character and bagels expressed their connection.

She says things like purple cat, just like that, and then you realise she has this book and it has a purple cat in it. To me, this is wonderful because we’re all Jewish, and she says bagel to me. How does she know that I’m the one that would give her a bagel? It’s because I do. . . . R for some reason really likes me. I think because I can be quite crazy, you know, and dance and sing . . . (H)

Similarly, T described the grandchild’s recognition of him as signifying their relationship, yet a relationship that was different from that which he experienced with her sister.

She knows when I’m there so if I wave and smile she knows it’s me and we have cuddles, and have done so since she was a baby. So there is a relationship of kinds but it’s a very different kind to her later younger sister. (T)

Layers

“Layers,” a term used by H, aptly reflected the multi-generational levels of concern as well as caring that were occurring within their families.

Participants’ concern for their own children

All the grandparents showed great concern for their struggles of their children with having to care for a severely disabled child—some seeing it as a life sentence.

I was concerned enormously about my daughter to start with rather than the child, because I thought, how is she going to cope with this. She’s got two boys and here comes a third daughter that she’s waiting for, and this. But she took it very well,
and her husband took it very badly. I heard her saying to him why not just relax. If anything had happened to a normal child after it was born and it became disabled you’d handle it, so handle it from the start. So I thought oh, she’s okay, she’s going to handle this. (E)

At times I’ve seen it as a life sentence for my son, his wife and their family. It is, it’s changed their life, and so I still struggle at that. (T)

My heart breaks more for my son and daughter-in-law than perhaps for my granddaughter, because it’s their life that’s shattered more than E’s. E doesn’t know any different, so her life is her life. But you know, as we said before, it’s a life sentence on my son and daughter-in-law and that’s where my heart would break more. (M)

It also makes my daughter, who I worry about most, the centre of all the caring. Within the last two months she’s had to have a partial mastectomy and she jokes about it and things. It wasn’t exactly cancerous but she’s had terrible mammograms for a long time, so they did this for a preventative thing. But the stress that she carries, and the fact that she couldn’t lift for six weeks and couldn’t drive kind of made it, like the centrality of her caring is so obvious. (H)

She later talked of her surprise at her own resourcefulness in order to be there for her daughter as a nurturing parent while the daughter was the primary caregiver for the grandchild.

My inability to do anything but be supportive, you know, it often would have been very stymieing to me. At least til now I haven’t found that a problem. At one point I really would have thought I wouldn’t hang in there, but of course you do. It’s surprising what you can pull out, and in the first instance it’s for your children, for your child. And this is the parent nurturing thing, so you’re there for the child. The end result is your grandchild, but it goes down through the layers. (H)

All the grandparents saw their role as one of support, not challenge, and chose not to openly disagree with their children on the care for the grandchild.
I feel my job, even when I disagree with my daughter is to support her. I would be very reluctant to tell her I disagree, and all along it just felt like she needed a child who she thought was very bright to counteract this child. She didn’t know where that kid was going, and I feel sorry for him in that way. (H)

The following exchange took place among participants:

Maybe if you don’t agree with what your kids are doing. There must be certain things where you would disagree. We don’t have any discussion about whether autism’s caused by inoculation or whatever. (H)

What’s the point? (E)

No, it isn’t helpful. (M)

It’s about supporting them, not criticising them. No, I wouldn’t say anything if I disagreed with anything – it’s hard enough for them. (T)

The **other children**: Concern for the well-being of siblings

These grandparents also showed great concern for the siblings of the disabled child and acknowledged that their childhoods were being affected by the attention that needed to be given to the disabled child.

So for instance, J [older grandson] now comes over for a weekend and we watch movies together and do things like that. And you know, he has no experience of getting things for himself from the refrigerator because that’s off bounds [because of the disabled child] and things. So it infantilises him in some ways. (H)

She noted further:

All the attention is on R because she’s so active and as we know dreadful things can happen to autistic children. They have no fear. The other children, you don’t want them growing up resenting the twin because they didn’t get the attention, because this one required all the attention. That’s a hard, hard situation, family wise. (H)

Inevitably the disabled sibling’s needs take priority:
I’ve observed with their second child, who has grown up, and she’s now eight, knowing that M’s needs always come first. They have to, it’s not their choice, but she lives with that. They’ve worked hard to help her not feel second in importance, but she knows. Certain things happen and M demands attention and that’s it. (T)

E, however, felt that in some ways the disabled child’s siblings had benefited from having a disabled sister.

I remember when my grandson was 14, him saying to me: I feel it’s great that we have K because I didn’t know how to respond to people with disabilities like this, but since we’ve had her, I’ve understood more about it. But he said it’s a great shame that we had to have her and she had to have her life for me to understand it. And I thought Wow, he’s 14! So, it’s not only us, it’s the rest of the family who have also gained what we’ve gained. (E)

This boy is now a professional adult who donates some of his free time to the Down’s Syndrome society in Australia, where he lives

H was particularly concerned for the disabled child’s twin:

I had a lot of worries about the other twin, the normal twin, as it just felt as if she was left out a lot, but things have worked out. Everyone has worked on that. We all went to work of getting S integrated. She’s a real little person now ... (H)

H was also concerned undue pressure was being put on her grandson to “make up” for the disabled child.

I think the sad thing is, my daughter put a lot of pressure on my eldest grandson, her oldest son, to be a genius. I feel that that’s been very tough on him. She really wanted him to be gifted in a way that I felt, I still feel, like he got skipped at school, he’s really immature in his class. There was a kind of need for her to have a gifted child. I mean, this sounds mean, but it’s true, he isn’t a gifted child but she was able to convince everyone he was. (H)

The attitudes of Others

A further relational dimension was the wider layer of social relationships beyond the family: friends and acquaintances as well as strangers who reflected attitudes in the wider community. The grandparents were frustrated by the
prejudice and ignorance in the community as regards disability, and the hurt that this caused their children and families was deeply hurtful to them too.

One of my daughter’s friends phoned and said oh, I hear she’s had a baby and I bought her a little dress. But now I hear she’s Downs Syndrome, what should I do? I said what do you mean what should you do, give her the little dress, she’ll love it. Oh, she said, fine. And I think that woke me up to the fact that there are other people outside of the family who also don’t know how to respond. (E)

There’s S [daughter-in-law] sitting up in bed after having had this baby and nobody came near her because nobody knew what to do. And that was, you know, other mothers were there getting flowers and all the things, and nothing for her because people didn’t know. That was heart breaking, absolutely heart breaking. (M)

H noted that her daughter kept information from her siblings – but also felt it wasn’t her story to share if her daughter didn’t want things shared.

I know my daughter is in some place ashamed, because she doesn’t tell the others the fullness, even though they’re in email contact or whatever. Like, she could say more and I feel I’m really limited by what she’s prepared to say to people, it’s her story on some level. Well sometimes I say, you know, but I don’t really say much because it’s really her story. (H)

Strangers could be harsh and judgemental, which was hurtful. When H described negative reactions, another participant identified strongly:

If you take her to the museum café sometimes she just goes over and stares at people or something. So what’s so bad about it, but people don’t, they don’t want to be touched by her. They kind of recoil from her. You watch other people’s responses to her and it’s like get a life, you know. It’s because she just stands there and looks. (H)

We had exactly the same, well I had exactly the same experience I should say. A cousin who lives in Shanghai was over here for a while last year, and that was the time E still had a nasal gastric feeding tube, you know, taped across her face. ...
We were in a very classy restaurant in St Heliers, because that’s where my cousin wanted to go. ... The people at the table next door they literally looked down their noses at this baby with this tube, and the mother, as if to say how dare you bring that child here. I felt so tempted to go up to these people and say now what is actually your problem. They do because they don’t know and it’s ignorance that it comes on other people’s part. Judgmental, for what, you know. (M)

T agreed that other people’s reactions could be harsh:

That whole, other people’s reactions, they [the family] got very used to the gaze. People staring at them, and people subtly disapproving. (T)

H felt very protective of her disabled grandchild because of others being judgemental.

Disapproval, for a little kid. Hello, not touching anybody. They just look a little different, because they’re not following our sense of politeness, you know. That part of me gets me very involved with her, I would fight all of her battles. (H)

Even a close friend didn’t understand, and another story H told suggests that such experiences can entail a loss of closeness or friendship because of such revelations of their lack of understanding.

Well one thing is when R does something, like says my name Granny R, that was a really big thing. That was only about a month ago maybe, I actually had a name to her and I was really very moved. ... But I told my friends, I was so excited, and one of my friends who I see as the most sensitive, you know the psycho-drama facilitator in my life, right, who said to me it’s amazing how little can excite you, and I thought fuck you, you know. This was big, this was big, what are you talking about? I mean, she has this four year old who Skypes with her, and I never felt jealous about it, but I thought how can you make this so little ... I realised I think that I don’t necessarily talk to my friends so much because their response and mine are so different in terms of the children. (H)

M realised that some people had tried to say something helpful, but it often came out as platitudes, as they didn’t truly understand.
You get all these platitudes and it comes from people just not knowing what to say and trying to make you feel a bit better. Or maybe it makes them feel better having said something, because it is hard. (M)

H found that at times even family can let you down. She’d asked for monetary help for the child from her brother – something she would never do for herself.

I have a wealthy brother and I begged him for money, which I normally wouldn’t do because he kind of elicits costs that are often hidden when he gives you favours. But I said give her one chance in a private school, maybe it’ll work. Anyway, he didn’t, it’s a lot of money. Part of my thing as a grandparent is I feel I should somehow, you know, by now I’m semi-retired and I’d have to win Lotto. (H)

**Disempowerment**

The grandparents showed distress that they were powerless to “fix” things for their adult children, something they believed they had been able to do when they were young children.

Challenging, challenging. Challenging to observe one’s children going through that because you can’t take it away, you can’t make it better. You can’t fix it, yeah. (T)

I would like to kiss it and make it better and I don’t know how. (H)

**Medical misadventure**

Two of the grandchildren were disabled because of medical misadventure.

She was born and things went wrong with the birth process. Sadly it was medical misadventure. She was nearly two-and-a-half hours without oxygen. Machines broke down, midwife didn’t take readings. It’s recorded that she did no readings for a whole hour when she’d gone into foetal distress. All these sort of, your worst nightmare stuff. (M)

The midwife who looked after K, her mother, was a very anti-technology person so she didn’t encourage scans and things. M was identified as a breach delivery position early on and the midwife said we can manage that. When she went into labour, K was admitted into a maternity unit in Taupo and it was quickly apparent
that the breach position was still the situation and the midwife said we can manage this. Of course, everything went wrong and so essentially M was deprived of oxygen during the birth process that stalled. (T)

T’s grandchild, who is now 10, wasn’t expected to live long.

The message came across ..., such children don’t survive long. Take her home and enjoy her while you’ve got her. She has severe anoxic encephalopathy so she has no control over any functions at all. So they took her home with the anticipation that she wouldn’t be with us for long. She’s now ten, so she’s got a strong spirit. (T)

This grandfather struggled with feelings of anger.

I’ve struggled to deal with my own anger at the midwife, because that’s been around and it remains from time to time. Partly because of the consequences. I understand that people make mistakes, that happens, but there appears to be a conspiracy of denial that anything was done wrong. I don’t think that’s true, I think there were some real things done wrong. ...

It [anger] wasn’t there at the beginning. At the beginning one was dealing with what was happening, and just being alongside one’s family as this happens ... I still get angry when I hear midwives say anything artificial or technological is bad. I say how dare you, because it isn’t that simple. If they’d rushed her off to have a caesarean she’d have given birth without the problems. It’s been more of an after event the anger, and I guess the seeing what it does to one’s children’s life. It changes and it always will. We love M, she’s a delight, but you have no idea what’s going on in her head, there’s no way of knowing. She can’t respond to you, so yeah. (T)

While the other grandparents felt he had a right to feel angry, M said that anger had not been part of her experience.

I never felt anger, that was the one thing that I was surprised at myself about. I thought later on, I don’t feel anger because we didn’t have room for that emotion.
We did not have room we were so overwhelmed with what we were dealing with. And even now I don’t feel bitter, I don’t feel angry because dealing with what you’ve got to deal with is just so overwhelming you’ve got to be focussed on that. (M)

However keeping the child alive at all costs could be tragic.

I can always remember the nurse saying to me we encourage parents to take these, these babies home. I thought oh, you know. So they went home, waiting for her to die, so we did. Tragic thing, in a sense, at the time was that in my generation they would have probably gone away, the doctors would have washed their hands and said I’m sorry but you’ve had a stillbirth. These days they have to revive the child, they absolutely have to. (M)

Grief
The grandparents expressed feelings of grief and acknowledged that their situations regarding their grandchild involved change, limitation and loss—particularly around concern for their grandchild’s future or lack thereof—but weren’t quite comfortable with using the word “grief”. M, for example, said that the difficulties in her life had been nothing in comparison with contemplating the fact that her grandchild had no hope of an enjoyable future.

In my life I’ve had breast cancer, severe diagnosis, I’ve had to have both breasts removed and had major surgery. I honestly thought that was a doddlle, absolute doddle, compared to having a granddaughter that’s so disabled. Nothing compares to a child that’s not going to have quality of life and no hope of a future that can be enjoyable. (M)

H feared what would happen to the family if they didn’t have her daughter

If my daughter died that’d be it for them all. (H)

They saw part of the process as realising that expectations had to change.
It changes your expectations actually. It changes your expectations for your grandchildren because you may not even verbalise your expectations, they’re a given expectation. Grow up, get married, have children and all that sort of thing. Now that’s not going to happen, you know. I think it does harm but it also gives you an understanding of what other people, not necessarily with Downs or whatever, other disabilities, those people want to be included, treated normally, understood. (E)

You know a quarter of all autistic children who are diagnosed on the spectrum wind up in their adulthood working on computers in their parents’ house. No life outside the home. As soon as they’re finished with school, into that. That’s hard to think of having a child who will grow up like that, but she is a real person to me, and like you say, I love her. (H)

Some saw that time may help:

So living with E is just, we’ve all got past, you know, it’s the tritest thing that people say is time heals, and you think if I hear that again I’ll scream. But it is the truest thing, it really is so true. Because I’m not living in fear of the phone going anymore, I know it will one day. I can’t imagine how I’m going to be when she does pass away, if she does, who knows. She’s defied all the odds so far but everything is a major struggle. (M)

Two grandmothers said it was about being active, and not stuck in grief and it being “unfair”.

You have to go through the grief – but it’s not about grief now – it’s about not getting stuck in unfair. I’ve had to move far beyond that – grief is an earlier stage in this progress. You have to go through the grief, at least the unfairness … (H)

You do have to question it. Why? It was this innocent young baby without a brain. The unfairness. I did do unfair – but I’ve thrown that away. (M)
One grandparent felt surprised at how enriched the grandparents’ lives were:

*We came here to talk about grief – but most of our discussion has been about how enriched we are.* (E)

**Gifts**

The grandparents felt that although none of them would have chosen their grandchild to be disabled, there were gifts in the experience. One grandmother wrote a book about her Down’s Syndrome grandchild in order to show the individuality of her grandchild, and also that disability wasn’t the end of the world—in fact that it could be enriching:

*It started from a chance remark from a teacher who said to me, “I spoke to her today and I said how do you feel about being Down’s Syndrome?” Now I got a bit of a shock, because I would never have thought of asking her that. I said, “Well, what did she say?” “She said, ‘It’s hard.’” That really woke me up to the fact that she knew that she was different and that spurred me on to write about it. ... I wanted to write this book so that other people could see that what might look like a disaster isn’t exactly a disaster. It can enrich your life in many ways. It enriched the siblings’ life, they all have to be properly introduced to this, not to shy away from it, not to hide the child and all that sort of thing. So that’s why I wrote the book about her life.* (E)

T said that having a disabled grandchild had indeed enriched his life.

