Love, Listen and Learn: Grandparents' Experiences of Pregnancy Loss

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Abstract

In Australia, approximately 15-20% of pregnancies result in miscarriage, and 0.69%, or six per day, result in stillbirth. Pregnancy loss is a deeply distressing experience for parents, many of whom may turn to their families, particularly their parents, for support. Pregnancy loss has been identified as an ambiguous loss leading to disenfranchised grief, and while there is greater knowledge of parents' experiences, little research has been conducted regarding grandparents' experiences following pregnancy loss. Much of what is known about grandparents comes indirectly from family studies of grief and loss. Using a qualitative research design, this study aimed to explore grandparents' experiences of grief, and both formal and informal supports following the loss of a pregnancy. Interviews were conducted with one grandfather and 14 grandmothers. A thematic analysis identified 13 themes, categorised into three sections reflecting the aims of the study. Findings indicated that pregnancy loss was an ambiguous and compound loss, with grandparent grief disenfranchised. Grandparents provided support to their children in multiple ways, but lacked confidence in doing so. Grandparents received few formal supports, and relied on close family and social networks. Grandparents indicated that early access to information would provide guidance, and ongoing face to face peer support would be beneficial, with flexible options for isolated grandparents. Community education was considered important, and participation in raising awareness was a helpful way for grandparents to honour their loss and assist others.

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University and, to the best of my knowledge, this thesis contains no materials previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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Chapter 1: Introduction

1.1 Overview

A large body of research literature has increasingly recognised the potential psychological distress that can be experienced following pregnancy loss (Cacciatore, 2013; DeFrain, Millspaugh, & Xie, 1996; Koopmans, Wilson, Cacciatore, & Flenady, 2013). Much of this literature and subsequent care guidelines focus on the specific needs of mothers, with a very small body of research pertaining to men's experiences of pregnancy loss and support (Bonnette & Broom, 2011; McCreight, 2004; Obst & Due, 2017). Studies investigating grandparents' experiences following pregnancy loss are rare, with much of the literature relating to grandparents' experiences described as 'by the way' knowledge, or knowledge gained incidentally from other research (Murphy & Jones, 2014; Schmid, 2000; White, Walker & Richards, 2008). Given the role that many grandparents play in family structures (Hagestad & Lang, 1986; Schmid, 2000; White et al, 2008) it could be anticipated that grandparents are also affected by pregnancy loss and therefore in need of support. This study aims to add to the limited knowledge in this area and to explore grandparents' experiences of support following the pregnancy loss of a grandchild.

1.2 Definitions and Terminology

1.2.1 Defining pregnancy loss

In Australia, a stillbirth is defined as a death in-utero from 20 weeks' gestation (or over 400 grams in weight) (Hure et al., 2012). Rates of stillbirth in Australia have remained relatively stable over the last two decades. In 2016, stillbirth accounted for 2160 births (0.69 %; Australian Bureau of Statistics [ABS], 2017). Miscarriage is defined in Australia as a pregnancy loss occurring at less than 20 weeks' gestation (Hure et al., 2012; Rinehart & Kiselica, 2010). The incidence of miscarriage is more difficult to determine, however

miscarriage is estimated to occur for 15-20% of recognised, and up to 50% of unrecognised pregnancies (Breeze, 2016; Hure et al, 2012). Across the literature, a range of terms have been adopted to distinguish between losses that occur at different ages of gestation, (Murphy & Cacciatore, 2017; Wright, 2011). While this must be accounted for in discussion of the literature, for the purposes of this research, Australian conventions will be followed, where miscarriage refers to a loss before 20 weeks' gestation, and stillbirth to a loss at or after 20 weeks' gestation.

While definitions vary between losses at different gestational ages, there is currently no evidence to suggest that the psychological experience of loss is affected by gestational age (McCreight, 2008). Rather, studies suggest that highly varied grief responses are common following all types of loss, and, rather than gestational age, grief reactions are determined by factors including level of attachment to the unborn baby, obstetric history, prospect of further children, coping strategies, and support options (Brier, 2008; Draper, 2002; Harpel & Hertzog, 2010; Hutti, Armstrong, Myers & Hall, 2015; Lin & Lasker, 1996; O'Leary, Walker and Parker, 2011; Schmid, 2000). Similarly, while outcomes for parents faced with the choice to have a medically indicated termination (eg., for non-viability) appear dependent upon gestational age, support and education level (Korenromp et al., 2005), no research was found to identify grandparents' outcomes following this type of pregnancy loss. Thus, for the purposes of this research, the term 'pregnancy loss' includes stillbirths, miscarriages and medically indicated termination of pregnancy.