*I have to say I think it has enriched my life. It’s not something I would ever have chosen, but it certainly has enriched my life ... I feel enriched and I’m challenged, and I think this is giving me things that I wouldn’t otherwise have got and I’m thankful for it in that sense. I guess I find a meaning in it in some way.* (T)

They agreed that having a disabled child in the family was life changing.
Definitely a life changing experience for the whole family, all the siblings and everything. (E)

H said she had to re-evaluate what she thought was important.

I've had to re-evaluate, and I've had to see that I care for her even though she's not bright. And that's a terrible kind of admission, that I even would have a question whether I would. Here I am saying I don't think my daughter needed to have to characterise her eldest child as gifted, but I mean, maybe she gets that from the whole family. We always thought of ourselves in a certain place. Not rich, but smart. (H)

M agreed that the experience changes everyone.

On another level I feel that I have gained so much. We have all learnt so much. We have all, in a weird sort of way, become better people through this experience. We've maybe learnt a humility, maybe we were more arrogant before, I don't know. But we've learnt a different humility and acceptance of other people that maybe I didn't have. (M)

M felt the disabled grandchild had brought her closer to her son.

Only having one son ... but often you hear that sons, when they're married, tend more towards the wife's family rather and slightly move away. Whereas your daughters stay more close to you. Well, whether that's true or not in my son's case I have no idea, but he rings me a lot more than maybe I would have hoped for. He keeps me up to date if the paediatrician's been round. So E has done that, and maybe he would have rung me but I don't think so. He's a pretty independent sort of guy. We've become closer that's something that Emma has done for us maybe. He rings me a lot more than I would ever have thought. When he was flatting for instance, if I heard from him once every couple of weeks that would be it. (M)

She also felt closer to her daughter-in-law, who hadn’t been married to her son for very long.
With E being the baby that she is, S and I have been brought closer. It has brought us a lot closer in a very short space of time maybe it would take some years to develop that relationship in normal circumstances – she can ring me at a drop of a hat too ... I’m grateful for that. (M)

Another grandmother agreed that she was now closer to her daughter.

I’m definitely closer to my daughter – we always have been close – it’s closer definitely. We phone each other at least two or three times a day ... (E)

Another grandmother agreed she felt she was now closer to her daughter, even though they had clashed in her teenage years.

I mean, everything she [daughter] knows she’s given to that kid and in a wonderful way. In some ways it has made us closer, we used to fight all the time. I mean, as a teenager. But because I’m a thousand percent behind what she’s doing we really have a much closer relationship. (H)

She had built a good relationship with her son-in-law too.

I think I am closer to R (son-in-law) than I probably would be. He’s ... he needs things too, like he’s a teacher and so lots of times the extra hands that J (H’s partner) and I represent he goes to work and does his reports. I mean you know it takes a lot of time on him too so ... it’s more like getting all the bases covered ... (H)

She talked of the good things alongside heartbreak, emotional devastation and physical exhaustion.

There’s still a lot of good stuff ahead though, I feel, you know. And a lot of stuff that you’re not thinking about because you can’t, because you’re so enmeshed in what’s there now. But there’s a lot of good stuff that comes out of all this in the end. Heart breaking, I think, emotionally devastating and physically exhausting, but there’s still quite a lot of good stuff there. One learns a lot of things from this, I think, and it’s amazing how life manages to swing along. (H)

E felt the experience had changed her attitude to disabled people for the better

I think that one tends to, before you have any association with anybody with a disability, you tend to stand at arm’s length. If you talk to somebody and there’s a child next to that person that’s not quite right, you don’t say how are you. You just
keep talking to that person and ignore that one. It’s not happening anymore. It teaches you to recognise people with a disability are people who want to be included. I think for me, that was a big one. (E)

A grandfather saw his experience with his grandchild has forcing him to re-evaluate the world.

It forces one to re-evaluate what the world gives value to in people. In world terms M is worthless, in world terms. She can’t earn, she can’t look after herself. But as a human being that we love, she’s priceless. I guess that’s something that kind of makes it okay in a funny sort of way. (T)

H agreed and said a video about an autistic girl had helped.

There was an amazing video that was sent to me ... It was about this autistic girl who had a vocabulary of post tertiary education, but had no language voice. She had a computer that spoke for her, so she could write all these things, but didn’t speak herself. She wrote that it’s only insofar as she conforms to what we think of as personhood that we regard her as a person. Because she doesn’t speak we see her as more of a person because she has this computer generated voice. You know, she’s the same person, but unless you opt into the straight world then nobody’s going to see you as a real human being. It was so moving and it changed my life, that video, because it confronted all of those things about what I regarded as personhood, who I saw as a full human being, who I would accord rights to even, you know. (H)

MEANING MAKING

Much of what the participants described in terms of the gifts relates to the ways in which they were able to find meaning in their experiences as grandparents of their disabled grandchild. As with the grandparents whose grandchildren had died, these grandparents worked at making meaning around their grandchild’s circumstances and their connection to the child.

We’ve had to ask questions, such as how do you make sense of such unfair events happening on people? My son and daughter didn’t deserve this. (T)
**Spirituality**

Spirituality is one of the ways people may choose to make meaning.

_Her life is what it is, and I attempt to communicate with her spiritually through my head somewhere._ (T)

Established religious or spiritual views could be hurtful and indeed harmful. T said he had found some religious thinking difficult to bear:

_I think we’re not overtly religious. I mean, I would call myself a loose Christian but I don’t go to church or that. We have some friends who are very committed Christians, lovely people... But this particular very Christian couple, I can remember, they would see life and they would see this event as something along the lines of and the sins of the fathers shall fall upon their children or their grandchildren. So they’re fairly fundamentalist in their thinking, and I know that’s how they think. Now I don’t subscribe to that logic, or that whatever. But I’d have to confess that at times I have allowed myself to entertain the thought of could that be true. Could there be something that I’ve done way back somewhere that has somehow resulted. Now I don’t believe that’s true, but it certainly is something that, I know that’s how they think, and they see things in those terms._ (T)

M questioned God and why he would let her tiny grandchild suffer.

_For myself, I’m not particularly religious. My generation were all brought up going to church, Sunday school and Bible class and all the rest. I don’t go to church regularly. I do have to say that in the early days when E was in hospital and S and S obviously stayed at the hospital the whole time, I did question in my head, if there is a God, why are you allowing this to an innocent child who has no brain, the brain stem gone. Why, why can’t you take her if you care for children so much, why can’t you just take her and let her have a quality of life rather than be on this earth suffering? And she did suffer, for a long time, until they got her drugs and everything sorted out. She did suffer._ (M)
Another grandparent said her experience with her grandchild fitted into her family belief that “things can go wrong”.

_I don’t go to synagogue very much, probably three or four times a year. But I grew up in a very orthodox Jewish family and so, of course, I reflect all of these experiences through that, I guess, in that I certainly don’t believe in a retributive God. I mean, I find anyone who would actually say that this has to do with, you know, payoff for evil, you know, I would probably throttle them. I certainly wouldn’t accept it. Firstly, I don’t think God’s that interested in my little life, right. I just cannot believe in the way some people do about, you know, whatever. I come from a family of holocaust survivors and I think that this experience kind of has, in some ways, confirmed that things can go wrong. (H)_

Some of the grandparents discussed having a spiritual connection with their disabled grandchild.

_So I have my own spiritual belief that on some level I can communicate with M.... So she and I have little chats, I chat to her via somewhere, via our heads. And I have a conviction that on some level she understands and that that’s possible. That may be my fantasy but I tell her through my thoughts the things I want her to know about. That I love her, that she’s cared about, all those things. I don’t know whether she hears that but I don’t care, I tell her that anyway and I believe it matters. But it’s been interesting, just being mindful of those kind of historical spiritual things that I don’t subscribe to, but they’re pretty loaded and pretty heavy. (T)_

_I did got and see a clairvoyant. Now I’ve never been to a clairvoyant in my life, and I went to a clairvoyant before Christmas because I didn’t know what else to do. She was most interesting, and most helpful to talk to. She felt, she was one that had the spirit guides and people there talking, and she felt there was a spiritual connection between E and I. She was talking about a triangle, and the mother, and she said I was the third part in that triangle because we have a strong spiritual connection. I choose to believe that, I choose to believe it. Whether it's true or not I don’t know, but I choose to believe because I know E does hear my voice and she does, you_
know, you can see her sort of stop. Not that she's doing anything to stop from, but she does that little freeze thing. So I do believe that we have a connection, and I'm happy with that. If that's all I get from her, that's just fantastic. (M)

Feeling all her life that she's “other” helped H feel a special bond to her disabled granddaughter:

I mean, if I do believe in God it's a very cynical God that I believe in. But I mean, I feel I do have a connection to R, whether that's spiritual or not. But I think that whole sense of being other comes from that place. Certainly being Jewish in New Zealand it's almost an impossibility I think. (H)

**Grandparent's role as a source of meaning**

As indicated earlier, the grandparents believed that their role was in supporting their children, and they were happy to be able to be there for them. For several it seemed to give their lives extra meaning, and seemed to empower rather than disempower them.

I'm there in an instant, or bringing meals when they're in hospital or whatever. And that's me as a grandparent, firstly supporting my son and daughter-in-law. I have to say I can't find a word in the English language that would describe how fantastic I think they are as parents. They've been thrown a very difficult ball, they've run with it, they've never complained, they're always smiling. (M)

The disabled child had helped two participants, E and M find a more meaningful role in their families.

It gives you a role that you are like a surrogate parent in a way, you need to step in whenever you're needed – even when you're not needed ... giving the carers respite is so important. (E)

I will do anything I can to help ease their life, ease their stress in any way that's possible. That's my job, I feel, as a grandparent. I feel delight when they do call me. That's my function, that's why I'm here. I'm here to help them whatever way I can and I love it, and I'm glad that they do. I don't see it as anything difficult. (M)
A grandfather wished he could do more, but cited job and some family particulars—the other grandmother’s hands-on support—that made it slightly difficult.

I have a frustration at times that I don’t have time to help them more in practical things because I work full time and commute ... There just isn’t time and space to do things. Some internal family dynamics have complicated it in that K’s mum lived with them. ... she moved in and lived with them soon after M was born and has provided a rock of support in a practical sense and has done that splendidly. That was ten years ago and she’s just going through some chemotherapy for breast cancer and things are going to change. (T)

A grandparent was deprived of having grandparents herself as a result of the Holocaust. This gave becoming a grandparent and finding a role great meaning.

So we’ve always had that, you know, and R having problems, you know, we had everyone murdered so this is just part of a similar kind of thing. But I think not having had any grandparents, I wanted to do my best. In some ways it gives me an ability to invent the role which is nice ... Not circumscribed by a lot of, you know. (H)

H felt in some ways she was failing her daughter because she couldn’t afford to help the family monetarily

But it feels like my role to make sure she has the best. Like they have music therapy things that she would love, but we can’t afford it, you know, in terms of the cost of a weekly music, I don’t know. I feel I should. (H)

But there was a way she had found to help

We found a place, we go away for J’s (disabled child’s brother) birthday every year and it’s my gift to them. They never get to go any place on holiday because they can’t book a bach or something because the house won’t be set up. (H)

E felt that grandparents with a disabled grandchild had an extra role in their “normal” grandchildren’s lives too.
One of the grandparent’s roles is to definitely be there for the other grandchildren too. It’s a different role that you’re performing as well. (E)

H agreed.

R can’t go to a movie – so if anyone is going to take them to a movie, it’s going to to be me and so I did – I’m a great movie buff, although I’ve drawn my line at Chipmunks, you know, forget it (laughter) … my job – or like J, whenever D (daughter) would allow, I’d say let him come round for the weekend, we watched DVDs of Star Wars. I took him to Tiritiri Matangi – lots of things you know, places they wouldn’t otherwise be able to go because R can’t go …. (H)

You’re doing a lot of what the parents would normally do, aren’t you? (M)

Coping
The grandparents found that taking things one day at a time helped, and in one participant’s words, was “the only way that we can cope” given the extremely stressful nature of the situation.

Today we enjoy, today she’s with us and we don’t know what tomorrow will bring so we’ll cope with that when we get there. That’s how we all live and it’s the only way that we can cope really without being totally destroyed. (M)

She also recalled that talking was helpful “in the early days.”

Coping in the early days, as I said, I had to talk. And I felt that made it easier for other people to deal with it because other people don’t know what to say, don’t know what to do. It’s awkward for them. The same as, going back to the breast cancer, when you’ve been diagnosed with cancer, people don’t know what to say either. So if I talked about it then they would think oh, she’s okayish with it, so it could become part of a conversation if necessary, or if they wanted to talk. So I think it just, you’ve just got to be more open and relax and, as my son used to say, roll with the punches. And you do really. (M)
T said just being involved helped him to cope.

*Just thinking of that coping notion, for me it’s a privilege to be around for support, albeit little support. Some support. I suppose I value the opportunity that it’s strengthened our relationship, between myself and my son and my daughter-in-law. We have a really strong relationship that we can talk about any aspect of the whole show. So when, at some points when she was quite unwell, they said we even thought about should we just let her go in the night somehow. Almost help her to go. I valued that we have the trust that allows us to have the conversations about thoughts that you wouldn’t share with anyone, that you think some people would be critical of you. So I value the opportunity of having a place in their life where they can be real about how it all is. … I value the opportunity of being in a place where I can have those kind of conversations and it helps me to cope. (T)*

E said her coping depended on how her children were coping

*I think our coping depends on our children’s coping. Not the grandchild’s coping, but on our children’s coping. If they’re doing okay then we feel okay. If your son and daughter are doing okay, you feel better. Even if the child is not doing that well, as long as they’re coping, you seem to be able to cope. (E)*

Getting older however could mean being able to help less, something difficult to come to terms with.

*One time I was taking care of R and we were at the Domain and she decided to run off. So I ran after her and I picked her up, but she’s a big kid, she weighs 60 pounds or something like that. So I carried her back as far as I could, then I put her down, and she ran down again. I realised I can’t even take care of her because I’m not strong enough, and I’m getting old you know. I’m 68, you know, I can’t keep running after a big child. (H)*

H said one way she copes is through holding on to hope

*I guess I’m not resigned to the fact that she’s not going to be able to talk and somehow this will work out … So I don’t know what’s going to happen to her and I don’t know where she’s going to plateau. I do know I still have a hope that she’ll come right. Because I don’t have this, you know, I don’t really believe it. It used to be that I thought if she learned to talk everything would be perfect. Now she’s
talking but it doesn’t move it along. She says these random things and they’re communication but only if you buy in. (H)

The child getting older can make things more complicated.