1.2.2 Defining 'Grandparent'

For the purposes of this research, a grandparent includes both maternal and paternal grandparents; grandmothers and grandfathers. Furthermore, diversity of family structures means that non-biological grandparents may be as attached to, and involved in the care of the child as the biological grandparent (Pashos, Schwarz & Bjorklund, 2016) and therefore

experience a pregnancy loss in similar ways. As no prior research was discovered that investigated these concepts with respect to pregnancy loss, any individual who identified as a grandparent was eligible for inclusion in the study.

1.3 The Unique Role of the Grandparent

Grandparents have a unique role in families. Each family has its own structure and norms, and consequently, the role that grandparents play in the lives of their children and grandchildren is equally varied (Hagestad & Lang, 1986; Schmid, 2000; Uhlenberg & Hamill, 1998; White et al., 2008). Some grandparents are instrumentally involved in the day-to-day care of their grandchildren, others are emotional supports, and yet others adopt a figurehead role. Physical distance also influences the role that grandparents may have in their grandchild's life (Joy, 2013; White, 2002). Furthermore, Rosenblatt (2017) proposed that families have rules and norms (eg., those related to cultural background) which are often unspoken, that guide and shape family dynamics and rituals, including those following a death. Therefore, each family has its own unique experience of grandparent/ child/ grandchild interrelationships.

Moreover, White (2002) proposes that the relationship between grandparents and grandchildren is mediated by parents of children, suggesting that the adult child's need for support activates the grandparent support system, particularly during times of severe stress. Grandparents can provide security and protection at times of crisis (O'Leary et al., 2011) Therefore, during events such as pregnancy loss, the need for grandparent involvement may be heightened, and the role that grandparents play may change to one that encompasses a more extensive array of supports.

1.4 The Impact of Pregnancy Loss

A growing body of research has acknowledged the potential psychological and emotional impacts of pregnancy loss for parents. High levels of psychological distress are

common immediately following the loss and can be long lasting (Cacciatore, 2013; Callister, 2006; Flenady et al, 2014; Hutti, 2005; Koopmans et al, 2013; O'Leary & Henke, 2017; Schmid, 2000). Advances in obstetric medical technologies such as the use of ultrasound imaging have facilitated early interaction with the baby, and provide parents, and grandparents, with opportunities to form attachments to the child at an early gestational age (Bonnette & Broom, 2011; Harpel & Hertzog, 2010; Koopmans et al., 2013). Historically, the death of infants was common, and families were encouraged to 'move on' and 'get over it' quickly. Improved medical technologies have increased expectations of a successful pregnancy and while miscarriage is still anticipated, other later term losses are more unexpected, particularly later in pregnancy (Schmid, 2000; Wagner, Vaughn, & Tuazon, 2018). Furthermore, while there is minimal research specifically investigating grandparent grief and pregnancy loss, findings of studies into the loss of a grandchild during the perinatal period suggest there is little difference in severity of grief between babies who die during late pregnancy, the neonatal period and infancy (Dent & Stewart, 2004; Frisman, Eriksson, Pernehed & Morelius, 2012; Stewart, 2000).

When a pregnancy is announced, many grandparents begin rehearsing their grandparent role in preparation for the birth (Harpel & Hertzog, 2010; Schmid, 2000). Many grandparents find pleasure in their relationship with their grandchildren, a relationship which can be mutually satisfying (Joy, 2013). The death of a grandchild is devastating for most grandparents; many have described the loss of a grandchild as the most difficult loss they have ever experienced (White et al., 2008). Therefore, it could be anticipated that for many, the loss of an expected grandchild would be equally distressing.