I’m interested as she’s getting older and bigger things get more complicated. Like, when she was a baby you could participate in helping doing any of the practical things like changing her or whatever. Now she can’t stand, but if she’s sitting on my lap I can hold her standing upright. Historically I’d just cuddle her and she has uncontrolled movements. I’d just put my arms around her middle so she didn’t fall or whatever. But I’m mindful now that’s entering early puberty, so whereas once I would hold her chest and think nothing of it, now she’s got breasts. (T)

We had to deal with that with K because when she went through puberty, it’s not just getting periods and breasts, there’s huge hormonal upheavals and so on. And that was quite tricky I have to say. She didn’t understand it too well either, she hated the idea of having periods. She said it shouldn’t happen to people. But how do you explain it, but eventually it falls into place with a lot of care and attention. (E)

A matter of concern was the question of what would happen to the child as time passed? That was a real concern.

We’ve just had R lose a tooth, and of course all the kids have lost their baby teeth but you can’t explain anything to her. She kind of could see that it wiggled and things, and so I can imagine. It was the first time we’d had to think about it, that she’d get periods. At this point I think the way I deal with it is I live very much in the present with her. Because, you know, I really don’t know what’s going to happen. R, my daughter’s partner, just mentioned it once, like how will she get older, what will happen. He’s 55 already, she’s about 41, 42 …. (H)

Information

These grandparents felt they didn’t need or want day-to-day information about their grandchild’s disability – some because different sources said different things and were therefore confusing.
Like my son M [the child’s uncle] he really wanted, when this started coming up which I guess is why my daughter hasn’t really talked about the full array of the severity of R’s condition, but he really wanted a diagnosis. And there was a time when I was invested in a diagnosis also. But really, what’s the difference. It isn’t the kind of thing that, it’s not like having measles. You know, they give you something. It really doesn’t matter what they call it or what it means. So that’s a really different thing, because I would have been a person who would have let’s get the diagnosis and then we’ll do it, you know. We’ll just do fine. (H)

I haven’t actively sought any information on E. S, my daughter-in-law’s a school teacher and she’s been very proactive from the word go about finding out everything. But then again, if you go onto the computer you find out so much, and it’s not all good stuff, and can be quite terrifying. (M)

It’s [information] really more to find support rather than explanations. There aren’t really explanations. (E)

The information that’s provided can be contradictory and confusing

When I ponder the notion of information and access and stuff like that, it’s a hard one it seems to me because the nature of the territory. There’s nothing standard about it. Like, you can’t say any two situations are the same. It is hard to predict outcomes, because you don’t know them. You get caught up with lots of different agencies and disciplines who have their own take on the situation based on their involvement. So you get these multiple pictures being presented by different agencies who are involved. What is clear is that nothing is easy, and all of the parents who go through this will say everything you have to do is uphill. Even if it’s going for things that you’re entitled to, that are approved, everything is that much harder. And so I suppose if one was going to say what information would you want people to have access to, it’s an awareness of the multiplicity of it all, the complexity, the hardness of it all. I don’t know how one could ease any of that. (T)

Support

Good friends help
I’ve got a great group of friends, they’re just wonderful. One particular one I can talk to anytime, day or night and there’s a few who have said, and I know they truly mean it. But sometimes you have those nasty hours, in the wee hours of the morning when you’re not sleeping and they’ve said look, just ring if you need to talk then. That was more in the early days, when things were just so much up in the air and emotions were really high. I never took them up on that, but I could go round, you know, and we’d sit down and share a bottle of wine and chat. (M)

A grandfather said he was attracted to this research as he saw it as a way to deal with the grief – and there was not much around.

I suppose one of the reasons that, when I heard about what you were doing, one of the reasons I was interested to be part of it was I have people I can talk to, and I have indulged in sharing some of the early parts of the journey with the students I teach, and saying I need to let you know this is what’s going on in my life right now. So in a sense I’ve had places where I can process elements of the journey. But I was aware of being attracted to what you’re doing, and this particular moment, somewhere along the line of there’s not that many places where one can acknowledge one’s own grief about it. Albeit second removed. (T)

Advice to other grandparents

The participants all advised other grandparents to be supportive of their children.

Be supportive, give as much time as you can to your daughter or son. I think the support comes naturally, I think it’s just an instinct. (M)

One of the grandmothers disagreed that helping was instinctual:

No, I’ve seen grandparents who can’t cope and haven’t been supportive. And I’ve seen families break up, quite a number of families have broken up because they couldn’t cope with a child that they felt wasn’t right in the family. It isn’t everybody who’s good, able to handle this actually. (E)

The grandfather mentioned a bit of what grandparents could do for themselves—and in particular that they should not underestimate their value.
What I would probably advise is have the courage to acknowledge that the journey for yourself is not easy. Just coming to terms with it for yourself, the grandparent, and it’s okay to acknowledge that it’s tough and not easy. So I’d advise that. But I also advise don’t underestimate the value you can be to your children. No matter what resources, expertise, knowledge, anything you’ve got or not got, you can be enormously helpful to them by being somewhere, being alongside. Having the courage to be alongside is priceless and you can’t buy it, you can’t get courses on it. But if your heart says I’m prepared to be alongside, and together we’ll do whatever we need to, I think that’s priceless. And I’d say anyone has the capacity if they just have the courage to say that’s what I’ll do. So I’d encourage them to not underestimate the value of just being there. You can’t be an expert, you can’t know the answers. (T)

Give the family your time was the advice of one grandmother.

I would just add to that that the most precious thing you can give in any of those situations is your time. Time is the thing that they need. Maybe time away, maybe time with them, maybe time talking to them, listening to them. In whatever way it’s needed, it’s time and in this society we seem to not have a lot of it these days. (M)

Reactions to taking part in the research

All the grandparents felt they benefited from taking part in the focus group, as a rare opportunity to talk with others in a similar situation, and they appreciated getting to know each other. One related the benefit of being involved to his sense of loss regarding unfulfilled hopes and possibilities, and the value of being in a place of acceptance and comfort.

There is a sense of loss of what might have been, what could have been, what should have been, what never will be and coming to a place of comfortably accepting that. I think that’s part of what connected me to say I’m happy to be part of this [research]. There are not many places where I would go, where I would talk with other people. And I guess even hearing your story has been comforting.
Comforting to know that, yeah, just comforting to know that there’s something we share about the particular things. There’s not many places you can do that. (T)

This is lovely and I feel a great kinship with you all. It’s really nice ... There’s a strength coming out of all of this, don’t you think. A strength, a combined strength I see. (E)

Yes, I do too and I’ve never sat down and just talked like this. It’s really nice. It is cathartic, yes. It’s the learning to live alongside it, isn’t it. Instead of having it in front of you as a huge thing, you learn to put it ... Because of the mere fact that we can sit here and we’ve all smiled, and we’ve all talked about it. The most hideous situation that none of us would ever choose. (M)

At the follow-up meeting one of the grandparents said she had had no expectation of the focus group, just that she may have something to contribute to other grandparents, her reaction surprised her—she found it to be cathartic.

I got more out of it than I had expected, um, and I’ve never been in the situation where I’ve talked to other grandparents before so I really felt at the end of it all it was a very cathartic experience even though my intention was for it to be for somebody else but I felt for me that it was really hugely helpful. Um I met a girlfriend for dinner that night and I just kept on saying what an amazing group of people I’ve just met, they’re so amazing with what they have to deal with... and I just realise all the strength that we have to pull on, that we don’t even know we’ve got until we need it ... and you commented H, that you would kill for R, that the love is so strong. It’s absolutely right. You absolutely would. You’d lay down and die for them if that was what was required to get them better or get them right and we’ve all got amazing strength and that’s what’s come out if it. And I think well, maybe I must be one of those people to – you don’t really see yourself as that. (M)

Another grandmother agreed, saying she felt she had been able to give her feelings words – but said it was hard to recognise the gifts in having a disabled grandchild as “you don’t want to say it’s worth it.”

Maybe it gave you another perspective ... other perspectives came in. ... And I really felt that this group last week really helped me to cherish her in a way – I mean I cherished her, but didn’t put words to that kind of to see how unique these kids
really are and they really do bring us something special – it’s hard though because you don’t want to say it’s worth it. (H)

H felt that the difference between having a disabled grandchild and one that had died was in having an ongoing role, something that made it a bit easier – the others agreed

We have something to deal with, you know? If your grandchildren die, you lose a role. (H)

Support groups

Although the grandparents described themselves as having benefited by taking part in the research, they said they would never attend a support group.

This has been great and I’ve thoroughly enjoyed it and would be quite happy if we meet again or whatever we have to do. But I don’t want to be part of a support group, that’s not really me, because then I’ll feel like a victim and I’m not a victim mentality. (M)

T wasn’t keen on a support group, but could see the value of sharing.

That (a support group) wouldn’t fit me personally. I know when I’ve read a few things on the internet, I mean, I was in care as a child, in a boarding school care home. I’ve recently gone back and read of other people who were in the same home and have written about their experience there. It was strangely comforting to read similar experiences of what I remember. Whether that says blog sites or some kind of, I don’t know, place where people can share their experience would be useful, I don’t know. I ponder that, because I do hear some themes that say ... I suppose I see the value of what we’re doing in that there’s something validating about hearing other experiences that connect. You can say oh yeah, there’s something helpful about being validated. (T)

H spoke of having been part of a support group in the past.

I joined a support group for children of holocaust survivors .... in Massachusetts ... But anyway, I thought to myself, and everybody told their story and everybody had similar things, right. Yay, yay, that’s where we’re going. I thought to myself was I
more comforted when I thought I was uniquely neurotic, or did I feel better now
that I saw that I was just like everybody else neurotic. I didn’t actually want to be
like everybody, it kind of cheapened it a bit, when everybody had the same. (H)

This brought laughter in the group

E felt there was benefit in uniqueness, but in sharing too.

I think uniqueness is special and precious but what can go with it is aloneness and
a feeling of does anyone else in the world have the faintest idea how horrible this is.
And I think that notion of being validated - There’s an empathy that’s lovely. I have
to say this is the first group of grandparents of disabled children that I had ever
spoken to. (E)

The others agreed this was true for themselves as well.

So you’re totally right, it’s validating how we all feel and what we acknowledge
each of us is having to cope with. We understand, because nobody else really does.
They think they do but have really no idea. (M)

Because you have a pariah status if there’s anything wrong with your family. The
question of, I mean, I think that’s a problem. They get stared at and it’s a question
of whether you want to accept that. I think I needed all the time I had to get used
to it. I don’t know that a support group would have helped me at the beginning,
because I would have said oh no. (H)

In the follow-up meeting, however, one of the grandmothers said she thought
perhaps a support group would be good.

I think on some level support groups can be good – it’s like T saying that he hadn’t
spoken to anyone who experienced what he had with M, that’s important... but I
realised I don’t want one, I don’t actually want to know ... there’s a place where I
don’t want the knowledge ... (H)

Just groups of people in the same boat can be helpful – we did that – it gave two
things ... people to support, and children to play with each other. (E)

My daughter’s done that – but not for grandparents. (M)

Have an open day when grandparents can talk – in an unstructured way. Let them
talk. There are people who would need that. (H)
H suggested that one of the advantages of this focus group was that it wasn't around a specific disability – that they had found commonalities even though they hadn't been compartmentalised into disability type. *Because the information isn’t always useful – well it doesn’t necessarily fit the child’s individual experience, because of that it might be nice to meet with a cross-section of grandparents – like this. Not autism go there, this go there, that go there. ... for people who are interested, this may work better. There are commonalities in what we’re all dealing with even though the actual disability is different. (H)*
CHAPTER 6

DISCUSSION

This descriptive study explored the bereavement experiences of grandparents when their grandchild had died or was terminally ill/severely disabled, in order to understand what their needs were and how they were being met, and whether more needed to be done within the community to help them. Of particular interest was how contemporary theories of loss and grief, and in particular disenfranchised grief, might relate to their experiences, and the grandparents’ responses to sharing their experiences with each other in focus groups. This would reflect the importance or otherwise of having their stories heard, and hearing of others’ experiences when they had been through similar challenges.

The first part of this chapter will look into how the experiences of the participants who lost their grandchild relate to existing research, and where they differ. It will then consider the information obtained about the experiences of grandparents with a disabled/terminally ill grandchild, and examine the similarities and differences between the two groups, and discuss the implications thereof.

Grandparents whose grandchild had died

The nature of the participant group

In considering the results it is important to acknowledge that this study was small in scale, and for that reason cannot be generalised to the general population, this is true also due to the particular nature of the participant group. Although various organisations were approached to help recruit for the project, and many expressed a willingness, such as Age Concern, Child Cancer, Heart Kids and the Muscular Dystrophy Society, a major children’s hospital proved to be the most helpful. Perhaps this is the reason why the majority of bereaved grandparents in the study had experienced their grandchild die of cancer. This was true of five of the seven grandparents in this part of the study.

Although there has been little research into the grief-related experiences of grandparents, what there is suggests that—contrary to the expectation that because they have experienced other griefs in their lives, they should cope—in fact, this loss can
be particularly hard on them (Gilrane-McGarry, 2011; Nehari, Grebler & Toren, 2007, 2009). The findings of the current study indicate that grandparents can experience a high level of loss and grief, and some felt that losing a grandchild had been the worst thing that has happened to them.

As this was a small study, it cannot make a claim of representing all grandparents. Because attendance at the focus groups was purely voluntary, it did seem to attract grandparents who were what’s been called “involved” grandparents (Eber, 2005)—people who were very hands-on when it came to the support of their children and grandchildren through their terminal illness rather than “remote” grandparents. Research has shown how valuable involved grandparents can be to the family, that grandparents have an important role in the family, and often have a special bond with their grandchildren (Brooks & Hill, 2009). But little has been done to discover what or who are supporting them, or to investigate their individual experiences (Lee & Gardner, 2010).

The grandparents in the current study described feeling connected to their grandchild, and spoke about being a support for the family during the tough times of the child’s illness. A few of the grandparents in the study took shifts looking after the child in hospital (two of the grandmothers shared night shifts between them) so that their children could have a break. Research by Muller and Litwin (2011) suggested that the more activities grandparents had outside the family, the more psychological wellbeing they experienced. It is interesting to note that the grandparents in the current study told of giving up various activities, including work, in order to look after their grandchild. It seemed that these were choices they generally felt positively about, as it showed they were there for their family. Many of the grandparents saw themselves as not only caring for their grandchild, but caring for the grandchild’s parents too, supporting them by making them healthy meals and making sure they had time for respite.

However, one grandmother did reflect that often her involvement was at her own expense, and in order to be there for her daughter and granddaughter she had experienced a “depression” of her own feelings.

According to the evolutionary approach, mothers’ mothers were the most likely to be involved with their grandchildren (Coall, 2010) and the father’s father the least. Because this is a small study, the results are not conclusive, but participants included mothers’
fathers and sons’ mothers and fathers—all of whom were extremely involved and caring grandparents—so the evolutionary approach did not seem to stand.

The relationship with the middle generation, the adult child and his/her partner

Earlier researchers claimed that the bond between grandchild and grandparent was reliant on the relationship with the middle generation (Fingerman, 2004), but in the current study it appeared that even if particular grandparents had a difficult relationship with their in-law or even their adult child, it did not prevent them from being there for their grandchild.