1.5 Loss and Grief

1.5.1 Ambiguous loss, disenfranchised grief and compound grief

This section will draw upon research on loss of grandchildren of any age, given the lack of research pertaining to grandparent experiences of pregnancy loss specifically. The unexpected loss of an unborn baby has been identified as a form of ambiguous loss (Betz & Thorngren, 2006; Callister, 2006; Lang et al., 2011; O'Leary et al., 2011). Ambiguous loss occurs where there is a physical presence of the person but a psychological absence, or, in the case of pregnancy loss, the physical absence but psychological presence of the person. While the death of a child is associated with particularly severe grief, the loss of an unborn baby is intangible and assumed to be less severe, remaining unrecognised and misunderstood (Betz & Thorngren, 2006). The absence of open acknowledgement and understanding among social support networks can lead to feelings of powerlessness, isolation, and difficulty accepting the loss. Families may find themselves unable to move through the grieving process, and may need help defining the loss in order to facilitate validation, processing and acceptance (Betz & Thorngren, 2006; Cacciatore et al, 2008; Lang et al., 2011; Rycroft & Perlesz, 2001; Worden, 2008).

Furthermore, pregnancy loss can result in disenfranchised grief, the grief experienced when a loss goes unrecognised or cannot be openly acknowledged (Callister, 2006; Doka, 1999; Kauffman, 2002; Lang et al., 2011; Mortell, 2015; Worden, 2008). Disenfranchised grief is common following pregnancy loss, where a lack of social recognition for the baby as a living individual, time limits imposed on grieving, and an absence of prescribed norms and rituals of mourning mean that open grieving is minimised (Brier, 2008; Cacciatore et al., 2008; Doka, 2002; Lang et al., 2011; Mortell, 2015; O'Leary et al., 2011; Rycroft & Perlesz, 2001; Wagner et al, 2018). Bereavement research that has focused on grandparents indicates that they are deeply affected by the loss of a grandchild, while simultaneously providing

significant support to their adult children (White et al., 2008). This can lead to self-disenfranchisement by the grandparents, as they prioritise support for their child over their own wellbeing (Betz & Thorngren, 2006; Dent & Stewart, 2004; Gilrane-McGarry & O'Grady, 2012; Murphy & Jones, 2014; Schmid, 2000).

Moreover, grandparent loss and grief has also been identified as a compound grief, a double, or even triple burden (Beder, 2004; Frisman et al., 2012; Gilrane-McGarry & O'Grady, 2012). Grandparents experience grief at the loss of not only their grandchild, but also at the grief of their child, and grief at the changes these losses bring to behaviour, connection, family dynamics and functioning. Some grandparents describe a permanent change in family relationships because of these compounded losses, further contributing to the weight of their grief (Beder, 2004; Frisman et al, 2012; Gilrane-McGarry & O'Grady, 2012; Schmid, 2000; White, 2002). While not wanting to exacerbate their child's grief, grandparents struggle to know how best to help their child, with this sense of helplessness and powerlessness adding to their grief (Betts & Thorngren, 2006; Schmid, 2000; White 2002).

1.5.2 Individual differences in grieving styles

A literature search found no research pertaining specifically to differences in grieving style between grandmothers and grandfathers following the loss of a grandchild either during pregnancy or in the perinatal period. Research relating to adult grief responses to pregnancy loss have supported stereotypes that men are less likely to outwardly display their emotions, and face challenges seeking or accepting help for grief (Conway & Russell, 2000; Obst & Due, 2017; Wagner et al., 2018). However, Doka and Martin (1998) propose a continuum of grief reactions, ranging from instrumental grief, marked by cognitive and problem-solving grief management, to intuitive grief, marked by emotive, help-seeking grief management. This model emphasises that grieving style is not solely determined by gender, and further

research has identified grief as a complex and dynamic process that varies according to contextual, individual and relational variables, for example age, cultural background, spirituality and prior experiences and coping skills (Addis & Mahalik, 2003; Doka & Davidson, 1998; O'Leary et al., 2011; Rosenblatt, 2017).

1.5.3 Impact of grief on health and wellbeing of older persons

Grandparents experience both physical and psychological effects of grief and describe symptoms ranging from disbelief, to somatic symptoms, anxiety, depression and thoughts of suicide, following the death of a grandchild (Youngblut, Brooten, Blais, Kilgore, & Yoo, 2015). Stress related health outcomes, including hypertension, angina and cancer are also found to increase (Ponzetti & Johnson, 1991). If, as mentioned, there is little difference in severity of grief between death of a child during late pregnancy, the neonatal period or during infancy (Dent & Stewart, 2004; Frisman et al, 2012; Stewart, 2000) exploring the psychological and physical consequences of pregnancy loss is important for understanding care needs.