However, grandparents did express feeling more frustrated, stressed and disempowered when the relationship with the middle generation was difficult. One grandfather, for example, told about the stress of having to walk on eggshells around his daughter as all her energy and patience went to her son. He did learn to deal with this through being understanding and “grateful” to be included in a way that the child’s other grandparents were not. A grandmother spoke of her frustration and difficulty with her son-in-law making it all about himself, when in fact it was about her small granddaughter and the baby’s needs. A couple kept feeling pushed away by their daughter-in-law, which made things particularly difficult, because all they wanted to do was help. So while the study did not find that grandparents with difficult relationships with the middle generation would have less involvement, it did find that difficult relationships could make things more stressful and traumatic, and the disempowerment greater for them.

The results also showed that for most of the grandparents their involvement with their grandchild had, in the long term, strengthened their relationship with their child. Mostly this was attributed to stepping back, being a support, being patient and never contradicting their children as far as decision-making was concerned. This could come at a cost and at times be disempowering – particularly when the grandparent was concerned that mistakes were being made. One participant had particular difficulties with this, as she felt natural medicine would have been a much better way of going about things, but she understood and accepted that she had to step back on this issue.

When I addressed a parents’ bereavement group in order to recruit participants for this study, their reply was telling: “I didn’t even think about what my parents were going through!” one man said. The others agreed that they hadn’t asked. It is understandable
that parents going through such grief would focus on themselves, the child they are losing or have lost, their partner and other children. This is perhaps where the problem begins for grandparents — they are seen, and clearly see themselves, as being there to support the family through this terrible time. Grandparents in the study expressed a reticence to showing their children the extent of their suffering.

**Bereaved grandparents and grief**

The majority of the findings do concur with the literature reviewed, and can be viewed through the prism of contemporary research on grief and loss, and disenfranchised grief, meaning that their grief, and particularly here the extent of their grief, is often left unrecognised (Doka 2002). Contemporary research shows that most people dealing with grief can initially suffer health effects and interpersonal difficulties, but manage to find or develop resilience and come to terms with the bereavement (Stroebe, 2010). The grandparents in the current study described their various ways of coping: through doing what they loved (one said gardening helped her feel connected with mother earth), keeping positive, talking and remembering their grandchild. However three of the seven grandparents spoke about needing extra help from mental health professionals after suffering such things as anxiety attacks and depression, symptoms they had not suffered before. At least one of the other grandparents displayed strong signs of depression and the need for extra help. Other grandparents showed significant levels of distress at times during the focus groups.

Perhaps if grief was better understood in the context of family relations, as Stroebe (2010) has suggested, grandparents would be given more consideration. However in her discussion she shows a bias towards the suffering of the immediate family, not necessarily the extended one, calling into question the definition of “family” used in loss and grief research.

**Continuing bonds**

There were strong indications that many of the grandparents were “continuing the bond” (Klass, 2006) with their grandchild, with one participant in particular feeling inspired to take a spiritual path that would one day reunited her with the child. A memorial ritual in day-to-day life was described by a couple who spoke of clinking their glasses and toasting their grandchild every time they had a drink, whether it was alcohol or not. All said the short life of their grandchild had changed them and their family, and
that they felt the need to see it as a gift they had been given that they would continue to value.

**Meaning making**

In line with contemporary perspectives on loss and grief, grandparents in the study engaged in making meaning (Neimeyer, 2000) around the illness and subsequent death of their grandchild. Some found meaning through their spirituality, while others found their spirituality challenged, a finding that is also in line with the research (Dent, 2004). One participant made the point that how you cope with death depends on how you look at life and the universe. All the grandparents showed gratitude for the short time they had with their grandchildren, feeling that this time had a purpose. A participant said he discovered that you didn’t have to have a long life to leave a legacy or to inspire people.

Some of the grandparents found meaning in charitable work. Others agreed that they had developed greater compassion for those who were suffering, and had realised the unpredictability of life and the importance of coping for themselves and people they loved. There was a realisation expressed of the preciousness of life. They seemed to create these meanings through reviewing their beliefs, spiritual meanings and through the development of personal qualities such as understanding and compassion, and through practical activities.

However, the meaning making around the role a grandparents should take, and reconciling that with their own emotions was difficult for some of the grandparents. One described her experience of suffering as a “double whammy” of being the child’s grandmother and the mother’s mother in explaining the complexity of the role and how difficult it was for her to look at her own emotions.

**Waves of grief**

The grandparents spoke of experiencing waves of grief from their inner most selves, something that is an accepted part of the grief process (Neimeyer, 2000). One spoke of it in terms of something being triggered and “memories flooding back” while another experienced a gut wrench when walking past a little boys’ clothing shop and a grandfather found himself weeping after hearing some lines from a song in church.
Layers of grief

Previous research into the bereavement experiences of grandparents has found that their grief comes in layers: in addition to grieving for themselves in the loss of their grandchild, they also grieve for the loss experienced by their adult child (Galinsky, 2001; Gilrane-McGarry, 2011; Ponzetti & Johnson, 1991). The grandparents in the current study expressed this very strongly, some sobbing as they described their sorrow on behalf of their adult children. One, for example, mentioned that her main concern and sorrow currently was that her son had had to go through what he did. The grandparents in the study also expressed distress at the pain and suffering their innocent grandchild went through. Two participants found the traumatic nature of their grandson’s death to be particularly hard to bear. There seemed to be a difference in levels of distress between grandparents whose grandchild’s death had been peaceful, and those for whom the death was traumatic, particularly if they witnessed it. This too is consistent with contemporary grief and loss theory (Neimeyer, 2000).

Culture

There is research that suggests that in Western culture the expression “bereaved grandparent” is rare, while that is not the case for “bereaved parent.” This may indicate that the predominant cultural understanding of bereavement is limited to the nuclear family, a narrow perspective that can disenfranchise other grievers (Nehari, Grebler & Toren, 2007). The grandparents in the study did describe a perceived lack of cultural support for bereaved grandparents in Western society. They perceived Māori as being far more accommodating to extended family, and having better structures for grieving. The one Māori participant said her culture had a place for grieving, something that the others, particularly those who didn’t identify strongly with a religion, felt they lacked. Another participant felt that having a funeral would have made things easier for her daughter.

The grandparents also commented on the amount of money the state spent on their grandchildren; there seemed to be an ambivalence over whether this was good or not, as the child had to endure great pain because of the sheer will in our culture to extend life. Thus their concern about this dominant value seemed heightened by their distress and grief from witnessing the child’s endurance of pain.
Disenfranchisement, disempowerment and isolation

Many of the grandparents in the study described feeling disempowered and isolated through the process of their grandchild’s illness and death. Extant research has suggested that grandparents seemed to find there was an absence of a clear social position and role for bereaved grandparents (Nehari, Grebler & Toren, 2007), that grandparents are the forgotten grievers (Gilrane-McGarry, 2011) and that their grief is the “silent grief” (Nehari, Grebler & Toren, 2009).

While the child was alive, however, the grandparents in the current study did seem to find a defined role, as discussed earlier in this chapter: that of support for their child and grandchild. However, one participant described feeling frustrated because she didn’t agree with her daughter’s choices, while others felt excluded from most of the decision-making. The general feeling in this group of grandparents seemed to be that they lacked information about what was going on for their grandchild, and wished they had more access to that. The grandmother who spoke about her grandchild’s death taking her by surprise may have been more prepared and may have been able to say goodbye if she had had more information.

The grandparents were generally understanding of privacy policies in the hospital, but felt perhaps that booklets, or ways of accessing information, should be made available to grandparents. In fact, their experiences in the hospital system seemed to be part of what made many of the grandparents feel isolated, disempowered and ultimately disenfranchised. Disenfranchisement happens when a loss is not properly recognised (Doka 2002) in the community.

The bereaved couple felt they were ignored by hospital staff (except for towards the end of their grandson’s life when the palliative care nurses included them after being asked to by their son). Even their children’s counsellor ignored them at the hospital, and apparently wouldn’t even look at them. They felt they were not acknowledged as grandparents – an important part of the family.

A grandfather felt in a way that the grandparent role was being replaced by a volunteer “grandmother” at the hospital.

Another participant agreed that the nursing staff had failed to acknowledge the grandparents. A male participant showed an appreciation that he had had a different
experience, where he got to know the duty nurse, who always had time for him.
However, he too agreed that grandparents should be more included. He also spoke of a
day when grandparents were taken around the hospital and given lunch, something he
appreciated – but his experience was seven years ago, and the grandparents who had
experienced more recent bereavements had no such experience.

Referring to friends, partners (who were not the other grandparent) and others in the
community, the grandparents in the study said all their relationships in and out of the
family were affected and some changed significantly. This is a usual experience of grief:
when someone close dies, one’s whole world changes (Neimeyer, 2000). Some of the
grandparents spoke of feeling isolated from others. They felt the enormity of what they
were going through could not be truly understood, even at times by a partner thinking
one should be “over it” and others’ expected reactions could be very different from
reality — trusted friends disappeared while people one didn’t know well were “useful
and helpful”. Ritual is important in the process of dealing with loss and grief (Dent &
Stewart, 2004). The grandparents in the study expressed gratitude for being included in
such things as Child Cancer’s remembrance day, where balloons are released in memory
of the children. Ways they remembered their grandchild included planting sunflowers
(seeds given by Child Cancer), and through photos. The grandparents were not always
included in anniversaries with their children, but showed appreciation when they were.
Most said they always acknowledged the anniversary by contacting their children on the
day.

Individual experiences
This study confirmed that grandparents’ grief is multi-faceted and complex, in line with
the research of Gilrane-McGarry (2011), as there were many individual as well as
societal aspects that came through for the grandparents. All grief is individual
(Neimeyer, 2000) and each person’s unique experiences and past losses that can make
the present loss harder to bear, contrary to what is the common assumption that
grandparents, because of their life experience, will find the death easier to bear
(Gilrane-McGarry, 2011). Individual experiences definitely affected the level of
bereavement experienced by the grandparents in the study. For one, it was her
professional background as a nurse, and she felt very conflicted and had difficulty
reconciling a grandmother’s hope for her grandson with what she knew was the medical
reality of his chances. For another, the timing of the death was particularly hard, as her
father died on the same day as her granddaughter. For a third it was the coincidence of
the big Christchurch earthquake occurring on the day of her grandchild’s stillbirth preventing the other grandparents from seeing the baby. Disagreement and frustration with the treatment and care of her granddaughter were highly traumatic for another participant.

**Advice to other grandparents**

The advice this group gave to other grandparents who may be going through the same thing was telling. They immediately went to what they (and the culture) saw as the role of the grandparent in the family — the supporter. They advised other grandparents to love and support their family, to be present and available, to back off rather than to be too intrusive by trying too hard and one grandfather even said that if your child needs a punching bag, be that punching bag.

However, when pushed they did give advice on self-care. The key seemed to be, don’t expect your children to look out for you, you need to find the help you need. The grandparents seemed to think that talking was important: talking about the child and expressing that that child still had value was particularly important, as was continuing to honour the child and his/her legacy (Doka, 2002).

One grandparent said sustaining oneself and one’s energy was important so one could remain useful. Her wording of: “... useful to the people who are actually going through it...” was particularly interesting. In it could underlie that societal disempowering idea that grandparents are a support to the family who are “actually going through it” not people who are also going through something terribly traumatic themselves. Yet as the research suggests, the level of grief a grandparent experiences can be equal to that of parent (Gilrane-McGarry, 2011). One of the grandparents admitted however that sometimes grandparents expect too much of themselves and try remain too stoic.

The fact that three of the seven grandparents went for counselling after the death of their grandchild, after experiencing worrying mental health reactions such as anxiety attacks and depression, is consistent with the findings of Youngblut, Brooten, Blais, Hannan and Niyonsenga (2010). These researchers found that grandparents can experience depression, anxiety, substance abuse and suicidal thoughts after the death of a grandchild, although there has not been a lot of research done in the area. In the current study one grandfather, who suffered anxiety attacks for the first time in his life, said it had taken a lot for him to realise he needed outside help. Another grandparent
described strong depressive symptoms saying that she was finding life meaningless and full of pain, and she was particularly aware of the pain and suffering of innocent young children.

It is possible that the reticence about seeking help for themselves is generational as most of the grandparents in the study were born just before or after the official start (1946) of the baby boomer generation, for whom talking about emotions was becoming acceptable. It is possible that many held on to the older pre-baby boomer view that people should stay stoic and “not grumble” (Brownlie, 2009).

What’s needed in the community
It was clear that the majority of grandparents in this study felt they would have been better off with more information. It would probably be good if they got information on not only the child’s illness and possible outcomes, but on how the grandparents could look after themselves (do self care), be there for the family and be there for themselves. One suggestion was that conveners of support groups for parents mention that participants’ parents may need help too, and give their participants an idea of what can be made available. Another suggested advertising outlining the importance of whanau when such things occurred, so that people realised that grandparents needed help too.

It was interesting that most of the participants in the focus groups said they had come to the research because they felt it would help others – and that they were unlikely to seek out a support group for themselves. However, all the grandparents said the focus groups had proved cathartic for them, they particularly embraced the opportunity to meet others who had faced the death of their grandchild. Sharing their experience helped, they said. One grandmother showed appreciation for been given “permission” to grieve in the way that a parent grieves.

Grandparents whose grandchild was terminally ill or disabled
As mentioned in the Method section, recruitment for this group proved difficult. The email reply from the music therapy centre may outline the problem: that centre and others were loath to help with the recruitment, because they did not want to be telling grandparents that they were grieving. They felt that that would be labeling their experiences. So, perhaps had the study had a different title—such as the experiences of grandparents with a disabled grandchild—recruitment would have been easier.
However, this study was different from other research of its kind in that it looked at both groups of grandparents from the perspective of contemporary theories on loss and grief—grandparents who had lost a grandchild and grandparents who had a grandchild with terminal illness or severe disability, rather than one or the other. Using the term grief was applicable to what was being studied. This was not primarily an attempt to compare the two groups, but to find out what the different grandparents’ needs may be and whether they were being met. Yet, of course there can be said to be certain similarities and differences between the two groups, which will be discussed as the findings from this focus group are considered.

As mentioned previously, separate focus groups were held for each of these two groups of grandparents, as it would possibly have been too distressing for the grandparents with disabled or terminally ill grandchildren to be mixed in with grandparents whose children had died, and vice versa. Members of this group did reflect on how much harder it all must have been for the other grandparents, because at least they themselves had an ongoing role as their grandchild was living.

In the end, I found four participants for this group, one of whom came through a major children’s hospital, and the other three through personal contacts who asked people they knew if they wanted to take part. I found it interesting that when I asked one friend’s mother if she knew anyone with a disabled grandchild who might be willing to take part in the research, she had the same concern as the music centre: she did not want to be telling grandparents that they were grieving.

Of course four people is a very small sample and the results cannot be generalised to the wider community, but although they didn’t always want to name it, a lot of what the participants did express was grief: grief for themselves, their children and the grandchild, in line with what earlier research says about the layers of grief (Sherman, Gardner, Brown & Schutter, 1995). Because the grandchild was living, and there was a big continuing role for these grandparents to play, there was also a lot of hope and an appreciation of the gifts the grandchild brought.

**Involvement with the grandchild**

All four of the grandparents were very involved in the care of their grandchildren: they spoke of being on call 24/7, setting up their house so the grandchild could visit safely, reducing work shifts, moving home so they could be closer to the family and more.
is consistent with the research of Miller, Buys and Woodbridge (2011), who looked into the experiences of 22 Australian grandparents with disabled grandchildren. One of the themes they found was self-sacrifice by the grandparents. The grandparents in this study certainly found their role expanded with the birth of the disabled grandchild, in accordance with previous research (Lee & Gardner, 2010).

It was interesting to find that the grandparents in the study embraced their enhanced role, and indeed relished it. However they were always cautious to add that the circumstances were not what they would have chosen.

**Loss and grief**
Themes of loss and grief definitely came through these grandparents’ descriptions of their experiences, even though mostly the grandparents didn’t want to call it “grief”. This reluctance may have been out of feelings of guilt and in general struggling with their emotions over what they were feeling, as the grandchild was still living. This may have accounted also for the difficulty in recruiting participants. Miller, Buys and Woodbridge (2011) have written about grandparents experiencing mixed emotions.

The grandparents in the current study acknowledged that their situation regarding their grandchildren involved change, limitation and loss, particularly around their grandchild’s future or lack thereof. One grandmother said her own cancer diagnosis and removal of both breasts was a “doddle” compared to her granddaughter’s severe disability. Her difficulty was in contemplating that the baby had “no hope of future that can be enjoyable”.

Both the current study and previous research shows that it was common for grandparents to experience feelings of grief upon learning that their grandchild was disabled (Scherman, Gardner, Brown & Schutter, 1995). Grandparents in the current study reflected on deep feelings of grief when a granddaughter was born with disability, and a type of bargaining when it was realised another’s granddaughter was not developing as expected. She had hoped the child was deaf, as that was a disability that could be dealt with reasonably easily. Two of the grandparents found that they had to move beyond being stuck in grief and “unfair”, which is where they were in the early stage of their process.
One of the concerns that was unique to this group of grandparents was the awareness that their ageing process and the child’s getting older complicated things: the grandparents felt constrained as they felt they had less and less strength and energy, while the child became less manageable because she was getting stronger. This was very much in line with the Miller, Buys and Woodbridge (2011) research which found that grandparents show a lot of concern for the future of the family when they grow too old to be a big help.

A different kind of concern related to ageing was expressed by a member of the other group (of grandparents whose grandchild had died) when she reflected on how she had lived her life, and it was so unfair that her grandchild had not been able to have hers.

**Layers of grief**

The layers of grief came out strongly in this study, as participants showed a lot of concern for the struggles of their children who had to care for a severely disabled child, and thus to an extent sacrifice their own lives and potential. One described it as a life sentence for his son and a grandmother said her heart broke for her son and daughter-in-law as it was their lives that were shattered, even more than that of the child. Existing research had also found that grandparents grieve for themselves, their adult child and the child who will never get to have a normal life (Johnson 1995).

All the grandparents felt they had a big role in supporting their children and grandchild as well as other grandchildren. One grandparent spoke of doing “normal” things with her other grandchildren, such as going to movies or a café, things they couldn’t do with the disabled child in tow as she would be too disruptive. This aspect differed to some extent with the grandparents who had lost a grandchild: a couple in that group told of focusing on the sick child and even neglecting the other to some extent, however one of the grandfathers in the other group reflected on the care he gave to the other children as well. A couple spoke of only now getting to know the deceased child’s sister as their time was taken up with being there for the sick child and his parents.

There seemed to be an additional layer for these grandparents in the second group at a broader societal level. Interestingly, existing research reflects on the grandparents’ acceptance of their grandchild and on prejudices against the disabled that they may hold which could keep them distant from the family (Baranowski & Schilmoeller, 1999; Lee & Gardner, 2010). However, there does not seem to be much research into how societal
prejudice against the child can deepen a grandparents' grief, and increase their frustration, anger and disempowerment in the situation. It was evident in the current study that the hurt caused to their children and families hurt them too. These experiences included the "heartbreaking" experience of a daughter-in-law being ignored in the hospital while others received flowers and all the celebratory trappings of having just given birth; a lot of public disapproval; and looks and responses towards a grandchild by the public, evoking deep hurt and anger. A grandmother's outrage over this type of prejudice made her even more protective of her grandchild, saying: "I would fight all of her battles".

Another aspect found in the current study was not just overt prejudice and "looks" from members of public, but also the experience of covert prejudice when people showed they just didn't understand. This included getting platitudes from people who didn't know what to say; a daughter's friends asking one grandmother what to do about a dress she had bought for the baby when she thought it would be healthy; and a friend of another not recognising how significant it was that her grandchild had learnt to say her name. This denied this grandmother the acknowledgment of her own delight.

Of their own prejudice against the disabled, the grandparents reflected on how their grandchildren had redefined what they thought it was to be human, had taught them a great deal about what was important, and had indeed enriched their lives. So rather than their prejudices getting in the way of their being there for their families, their preconceived ideas were challenged and discarded. One showed some understanding of the way people behaved—because she said that had probably been her before the birth of her grandchild. Another reflected that previously being intelligent and speaking well had been what she valued in people, but with her granddaughter her priorities and worldview had changed, and she had truly bonded with the child. Perhaps it's not so much the existing prejudices grandparents hold that affect their involvement as research claims, but rather what may count above everything else is their individual innate adaptability and capacity to love.

**Meaning making**

In terms of making meaning out of loss (Neimeyer, 2000), interestingly, the grandparents of severely disabled grandchildren in the study spoke of having a special connection with the disabled grandchild—even a spiritual connection. Three of the grandparents spoke of communicating with the child on a spiritual level. One
grandmother spoke of going to a clairvoyant who had affirmed that they had a strong bond; she spoke of wanting to believe that to be true and therefore believing it. It is common also in the grief process for one’s religious and spiritual beliefs to be challenged—this is part of grief being active, not passive (Attig, 1996). The biggest difficulty for the grandparents seemed to be that it was a small, innocent child that was suffering.

One grandfather found dealing with the idea of “sins of the fathers” difficult – he spoke of questioning whether he had done something to inflict this pain on his family. The grandparents also spoke of prizing the smallest indications that their grandchild knew them. Most felt an ambiguity that there was “lots of good stuff” in the situation, but also heartbreak, physical exhaustion and emotional devastation.

**Gifts**

In saying there were gifts in having a disabled grandchild, the grandparents emphasised that although they experienced these, they would never have chosen to have them at the cost of their grandchild’s disability. Rather, they were an unasked-for but precious outcome. The literature around such gifts coming out of the disability for grandparents seems weak, as it seems to focus more on the challenges than possible “advantages”. In a research on parents with disabled children, Kearney and Griffin (2001) found that “although they [the parents studied] experienced much anguish and sorrow, the parents also spoke of hope, love, strength and joy” (p 582). From the responses of the grandparents, it seems that this pertains for grandparents too.

A grandfather said he felt both enriched and challenged by having a disabled granddaughter, and he spoke of finding meaning in it. One reported that the whole family had learnt a lot, and become better people through her grandchild. She spoke of learning humility and acceptance. Another reflected on how compassionate her grandson had become as a result of his disabled sister.

Research shows that the disability of a child can have a profound effect on the family system (Seligman & Benjamin-Darling, 1997). The grandparents spoke of how the disabled grandchild had brought the family closer together – particularly them with the middle generation. One grandmother felt closer to both her son and daughter-in-law since her granddaughter’s birth, another said in the past she hadn’t had a good
relationship with her daughter but they had now become close – particularly as her daughter appreciated that she was so there for her grandchild.

The grandparents spoke about their role of being an extra support for their child and grandchild as being a source of meaning. For several it seemed to give their lives extra meaning and empowered, rather than disempowered them. They spoke of being an active help. Two grandparents said the child helped them find an even more meaningful role in the family and finding delight in helping. However, others spoke of the frustrations of being constrained by work or money, and not being able to do as much as they wanted to hurt.

The grandparents also found an extra role in their “normal” grandchildren’s lives, as mentioned previously – through giving them normal experiences that could not be had with their often disruptive disabled sibling.

As mentioned, this group felt that the fact that they had a continual role made things easier for them than what they imagined the group who had lost their grandchild would be experiencing. The other group did not talk of loss of role as a big concern, as of course they still saw themselves as supporting their children and the other grandchildren in carrying on the child’s memory – rather the issues of the grandchild’s suffering and loss of a future were their big griefs.

**Coping**

In line with the research by Miller, Buys and Woodbridge (2011), who found that grandparents with a severely disabled grandchild struggled with their emotions, but generally chose to focus on what was in front of them and tried to remain emotionally tough and positive, the grandparents in this study expressed a lot of resilience. One of the grandparents said that taking things one day at a time helped and was in fact the only way she could cope – expressing just how stressful the situation was. Another said how she coped depended on how her children were coping and another said just being involved helped him cope.

Certainly it seemed being an active help in the family helped these grandparents to cope, and research shows it certainly makes a big difference for the family (Seligman & Benjamin Darling, 1997), (Ponzetti & Johnson).
Information
Interestingly this group of grandparents didn't seem to want day-to-day information about their grandchild’s disability, this they said was because sometimes the prognosis was not correct (two grandparents’ grandchildren have lived a lot longer than predicted), and also different information from different sources could be confusing and contradictory. Information could also be “terrifying”, so the grandparents felt it was probably better to take every day as it came and not know too much. Why this is interesting, is that the grandparents in the other group, where the grandchild has died, said one of the things that had really disempowered them was the lack of information – and they spoke of how this information could be imparted. Particularly in the cases of two of the grandparents in the disabled group, it could be said that they were in the “early stages” of what the other group went through i.e. the prognoses for their grandchildren was not good, and death could come at any time. Could wanting to have more information be more something of hindsight than what the grandparent wants while the child is alive? This study was too small to make any such generalisation – but it may be a useful course of future study: When is information helpful and when is it perhaps even damaging? Certainly, research on what the grandparents could do to help themselves and keep strong for themselves and the family could help, and certainly wouldn't harm.

Support
The grandparents said good friends who are ready to talk help. A grandfather said he was attracted to this study as he saw it as a way to deal with grief – and there was not much of such help around. Interestingly, he said although he was quite far on the road of his journey, and had spoken to people about it, that there were not many places where one could acknowledge one’s grief about it – could the attitude that I came across when recruiting participants that you can’t tell grandparents that they’re grieving be denying them the acknowledgement of what they’re going through and therefore disenfranchising the grief further than it already is (Doka, 2002)?

Advice to other grandparents
The grandparents in the study all advised other grandparents to be supportive of their children – one saying it was just about going with parental instinct, but another mentioned seeing grandparents who couldn't cope and haven’t been supportive, and families that have broken up as a result of the stress caused by the child’s disability.
Like the grandparents in the other group, these grandparents initially suggested what grandparents could do for the family and not for themselves. One grandfather did say he encouraged grandparents to acknowledge the difficulty of the journey for themselves, and to come to terms with it. He saw being involved as being courageous, and the rewards as priceless.

A grandmother suggested that the most precious thing a grandparent could give was their time – in whatever way it was needed. As Scherman, Gardner, Brown and Schutter, 1995, suggest grandparents can be active partners with the family and have an important role.

The research
Interestingly, all the grandparents expressed that they had benefited from taking part in the focus group – they said they had never met other grandparents in the same situation as them and had appreciated getting to know each other. A grandfather said there were not many places he would go to where he would talk with other people and share stories. A grandmother expressed feeling a great kinship with the others – and finding a combined strength.

In the follow-up meeting, a grandmother expressed surprise that she had got a lot more out of being part of the group than she had expected. She had found it cathartic. She had said her intention of participating in the study was to have been a help to other grandparents who may be going through the same thing.

The other grandparents agreed that they had benefited. However, even though they found being part of the focus group to be helpful, these grandparents were not particularly keen on joining a support group. This may be more about a prejudice towards admitting that they needed support or what “support group” meant to them rather than anything else. A grandmother said the reason for her ambivalence was “then I'll feel like a victim and I'm not a victim mentally”. A grandfather expressed not being keen on a support group, but that he could see the value of sharing.

When they really entertained the idea of a support group, the grandparents decided it could be good for grandparents, although they would not go for such a thing. The suggestion was that support groups should not be disability specific and should be reasonably unstructured.
Considering the fact that the grandparents were mainly attracted to the research because there was the possibility that it could be a help to others – any support group should perhaps look at it in this way: Market it as a way of helping grandparents help grandparents help their families.

The clear differences between the two groups of grandparents would suggest that if there were support groups for the bereavement experiences of grandparents it would be a good idea to have different ones for those whose grandchildren had died and those whose grandchildren were disabled.
Chapter 7

Conclusion

The aim of this small, qualitative study was to explore the loss, grief and bereavement-related experiences of grandparents when a grandchild has died, is terminally ill or is severely disabled. The purpose of the study was to look at these experiences through the prism of contemporary research on grief and loss and to discover what needs these grandparents had that could be provided in the community.

Using a qualitative exploratory approach, the participants were asked to attend a focus group, and a subsequent non-compulsory follow-up meeting. The two groups of grandparents were divided so as not to distress the ones with terminally ill or severely disabled grandchildren by putting them with the group whose children had died and vice versa. This split proved a good decision for the quality of the research when it became clear that although there were key similarities in the experiences (mainly to do with grief and loss), there were also key differences. Of special note is that the former group wished that they had been given more information, while the second were emphatic that this was not wanted.

One of the participants in the group who had lost a grandchild was not able to attend the focus groups because of going overseas – so instead the researcher did a face-to-face interview with her. It was interesting to find that in some ways this enabled this grandparent to go deeper into her own experience, yet the sharing and finding of commonalities in the focus groups was invaluable. Both ways of researching the experiences of the grandparents seemed viable and valuable data were obtained.

This grandparent, like the others in the focus groups, described finding her participation to be cathartic, as it gave her permission to grieve as a parent would. This was probably the most important thing that came out of the study:
the discovery that the participating grandparents indeed felt disenfranchised, although they did not necessarily have a name for it, and needed permission to express the emotions they were feeling.

A system of thematic analysis was used to analyse the data for this study. Concepts and sub-concepts were extracted through repeatedly listening to the digital voice recordings with reference to the transcripts. This helped the researcher listen for emphasis and emotion within the voices of the participants, so she was not reliant simply on the words they used to express their experiences. Certain themes were noted as they emerged, and then considered in order to refine them as the results of this study.

This study gave voice to a specific group of people in the community who are often disregarded, ignored or who are simply expected to cope because they have life experience behind them. The grandparents themselves articulating their perspectives gave insight into the complexity and multi-dimensional nature of their experiences and how these have shaped their present lives.

This study will help to increase the visibility of what it is to be a grandparent, particularly when there is great hardship for their children’s family. It also suggests the importance of maintaining the wellbeing and mental health of the older members of the family for their own sake, and in order for them to be able to be a continuing support for the whole family unit, to the advantage of all.

**Limitations and strengths**

Because this was a small qualitative study of grandparents facing loss, grief and/or bereavement concerning their grandchild that was conducted in Auckland, New Zealand, there are limitations of the generalisability of the findings to the broader population. Also, because the research was voluntary it tended to attract “involved” grandparents rather than “distant” ones. This would mean that again the results are not generalisable to the experiences of all grandparents who have lost grandchildren or whose grandchildren are disabled, as how connected the grandparent is to the family and the child would possibly
have an effect on the depth of grief experienced. This could be the focus of further study.

The main strength of this study was the use of an exploratory qualitative design in which the grandparents were free to share their experiences in their own words within the focus groups and a face-to-face interview for one of the participants. The design assisted the participants to share their experiences and express and discuss their meanings, perceptions, attitudes and feelings with minimal interference from the researcher, who guided the conversation, reflected things back to the participants, but generally stepped back and let the participants speak their own truths.

Participants said that they found being part of their focus group was valuable in dealing with their experiences. While the grandparents participated in the study in order to help others, it seems that the greatest strength of the study for them was that it gave them permission to grieve—not only for their children, but for themselves as well. A few thanked me for bringing the often hidden plight of grandparents in to the open.

A further strength of the study also was in looking at the two groups of grandparents rather than one or the other as is more common in the research in this area. It was interesting to note that there were indeed many commonalities in their grief experiences, and indeed some strong differences in what the grandparents felt was needed, some of them being quite contradictory.

Of all the organisations asked to help with recruitment of participants, Starship Hospital was the most helpful, particularly with the focus group comprising grandparents whose grandchild had died. This may be why there is a heavy weighting on cancer being the cause of death. It’s important to note therefore that a lot of the grandparents’ experiences are associated with the child dying of cancer, a slow and distressing death with hope and devastation as part of the journey, rather than a sudden and shocking death. While the grandparents commented on the many services that are made available to the parent of the
child, this may be particularly applicable to parents of a child with cancer. Child Cancer is known to be particularly good at creating and sharing resources with parents.

Because of the difficulty of finding participants for the focus group for grandparents with a disabled/terminally ill child, the researcher asked people she knew to ask people they knew if they would participate. The result was that all of the participants had disabled grandchildren, rather than ones who were terminally ill, although it could be argued that two could also be said to be terminally ill, as the prognosis for a long, healthy life was not there. In fact, one grandmother was aware that her severely disabled granddaughter could die at any time. However, a lot of the experiences described by the grandparents in this part of the study are connected to the lack of communication skills of their grandchild and this would not necessarily be true of a child with a terminal illness, such as cancer. This aspect could make the two groups less comparable than originally intended.

A strength of the study was the use of a wide lens of contemporary grief and loss theory in looking at the range of variables that could be affecting the grandparents intrapersonally, interpersonally, within the family culture and the wider culture and community. Although it appeared that there was a cultural reluctance to “tell” the grandparents with disabled grandchildren that they were grieving (which is what made recruiting for the study under this name difficult), the current study found that aspects of loss and grief, and in particular, disenfranchised grief, were very applicable to both groups’ experience and there was a need for that grief to be recognised. Further study could be done into whether the attitude of not wanting to tell grandparents that they were grieving was helpful or damaging, or neither.

Continuing with this point, while using the term “grief” in the title of the study was fine for the grandparents who had lost their grandchild, as mentioned it was more problematic for the recruitment of the other group. However, since the intention was to look at the grandparents’ experiences through the prism of grief
and loss, and because both groups were being looked at within the same study, the term seemed unavoidable. It may have been an option to simply call it “The experiences of grandparents who have lost a grandchild or whose grandchild is severely disabled”: but using the term “grief” makes the purpose of the study clearer to the participants and is perhaps more congruent. Perhaps if a researcher wants to look at the latter group more closely, however, it would be a good idea to not use the terms grief or bereavement in the title, but to be aware that it’s likely that aspects of this will be found.

**Recommendations**

*Future research*

The aim of the study was to explore the lived loss and grief experiences of grandparents who had lost a grandchild, or whose grandchild was terminally ill or severely disabled, and therefore had little chance of living a normal life. The intention was also to find out what community support the grandparents accessed and what more was needed. The primary recommendation is that this research be used as a pilot study to form the basis of a larger study to gain further understanding and insight into the needs of grandparents that is more generalisable, and in fact perhaps extending that even further to the needs of the wider family (such as uncles and aunts) and close friends when such tragedy occurs, as these can all be forgotten grievers.

Further research could also be done into more narrow areas of the grandparents’ experiences, such as a more detailed study into grandparents’ prejudice against the disabled and their involvement or not with their grandchild as a consequence. This study seems to show that having a disabled grandchild increases awareness of the plight of disabled people, and that they can become important advocates for their grandchild and his/her family.

Also, the study showed that grandparents with disabled grandchildren (and grandparents dealing with a grandchild with cancer) found their role in the family expanded. Instead of being a “companionate” grandparent who took delight in their grandchild through fun activities, they tended to become
“involved” grandparents where they were more of a support. More research may be useful into the loss of this new-found role by the grandparents whose grandchild has died. Also, while there seem to be many gifts in this new role, it would be interesting to research whether there is a reversal in the normal of pattern of things: it is usual that as parents get older, their child starts to look after them. In the case of a disabled grandchild, it’s possible that grandparents don’t get their “chance” of being looked after as all attention is on the grandchild. It would be interesting to research this, as it would perhaps highlight more practical help and care that may be needed by these grandparents as they get older in the community.

Further research into the grandparents’ role as the culture sees it and as individuals see it, would be interesting, as the study showed that often grandparents would deny themselves and their emotions in order to be there for their children. They saw being strong for their children as part of their “role” and this seemed to come as a cost to the grandparents’ wellbeing.

A number of the grandparents in the study mentioned mental health issues developing, such as depression and anxiety that led them eventually to counselling. It would be interesting to investigate further what was particularly helpful or unhelpful for them during their therapy, and whether there are particular approaches that work well for people facing this sort of grief? Or is it simply the therapist having an understanding of the complexity of emotions they experience? From this study it would seem that it’s about the grandparents being given permission to grieve that truly counts, but further, more generalisable, research would be useful.

There are also cultural aspects that would be interesting for further research. The grandparents in this study spoke about Western culture lacking in support of griever, particularly grandparents (they felt there was support for parents). It was interesting that the grandparents felt Māori culture did a lot better, and that’s certainly what is perceived in the community. Further research into
whether this is actually so, and if it is, what it is that Māori culture does that is not available to Pākehā, would be interesting.

**Recommendations for the community**

This research shows there is a clear need for grandparents’ grief to be acknowledged, so they can no longer be the “forgotten grievers” for whom grief is often disenfranchised.

Since the grandparents identified that the most important thing for them was to keep strong and be a support to their children and grandchildren, and since research shows grandparents’ support can be very helpful to families experiencing trauma, it seems vital that recognition, permission to grieve and help is given to the grandparents.

Because of the grandparents’ reluctance to acknowledge that their needs and emotions are important too, it would probably be advisable to address these things in subtle ways. Since many of the grandparents felt ignored in the hospital, perhaps hospital staff should be made more aware of the importance of acknowledging their presence. A friendly gesture, an acknowledgement of the person as a grandparent, seems to go a long way.

Certainly the counsellor at the hospital/ palliative care unit should acknowledge the grandparents and even find out if they needed any extra help. This could be done without breaking any privacy concerns that the hospital may hold.

In addition, this research found that grandparents, through their idea of what their role should be, often disempowered themselves because they did not recognise that they too had a right to grieve and that it wasn’t “only” about the parents of the child. In fact, the grandparents often pointed the way to counselling and support group help for their children. I would therefore recommend that pamphlets directed at grandparents, acknowledging their role, their importance to the families and healthy ways for them to deal with their grief could be invaluable. These could be distributed in hospitals, community
centres and counselling centres. In itself, that would be acknowledging the grandparents as a unique group with unique needs. This pamphlet should acknowledge the layers of grief experienced and that there are times when grandparents need extra support for themselves. It could also perhaps list some warning signs to know when they’re in trouble.

Also, I would recommend that those pamphlets be distributed to parents’ groups and that facilitators of those groups mention that members’ parents could be suffering too. Although it is understandable that these parents may be too grief stricken themselves to look after their parents’ grief, they may be able to acknowledge their parents and suggest that they too get some help in the form of either a bereavement group or face-to-face counselling.

All the grandparents in this study felt closer to their children through their grandchild’s illness, death of disability. However, family therapy may be useful if and when relationship difficulties appear. This could help family members who may feel misunderstood or not supported.

The grandparents expressed appreciation of being involved in such things as the Child Cancer Family Day, and one grandfather said that seven years ago he was given a tour of the hospital with other grandparents. This research shows that such things are important and go along way in helping the grandparents cope. Grandparents should be included in more of these events, as they go a long way in recognising them.

The value of participating in the study for the majority of the grandparents suggests the positive effects of support and shared experience. These grandparents learnt that they were not alone in their situation, or in the emotions they experienced. This experience of universality and normalising of course leads to the thought of support groups for helping grandparents through their loss, grief and bereavement experiences. As far as the possibility of setting up support groups for grandparents goes, however, the reflections of the grandparents on being part of this study were interesting. They seemed to be
drawn to it because they felt their participation would help others, but in the end they gained a lot through sharing their experiences and being given permission to grieve. Particularly in the disabled group, the grandparents expressed resistance to attending a support group, but some of that seemed to be concern with what they thought support groups were about (there was an indication that they thought it was about being “weak” which could be a generational belief). So, if a support group were to be formed, it would probably need to be done in a different guise than simply “support group”. Perhaps it could be set up as a group where grandparents help grandparents to be there for their families; or a group about how to be the best support for their family would motivate grandparents to attend and get value from shared experience.

In short, this study found that indeed the grief of grandparents is very real and often disenfranchised. As the research suggests, they are often the forgotten grievers who are expected to stay strong and supportive. It became clear in this study that their grief can indeed be at the same level of the parents and in fact it is complex, multi-dimensional and in layers – grief for themselves, the child and the adult child and his/her family. More recognition of their plight, their needs and appreciation of their importance in supporting their child and their family is needed.
References


Lee, M., Gardner, E. (2010). Grandparents' involvement and support in families


Miller, E., Buys, L., Woodbridge, S. (2012). Impact of disability on families:


Focus group process and question guide:

The aim of these questions is to stimulate interaction and discussion within the focus group.
Tea, coffee and biscuits will be served in the beginning of each group to help create a relaxed, informal atmosphere.
We will start the group with a brief introduction from myself, outlining who I am, and why I am conducting the research and will facilitate introductions among the participants. I will provide an opportunity for participants to ask any remaining questions they may have about the research, and to sign consent forms if they have not already done so.
I will be building trust and safety within the group through this process, which will include, explaining to the group members the importance of agreeing to maintain absolute confidentiality regarding all the information that is shared within the group. This will be reinforced by asking participants to sign the confidentiality agreement as well.
Participants will be invited to draw a sociogram (symbolic drawing) showing their family constellation and sources of support as regards what is happening with their grandchild. They will then be invited to tell their story, using the drawing if they so wish, so they can get to know each other better and gain an understanding of how the research is relevant to them and their situation. This will be achieved in an invitational way, using a phrase such as:

Would you like to tell the group about what’s happening in your family regarding your grandchild that has led you to take part in this research. As the participants tell their stories and begin discussing their experiences with one another, the following questions will be used as prompts:
How is what’s happening affecting you (for example practically, emotionally and in terms of your relationships, etc)?

I’m wondering whether you’re needing to take on extra responsibility in regards to your grandchild?

How is this affecting your lifestyle?

Through the discussion, I will be identifying factors that require more exploration – for example the grandparents’ coping skills and resilience; how they cope with possible clashes of values with their children as far as medical care is concerned; and how they feel their grandchild’s illness has changed them and their relationships as this change can be transformative.
In terms of their resources, will also ask about participants’ spirituality and how they feel that has helped or hindered them in the process. I will be careful not to make anyone uncomfortable by assuring them that there is no “correct” answer:
Some people find their religion or spirituality helpful in times when they are experience great change, loss and grief. What are your beliefs, and are you finding them helpful?

We will discuss meaning making around what has happened and whether this has inspired them into action in the community (such as fundraising for cancer charities, getting more involved in the church or helping out in hospitals etc), and if this has occurred or is something they intend to do, has it helped them make sense of their situation:

**Do you feel that this experience has changed you/ is changing you? If so, in what ways?**

**Do you see growth or narrowing in your relationships within the family? Please tell me about this.**

**Are you involved with any community groups/ charities now that you did not consider before?**

I will also explore other resources and resilience that the participants might have by asking:

**What coping strategies are you using?**

**Do you have someone who you feel able to talk freely to?**

This will lead to questions on self care.

**What are you doing to look after yourself?**

**Are you setting boundaries for yourself in this situation?**

I will be also asking:

**Do you feel your relationships with your peers have changed – are there people who seem to be ’keeping a distance’ because they don’t know how to deal with what’s happening for you, or are your friends closer now than before?**

I will also explore whether the grandparents are feeling disempowered in any way. After all, they’re not the ones who are receiving the information first hand from doctors. I will ask:

**Are you being kept in the loop by your family, and do you want to be? How do you feel about the decisions your adult children are making? Do they discuss things with you?**

I will ask also:

**What empowers you in the situation and what might be undermining or disempowering you?**
I will also ask:

**Have you engaged with support services, and if so what has been your experience of them?**

Finally I will ask:

**What do you think should be made available for people in your situation?**

**What may be needed that you haven't been able to access?**

**What advice would you give to other grandparents in your situation?**

At the end of the group, I will suggest that participants consider what has been discussed in the group and what they want to discuss further in the follow-up meeting. I would also ask them to note down things they wish they had said in the first group during the break between the two meetings.

By the time we have the follow-up meeting (probably a week after the focus group), I will have listened to the tape of the group and picked up some points that seem relevant for further discussion.

Throughout the focus group and follow-up meeting, in my role as facilitator, I will monitor closely the emotional and support needs of the participants and ensure their comfort and safety at all times within the group. Should they show indications of needing or request further support I will assist them to access counselling through the Grief Centre.

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APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19.9.11 FOR A PERIOD OF 3 YEARS. Reference number. 2011/ 423.
APPENDIX B

Consent Form (Participant)
(This consent form will be held for a period of six years)

Project Title: Grief-related experiences of grandparents

Researcher: Val Leveson

I have read the Participant Information Sheet, and have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction. I understand the voluntary nature of my participation. I understand that the focus group discussion and the follow up discussion will be audio-recorded.

- I agree to take part in this research
- I agree to not disclose anything discussed in the groups. I understand confidentiality rests with individual group participants, over whom I have no control.
- I understand that I am free to withdraw from participating at any time.
- I understand I cannot withdraw group interview data (because of other group members’ information on the same tape). However, I can edit out from the transcript any information that may not be relevant to the study e.g. identifiable information or names.
- I understand that neither my name, nor any personally identifiable information about me or about any other family member will be used in the research report.
- I understand that Val or a third party who has signed a confidentiality agreement will transcribe the tapes.
- I wish /do not wish to receive the summary of findings.
- I understand that the data from this research may be used in conference presentations or articles for publication. I will be anonymous within the research writing.
- I understand that data will be kept for six years, after which they will be destroyed.
- I understand that this consent form will be securely stored separately from the research data for six years beyond the completion of this project, when both will be destroyed by shredding.
Name……………………………………………………………………………………………..

Signature………………………………………………….
Date……………………

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS
COMMITTEE ON 19.9.11 FOR A PERIOD OF 3 YEARS. Reference number. 2011/ 423.
Grief-related experiences of grandparents

Researcher: Val Leveson

PARTICIPANT INFORMATION SHEET

My name is Val Leveson, and I am undertaking a research project in order to complete the requirements for a Master of Counselling degree at the University of Auckland. I have a particular interest in loss and grief.

As a counsellor at the Grief Centre in Birkenhead, I’ve heard many courageous stories of the invaluable help and support often given by grandparents to their children and grandchildren in this tragic situation. But I am also aware that many feel they have to be strong for the family and have no real outlet for their own grief. The focus of my research is to look at the experiences of grandparents when their grandchild is terminally ill, has severe disability or has died and to assess whether their needs are being catered to. I am aware that there are many layers of stress, loss and grief for family members experiencing the illness of a child. For grandparents in particular there can be distress on behalf of their child, their grandchild, siblings of the grandchild and of course their own loss and grief. There can also be stress created by disempowerment for people in this situation – while grandparents have a lot of wisdom and knowledge, and may have been used to making major decisions for their children, it’s now their adult children who are given the information and are in the position of making life and death decisions on behalf of their grandchild.

I am inviting you to take part in this research project, in which I am seeking to create an opportunity for you to share your experiences associated with your grandchild’s illness or death. I am interested in hearing about the ways in which you have been affected by change, loss and grief, the resources and strengths that you draw on and the ways in which you cope, as well as your opinions about what you think is needed in the community to provide others in your situation with effective support.

The research will take the form of a focus group and a follow-up meeting at the Grief Centre, 94 Hinemoa Street, Birkenhead. Coffee, tea and muffins will be served. Participation in this research is entirely voluntary. Separate groups will be held for grandparents of children who have died, and those who have a seriously ill or disabled
grandchild. Each focus group will be between 1 ½ and 2 hours long. I will facilitate
the focus groups and the follow up discussions, and both will be audio-recorded.
Should you or any other participant become distressed within a group discussion, I am
able to provide immediate support as I am experienced in working with people in loss
and grief, and am a Provisional Member of the New Zealand Association of Counsellors. I will do my utmost to insure your comfort and safety at the focus group.
You will be served coffee, tea and muffins. Should you become distressed within a
group discussion, I am able to manage the immediate situation and provide support as
I am experienced in working with people in loss and grief, and am a Provisional Member of the New Zealand Association of Counsellors.
Besides myself, there will be a qualified support person on the premises if anyone
needs to leave the focus group and get immediate support. If it becomes apparent that
you need further support, a practitioner of the Counsellor Education Programme at the
University of Auckland would be able to provide counselling at the Grief Centre
premises free of charge, or you would be provided with the names of other qualified counsellors who could assist.
To ensure I have no conflict of interest in this research, none of the participants will
be my private clients.
The utmost care will be taken to ensure the privacy your information. You will be
asked to choose a pseudonym that will be used in the research report. Any potentially
identifiable information about you or any family member will be disguised or omitted
from the research report. However, while the importance of maintaining confidentiality within the groups will be stressed with participants, and while I am
able to make undertakings on my own behalf as researcher to protect their confidentiality, I cannot make guarantees on behalf of the group members.
As participation is voluntary, you will have the right to withdraw at any time without
having to give a reason prior to the completion of data collection on ....... It
will not be possible for you to withdraw the data you have provided from the group
discussions because of other group members’ information on the same recording.
However, any participant may request the withdrawal from the research report of a
particularly sensitive personal story or information through which they could be
personally identifiable
The only people who will see the transcripts other than myself will be my academic supervisors, Dr Margaret Agee and Dr Jan Wilson. You will be invited to choose a pseudonym that can be used in the research report.
While I am analysing the questionnaires they will be stored at my home in a locked
cabinet when I am not working on them. Data stored on my computer will be
password protected. When my research report has been completed, the transcripts of
the focus group discussions, the sociograms, and material used in the analysis will
then be transferred to my supervisor’s office at the University of Auckland, where
they will be stored securely for a period of six years. The transcripts will then be
shredded and the audio-recordings erased.
When the project has been completed, the information gathered will be incorporated
into my Research Portfolio for the University, and will possibly also be used for the
preparation of papers for publication or conference presentations. I would be happy
to provide a summary of the findings to you.
If you would like to participate or are interested in receiving further information,
please contact me via phone or email. My contact details are Val Leveson at (09) 483-
3923 or 021 1684 502 or vlev003@aucklanduni.ac.nz
My supervisors are:
Dr Margaret Agee and Dr Jan Wilson
School of Counselling, Human Services and Social Work,
Faculty of Education,
The University of Auckland
Private Bag 92601, Symonds Street,
Auckland.
Phone 373 7599 ext. 87852 or ext. 87577
Email  m.agee@auckland.ac.nz   jd.wilson@auckland.ac.nz

The Head of School is:
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For ethical concerns please contact:
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The University of Auckland, Office of the Vice-Chancellor
24 Princes Street
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Auckland 1142.
Phone 373 7599 ext. 83711

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19.9.11 for 3 years, Reference Number 2011/423.
Grief-related experiences of grandparents

Researcher: Val Leveson

Recruiter Information Sheet

My name is Val Leveson, and I am undertaking a research project in order to complete the requirements for a Master of Counselling degree at the University of Auckland. I have a particular interest in loss and grief.

The focus of my research is to look at the experiences of grandparents when their grandchild is terminally ill, has severe disability or has died and to assess whether their needs are being catered to. I am aware that there are many layers of stress, loss and grief for family members experiencing the illness of a child. For grandparents in particular there can be distress on behalf of their child, their grandchild, siblings of the grandchild and of course their own loss and grief. There can also be stress created by disempowerment for people in this situation – while grandparents have a lot of wisdom and knowledge, and may have been used to making major decisions for their children, it’s now their adult children who are given the information and are in the position of making life and death decisions on behalf of their grandchild.

I am inviting grandparents in this situation to take part in this research project, in which I am seeking to create an opportunity for them to share their experiences associated with a grandchild’s illness or death. I am interested in hearing about the ways in which they have been affected by loss and grief, the resources and strengths that they draw on and the ways in which they cope, as well as their opinions about what they think is needed in the community to provide others in their situation with effective support.

Since you may be in contact with grandparents who could be interested in taking part in this research, I am asking for your assistance in contacting prospective participants and providing them with information about the project. I will provide you with a Participant Information Sheet explaining the project, inviting them to take part and describing what this would involve, as well as a Consent Form, and am asking you to pass these on to grandparents who are potential participants.

I will do my utmost to insure participants’ comfort and safety at the focus group. They will be served coffee, tea and muffins. Should any participant become distressed within a group discussion, I am able to manage the immediate situation and provide...
support as I am experienced in working with people in loss and grief, and am a Provisional Member of the New Zealand Association of Counsellors. Besides myself, there will be a qualified support person on the premises if anyone needs to leave the focus group and get immediate support. If it becomes apparent that they need further support, a practitioner of the Counselling Education Programme at the University of Auckland will provide counselling at the Grief Centre premises free of charge, or they would be provided with the names of other qualified counsellors who could assist. To ensure I have no conflict of interest in this research, none of the participants will be my private clients.

Participation in this research is entirely voluntary and will involve taking part in a focus group discussion and a follow-up meeting at the Grief Centre, 94 Hinemoa Street, Birkenhead. Each will be between 1 ½ and 2 hours long, and separate groups will be held for grandparents whose grandchild has died, and those whose grandchild is seriously ill or disabled. I will facilitate the focus groups and the follow up discussions, and both will be audio-recorded.

The utmost care will be taken to ensure the privacy of participants’ information. They will be asked to choose a pseudonym which will be used in the research report. Any potentially identifiable information about them or any family member will be disguised or omitted from the research report. However while the importance of maintaining confidentiality within the groups will be stressed with participants, and while I am able to make undertakings on my own behalf as researcher to protect their confidentiality, I cannot make guarantees on behalf of the group members.

As participation is voluntary, participants will have the right to withdraw at any time without having to give a reason prior to the completion of data collection on ..../..../........ It will be made clear to participants that it will not be possible for participants to withdraw the data they have provided from the group discussions because of other group members’ information on the same recording. However, any participant may request the withdrawal from the research report of a particularly sensitive personal story or information through which they could be personally identifiable.

While I am analysing the questionnaires they will be stored at my home in a locked cabinet when I am not working on them. Data stored on my computer will be password protected. When my research report has been completed, the transcripts of the focus group discussions, the sociograms, and material used in the analysis will then be transferred to my supervisor’s office at the University of Auckland, where they will be stored securely for a period of six years. The transcripts will then be shredded and the audio-recordings erased.

When the project has been completed, the information gathered will be incorporated into my Research Portfolio for the University, and will possibly also be used for the preparation of papers for publication or conference presentations. I would be happy to provide a summary of the findings to you and to members of the pastoral care team and the church community, and discuss the results with them.

Your agency manager has agreed that your own participation or non participation as a recruiter is completely voluntary and there will be no consequences either way for your relationship with the agency or your manager.

If you know anyone in this situation, could you please tell them of my study and give them my contact details. If you would like to participate or are interested in receiving
further information, please contact me via phone or email. My contact details are Val Leveson at (09) 483-3923 or 021 1684 502 or vlev003@aucklanduni.ac.nz

My supervisors are:
Dr Margaret Agee and Dr Jan Wilson
School of Counselling, Human Services and Social Work,
Faculty of Education,
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APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19.9.11 for 3 years, Reference Number 2011/ 423.
Grief-related experiences of grandparents

Are you a grandparent of a child who has died, is suffering from terminal disease or is severely disabled?

Would you consider taking part in my research project?

My name is Val Leveson, and I am an Auckland-based counsellor who has a particular interest in the area of grief and loss. I am currently completing my Master of Counselling degree at the University of Auckland.

I am aware that there can be many layers of change, loss and grief for family members suffering the illness or death of a child. For grandparents there’s the grief on behalf of their child, their grandchild, siblings of the grandchild and of course themselves – and there is often a demand for grandparents to be a major support for the family – but the question is, who is supporting them?

While some grandparents play vital roles in their families at such times, some may also find themselves feeling helpless, unheard or disempowered. While grandparents have a lot of wisdom and knowledge, and used to make decisions for their children, when a grandchild is ill it is now their children who are in the primary role, who are given information and make crucial decisions on behalf of the grandchild. When a child dies, grandparents may feel unable to acknowledge their grief fully.

You are invited to take part in this research, which will take the form of a group discussion and a follow-up meeting two weeks later at the Grief Centre, 94 Hinemoa Street, Birkenhead. Coffee, tea and muffins will be served. In the group discussion I will be interested to know about your personal experiences of loss and grief when a grandchild has died, is terminally ill or is severely disabled, and what you think is needed in the community to support grandparents like yourself in this situation. Participation is entirely voluntary. If you would like to participate or are interested in receiving further information, please contact me via phone or email. My contact details are Val Leveson at (09) 483-3923 or 021 1684 502 or vlev003@aucklanduni.ac.nz
APPENDIX D

Grief-related experiences of grandparents

Researchers: Val Leveson

Grief Centre Information Sheet
Attention Carol Blair

My name is Val Leveson, and I am undertaking a research project in order to complete the requirements for a Master of Counselling degree at the University of Auckland. I have a particular interest in loss and grief.

The focus of my research is to look at the experiences of grandparents when their grandchild is terminally ill, has severe disability or has died and to assess whether their needs are being catered to. I am aware that there are many layers of stress, loss and grief for family members experiencing the illness of a child. For grandparents in particular there can be distress on behalf of their child, their grandchild, siblings of the grandchild and of course their own loss and grief. There can also be stress created by disempowerment for people in this situation – while grandparents have a lot of wisdom and knowledge, and may have been used to making major decisions for their children, it’s now their adult children who are given the information and are in the position of making life and death decisions on behalf of their grandchild.

I am inviting grandparents in this situation to take part in this research project, in which I am seeking to create an opportunity for them to share their experiences associated with a grandchild’s illness or death. I am interested in hearing about the ways in which grandparents have been affected by change, loss and grief, the resources and strengths that they draw on and the ways in which they cope, as well as their opinions about what they think is needed in the community to provide others in their situation with effective support.

I am seeking your permission to conduct this research on the premises of your agency, by facilitating the focus groups there and inviting staff members to act as recruiters of participants by passing on information about the project to grandparents they know of who could be interested. I will provide the staff members with a Participant Information Sheet explaining the project, inviting them to take part as recruiters and describing what this would involve, as well as a Consent Form, and with Participant
Information Sheets and Consent Forms for prospective participants to pass on to them.

I will do my utmost to insure participants’ comfort and safety at the focus group. They will be served coffee, tea and muffins. Should any participant become distressed within a group discussion, I am able to manage the situation and provide immediate support as I am experienced in working with people in loss and grief, and am a Provisional Member of the New Zealand Association of Counsellors. If it becomes apparent that they need further support beyond the group session, I am asking you to confirm that they would have access free of charge to counselling from other staff members at the Grief Centre, or would be provided with the names of other qualified counsellors who could assist.

If you allow me to undertake this research within your agency I would need to be able to assure the staff members who are considering taking part as recruiters that their participation or non-participation would not affect their relationship with you or with the agency.

Participation in this research is entirely voluntary and will involve taking part in a focus group discussion and a follow-up meeting at the Grief Centre, 94 Hinemoa Street, Birkenhead (as agreed by you). Separate groups will be held for grandparents of children who have died, and those who have a seriously ill or disabled grandchild. Each will be between 1 ½ and 2 hours long. I will facilitate the focus groups and the follow up discussions, and both will be audio-recorded.

The utmost care will be taken to ensure the privacy of participants’ information. They will be asked to choose a pseudonym that will be used in the research report. Any potentially identifiable information about them or any family member will be disguised or omitted from the research report. However while the importance of maintaining confidentiality within the groups will be stressed with participants, and while I am able to make undertakings on my own behalf as researcher to protect their confidentiality, I cannot make guarantees on behalf of the group members.

As participation is voluntary, participants will have the right to withdraw at any time without having to give a reason prior to the completion of data collection on …./…./...... However it will be made clear to participants that it will not be possible for participants to withdraw the data they have provided from the group discussions because of other group members’ information on the same recording. Any information that may not be relevant to the study e.g. identifiable information or names could be edited out from the transcript.

The only people who will see the transcripts other than myself will be my academic supervisors, Dr Margaret Agee and Dr Jan Wilson. You will be invited to choose a pseudonym that can be used in the research report.

While I am analysing the questionnaires they will be stored at my home in a locked cabinet when I am not working on them. Data stored on my computer will be password protected. When my research report has been completed, the transcripts of the focus group discussions, the sociograms, and material used in the analysis will then be transferred to my supervisor’s office at the University of Auckland, where they will be stored securely for a period of six years. The transcripts will then be shredded and the audio-recordings erased.

When the project has been completed, the information gathered will be incorporated into my Research Portfolio for the University, and will possibly also be used for the preparation of papers for publication or conference presentations. I would be happy to provide a summary of the findings to you and to members of the pastoral care team and the church community, and discuss the results with them.
Participation is entirely voluntary. If you would like to participate or are interested in receiving further information, please contact me via phone or email. My contact details are Val Leveson at (09) 483-3923 or 021 1684 502 or vlev003@aucklanduni.ac.nz

My supervisors are:
Dr Margaret Agee and Dr Jan Wilson
School of Counselling, Human Services and Social Work,
Faculty of Education,
The University of Auckland
Private Bag 92601, Symonds Street,
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Phone 373 7599 ext. 87852 or ext. 87577
Email  m.agee@auckland.ac.nz     jd.wilson@auckland.ac.nz

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APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19/9/11 FOR A PERIOD OF 3 YEARS. Reference number 2011/423.
Consent Form (Carol Blair, Grief Centre)
(This consent form will be held for a period of six years)

Project Title: Grief-related experiences of grandparents
Involving children with disability, cancer or other terminal illness or has died

Researcher: Val Leveson

I have read the Recruiter Information Sheet, and have understood the nature of the research and why I have been approached to assist. I have had the opportunity to ask questions and have them answered to my satisfaction. I am giving my consent to assist Val Leveson with her research by allowing the research to be conducted on the agency premises. This includes allowing staff members to pass on information about this project to grandparents who could be interested in taking part/ allowing the focus groups to take place at the Grief Centre. I understand that participation is entirely voluntary for both staff members acting as recruiters and the participants themselves, and I will not pressure anyone in any way to take part. I am willing to provide an undertaking that participation or non-participation will not affect the relationship of any staff member or any client with the agency.

I agree to take part in this research.

➢ I have been given an explanation of and have understood the purpose of this research.
➢ I understand that their participation will involve taking part in a focus group discussion and a follow up discussion and that both will be audio-recorded,
➢ I understand that this consent form will be securely stored separately from the rest of the research data for six years beyond the completion of the project when both will be destroyed by shredding.
➢ I understand that neither my name nor any personally identifiable information about me will be used in the research report.

Name………………………………………………………………………………………………………………………………………………………………………………………………………………

Signature………………………………………………….
Date…………………….

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19/9/11 FOR A PERIOD OF 3 YEARS. Reference number 2011/ 423.
Grief-related experiences of grandparents

Researcher: Val Leveson

Agency Manager Information Sheet

My name is Val Leveson, and I am undertaking a research project in order to complete the requirements for a Master of Counselling degree at the University of Auckland. I have a particular interest in loss and grief.

The focus of my research is to look at the experiences of grandparents when their grandchild is terminally ill, has severe disability or has died and to assess whether their needs are being catered to. I am aware that there are many layers of stress, loss and grief for family members experiencing the illness of a child. For grandparents in particular there can be distress on behalf of their child, their grandchild, siblings of the grandchild and of course their own loss and grief. There can also be stress created by disempowerment for people in this situation – while grandparents have a lot of wisdom and knowledge, and may have been used to making major decisions for their children, it’s now their adult children who are given the information and are in the position of making life and death decisions on behalf of their grandchild.

I am inviting grandparents in this situation to take part in this research project, in which I am seeking to create an opportunity for them to share their experiences associated with a grandchild’s illness or death. I am interested in hearing about the ways in which grandparents have been affected by change, loss and grief, the resources and strengths that they draw on and the ways in which they cope, as well as their opinions about what they think is needed in the community to provide others in their situation with effective support.

I am seeking your permission to conduct this research on the premises of your agency by inviting staff members to act as recruiters of participants by passing on information about the project to grandparents they know of who could be interested. I will provide the staff members with a Participant Information Sheet explaining the project, inviting them to take part as recruiters and describing what this would involve, as well as a Consent Form, and with Participant Information Sheets and Consent Forms for prospective participants to pass on to them.
I will do my utmost to insure participants’ comfort and safety at the focus group. They will be served coffee, tea and muffins. Should any participant become distressed within a group discussion, I am able to manage the immediate situation and provide support as I am experienced in working with people in loss and grief, and am a Provisional Member of the New Zealand Association of Counsellors. If it becomes apparent that they need further support beyond the group session, they would have access free of charge to counselling from other staff members at the Grief Centre, or would be provided with the names of other qualified counsellors who could assist. If you allow me to undertake this research within your agency I would need to be able to assure the staff members who are considering taking part as recruiters that their participation or non-participation would not affect their relationship with you or with the agency.

Participation in this research is entirely voluntary and will involve taking part in a focus group discussion and a follow-up meeting at the Grief Centre, 94 Hinemoa Street, Birkenhead. Each will be between 1 ½ and 2 hours long, and separate groups will be held for grandparents whose grandchild has died, and those whose grandchild is seriously ill or disabled. I will facilitate the focus groups and the follow up discussions, and both will be audio-recorded.

The utmost care will be taken to ensure the privacy of participants’ information. They will be asked to choose a pseudonym which will be used in the research report. Any potentially identifiable information about them or any family member will be disguised or omitted from the research report. However while the importance of maintaining confidentiality within the groups will be stressed with participants, and while I am able to make undertakings on my own behalf as researcher to protect their confidentiality, I cannot make guarantees on behalf of the group members. As participation is voluntary, participants will have the right to withdraw at any time without having to give a reason prior to the completion of data collection on ....... It will be made clear to participants however that it will not be possible for them to withdraw the data they have provided from the group discussions because of other group members’ information on the same recording. However, any information that may not be relevant to the study e.g. identifiable information or names, could be edited out from the transcript.

The only people who will see the transcripts other than myself will be my academic supervisors, Dr Margaret Agee and Dr Jan Wilson. You will be invited to choose a pseudonym that can be used in the research report. While I am analysing the questionnaires they will be stored at my home in a locked cabinet when I am not working on them. Data stored on my computer will be password protected. When my research report has been completed, the transcripts of the focus group discussions, the sociograms, and material used in the analysis will then be transferred to my supervisor’s office at the University of Auckland, where they will be stored securely for a period of six years. The transcripts will then be shredded and the audio-recordings erased.

When the project has been completed, the information gathered will be incorporated into my Research Portfolio for the University, and will possibly also be used for the preparation of papers for publication or conference presentations. I would be happy to provide a summary of the findings to you and to members of the pastoral care team and the church community, and discuss the results with them. Participation is entirely voluntary. If you would like to participate or are interested in receiving further information, please contact me via phone or email. My contact
details are Val Leveson at (09) 483-3923 or 021 1684 502 or vlev003@aucklanduni.ac.nz

**My supervisors are:**
Dr Margaret Agee and Dr Jan Wilson  
School of Counselling, Human Services and Social Work,  
Faculty of Education,  
The University of Auckland  
Private Bag 92601, Symonds Street,  
Auckland.  
Phone 373 7599 ext. 87852 or ext. 87577  
Email m.agee@auckland.ac.nz  jd.wilson@auckland.ac.nz

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Phone 623 8899 ext. 48562  
Email p.harington@auckland.ac.nz

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Phone 373 7599 ext. 83711

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19/9/11 FOR A PERIOD OF 3 YEARS. Reference number 2011/423.
Consent Form (Agency Manager)
(This consent form will be held for a period of six years)

Project Title: Grief-related experiences of grandparents
Involving children with disability, cancer or other terminal illness or has died

Researcher: Val Leveson

I have read the Recruiter Information Sheet, and have understood the nature of the research and why I have been approached to assist. I have had the opportunity to ask questions and have them answered to my satisfaction. I am giving my consent to assist Val Leveson with her research by allowing the research to be conducted on the agency premises. This includes allowing staff members to pass on information about this project to grandparents who could be interested in taking part. I understand that participation is entirely voluntary for both staff members acting as recruiters and the participants themselves, and I will not pressure anyone in any way to take part. I am willing to provide an undertaking that participation or non-participation will not affect the relationship of any staff member or any client with the agency.

I agree to take part in this research.

➢ I have their participation will involve taking part in a focus group discussion and a follow up discussion and that both will be audio-recorded,
➢ I understand that this consent form will be securely stored separately from the rest of the research data for six years beyond the completion of the project when both will be destroyed by shredding.
➢ I understand that neither my name nor any personally identifiable information about me will be used in the research report.

Name………………………………………………………………………………………………………………………………………
…. Signature…………………………………….
Date……………………………

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19/9/11 FOR A PERIOD OF 3 YEARS. Reference number 2011/ 423.
Grief-related experiences of grandparents

Factual information Sheet
Surname

…………………………………………………………………………………………………………………………
First names
…………………………………………………………………………………………………………………………
Pseudonym you would like to use for the project
…………………………………………………………………………………………………………………………
Email:
……………………………………………………………………………………………………………………………………
Address:
……………………………………………………………………………………………………………………………………
Phone number: …………… (Day) ……………… (Night) ……………………..
-Mobile
Age……………………………………
Ethnicity………………………………………
Are you currently employed?
…………………………………………………………………………………………………………………………
Age / gender of grandchild
…………………………………………………………………………………………………………………………
What is your grandchild’s diagnosed condition?
…………………………………………………………………………………………………………………………
Is the grandchild your daughter or son’s child?
…………………………………………………………………………………………………………………………
Does this grandchild live in Auckland?
…………………………………………………………………………………………………………………………
Does the grandchild have siblings? ........ If so, how many?

........................................

How many grandchildren do you have in all?

............................................................

How many are in Auckland?

..........................................................

Have you attended any help groups or counselling connected to your grandchild’s diagnosis?

..........................................................

…
Grief-related experiences of grandparents

Researcher: Val Leveson

Recruiter Information Sheet

My name is Val Leveson, and I am undertaking a research project in order to complete the requirements for a Master of Counselling degree at the University of Auckland. I have a particular interest in loss and grief.

The focus of my research is to look at the experiences of grandparents when their grandchild is terminally ill, has severe disability or has died and to assess whether their needs are being catered to. I am aware that there are many layers of stress, loss and grief for family members experiencing the illness of a child. For grandparents in particular there can be distress on behalf of their child, their grandchild, siblings of the grandchild and of course their own loss and grief. There can also be stress created by disempowerment for people in this situation – while grandparents have a lot of wisdom and knowledge, and may have been used to making major decisions for their children, it’s now their adult children who are given the information and are in the position of making life and death decisions on behalf of their grandchild.

I am inviting grandparents in this situation to take part in this research project, in which I am seeking to create an opportunity for them to share their experiences associated with a grandchild’s illness or death. I am interested in hearing about the ways in which they have been affected by loss and grief, the resources and strengths that they draw on and the ways in which they cope, as well as their opinions about what they think is needed in the community to provide others in their situation with effective support.

Since you may be in contact with grandparents who could be interested in taking part in this research, I am asking for your assistance in contacting prospective participants and providing them with information about the project. I will provide you with a Participant Information Sheet explaining the project, inviting them to take part and describing what this would involve, as well as a Consent Form, and am asking you to pass these on to grandparents who are potential participants.

I will do my utmost to insure participants’ comfort and safety at the focus group. They will be served coffee, tea and muffins. Should any participant become distressed within a group discussion, I am able to manage the immediate situation and provide support as I am experienced in working with people in loss and grief, and am a Provisional Member of the New Zealand Association of Counsellors.
Besides myself, there will be a qualified support person on the premises if anyone needs to leave the focus group and get immediate support. If it becomes apparent that they need further support, a practitioner of the Counselling Education Programme at the University of Auckland will provide counselling at the Grief Centre premises free of charge, or they would be provided with the names of other qualified counsellors who could assist.

To ensure I have no conflict of interest in this research, none of the participants will be my private clients.

Participation in this research is entirely voluntary and will involve taking part in a focus group discussion and a follow-up meeting at the Grief Centre, 94 Hinemoa Street, Birkenhead. Each will be between 1 ½ and 2 hours long, and separate groups will be held for grandparents whose grandchild has died, and those whose grandchild is seriously ill or disabled. I will facilitate the focus groups and the follow up discussions, and both will be audio-recorded.

The utmost care will be taken to ensure the privacy of participants’ information. They will be asked to choose a pseudonym which will be used in the research report. Any potentially identifiable information about them or any family member will be disguised or omitted from the research report. However while the importance of maintaining confidentiality within the groups will be stressed with participants, and while I am able to make undertakings on my own behalf as researcher to protect their confidentiality, I cannot make guarantees on behalf of the group members.

As participation is voluntary, participants will have the right to withdraw at any time without having to give a reason prior to the completion of data collection on …/…/…….. It will be made clear to participants that it will not be possible for participants to withdraw the data they have provided from the group discussions because of other group members’ information on the same recording. However, any participant may request the withdrawal from the research report of a particularly sensitive personal story or information through which they could be personally identifiable.

While I am analysing the questionnaires they will be stored at my home in a locked cabinet when I am not working on them. Data stored on my computer will be password protected. When my research report has been completed, the transcripts of the focus group discussions, the sociograms, and material used in the analysis will then be transferred to my supervisor’s office at the University of Auckland, where they will be stored securely for a period of six years. The transcripts will then be shredded and the audio-recordings erased.

When the project has been completed, the information gathered will be incorporated into my Research Portfolio for the University, and will possibly also be used for the preparation of papers for publication or conference presentations. I would be happy to provide a summary of the findings to you and to members of the pastoral care team and the church community, and discuss the results with them.

Your agency manager has agreed that your own participation or non participation as a recruiter is completely voluntary and there will be no consequences either way for your relationship with the agency or your manager.

If you know anyone in this situation, could you please tell them of my study and give them my contact details. If you would like to participate or are interested in receiving further information, please contact me via phone or email. My contact details are Val Leveson at (09) 483-3923 or 021 1684 502 or vlev003@aucklanduni.ac.nz
My supervisors are:
Dr Margaret Agee and Dr Jan Wilson
School of Counselling, Human Services and Social Work,
Faculty of Education,
The University of Auckland
Private Bag 92601, Symonds Street,
Auckland.
Phone 373 7599 ext. 87852 or ext. 87577
Email  m.agee@auckland.ac.nz  jd.wilson@auckland.ac.nz

The Head of School is:
Phil Harington
School of Counselling, Human Services and Social Work,
Faculty of Education,
The University of Auckland
Private Bag 92 601, Symonds Street,
Auckland 1150.
Phone 623 8899 ext. 48562
Email  p.harington@auckland.ac.nz

For ethical concerns please contact:
The Chair
The University of Auckland Human Participants Ethics Committee
The University of Auckland, Office of the Vice-Chancellor
24 Princes Street
Private Bag 92019
Auckland 1142.
Phone 373 7599 ext. 83711
Consent Form (Recruiter)
(This consent form will be held for a period of six years)

Project Title: Grief-related experiences of grandparents

Researcher: Val Leveson

I have read the Recruiter Information Sheet, and have understood the nature of the research and why I have been approached to assist. I have had the opportunity to ask questions and have them answered to my satisfaction. I am giving my consent to assist Val Leveson with her research by passing on information about this project to grandparents who could be interested in taking part. I understand that the participation of anyone I approach is voluntary, and I will not pressure them in any way to take part.

I agree to take part in this research.

- I have been given an explanation of and have understood the purpose of this research.
- I understand that my role in this project is to pass on information about it in the form of the Participant Information Sheet and Consent Form to potential participants who are sufficiently psychologically stable to take part.
- I understand that their participation will involve taking part in a focus group discussion and a follow up discussion and that both will be audio-recorded,
- I understand that this consent form will be securely stored separately from the rest of the research data for six years beyond the completion of the project when both will be destroyed by shredding.
- I understand that neither my name nor any personally identifiable information about me will be used in the research report.

Name………………………………………………………………………………………………………………………………………………

Signature………………………………………………….

Date…………………….

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19/9/11 FOR A PERIOD OF 3 YEARS. Reference number 2011/ 423.