1.6 Current Care and Support Guidelines

As a consequence of the growing body of research literature on pregnancy loss, guidelines for perinatal healthcare professionals have been produced to inform quality care practices (Koopmans et al., 2013; Peters, Riitano, Lisy, Jordan, & Aromataris, 2014). In Australia, the Perinatal Society of Australia and New Zealand (PSANZ) have published clinical practice guidelines which include the psychological and social aspects of perinatal bereavement and care (Flenady et al., 2009). While many of the recommendations are applicable to both miscarriage and stillbirth, it should be noted that these guidelines focus primarily on support for later loss experiences, beyond 20 weeks' gestation. Furthermore, there are no current guidelines or recommendations addressing grandparent needs. Stillbirth

and Neonatal Death Support (SANDS) Australia produce a leaflet for grandparents, however access to this is reliant on grandparents independently seeking assistance.

1.7 Grandparent Support

1.7.1 Generational changes in support for pregnancy loss

There have been significant changes in support provided to mothers over the last 40 years (Cacciatore, 2013; Flenady et al., 2014; Koopmans, 2013). Practices focus on the parents, time with the baby and establishment of support networks (Schmid, 2000; Wagner et al, 2018). This represents a significant change from care practices grandparents may have experienced during their childbearing years, who, prior to the 1980's, were more likely to have their baby removed by hospital staff, and be advised to simply forget about their baby and carry on with their lives (Schmid, 2000; Wagner et al, 2018; White, 2002). These changes may lead to uncertainty on the part of grandparents regarding their role in supporting their child following pregnancy loss.

1.7.2 Supporting their child

Grandparents are frequently the first people notified of the loss of a grandchild, and therefore the first to provide support. Bereavement in families is as complex as bereavement in individuals, with each journey through grief being unique (White, 2002). With the loss of a grandchild post-natally, many grandparents report the desire to support their child, but lack confidence in knowing how best to do so. The complexities of grief can result in misunderstandings and a sense of helplessness for grandparents, which can be compounded by the ambiguity of pregnancy loss, and generational differences in experience and expectations (Betz & Thorngren, 2006; de Montigny, Beaudet, & Dumas,1999; Gilrane-McGarry & O'Grady, 2012; Murphy & Jones, 2014; O'Leary et al., 2011; O'Leary & Henke, 2017). Furthermore, families may be widely dispersed, adding further complexity and a physical barrier to providing support (Schmid, 2000; White, 2002).

1.7.3 Receiving support

Based upon studies of neonatal and infant loss, grandparents often provide extensive support for their family when a grandchild dies (Youngblut et al., 2015) and may neglect self-care and seeking support (Gilrane-McGarry & O'Grady, 2012; Schmid, 2000; White et al, 2008). With a lack of formal guidelines, supports may not be offered in health care settings, and while a range of support organisations exist for pregnancy loss, few advertise specific support services for grandparents. As a result, this age group, more vulnerable to the consequences of stress and grief, may face challenges receiving the supports needed for their own wellbeing (O'Leary et al., 2011; Youngblut et al., 2015). Therefore, identifying existing support networks and areas of need allows for education of the community, and appropriate targeting of support services, facilitating ongoing positive outcomes for these forgotten grievers.

1.8 Aims and Research Questions

While research has resulted in increased understanding of the support needs of parents (Cacciatore, 2013; Flenady et al, 2014; Koopmans et al., 2013; Murphy, 2012, Obst & Due, 2017), there continues to be minimal research regarding grandparents' grief following a child's pregnancy loss. The lack of knowledge and recognition of the complexity and extent of grandparent experiences, may result in long-term impacts on their own wellbeing, and on the wellbeing of the family. Moreover, grandparents support needs remain unrecognised in the perinatal loss care guidelines. To address this gap in the literature, this study aims to explore grandparents' experiences of support following pregnancy loss, through the following research questions: 1) How do grandparents experience grief following a pregnancy loss, and what effects does this have? 2) What supports are provided by grandparents to their child following pregnancy loss? 3) What supports are available to

grandparents following their child's pregnancy loss? and finally 4) What supports would grandparents see as valuable, and what barriers and facilitators exist to accessing support?

Chapter 2: Method

2.1 Participant Characteristics

Participants were one male and 14 females from across Australia, whose child had experienced a pregnancy loss between six months and five years ago, and who were fluent in English. The exact nature of the pregnancy loss varied, with four grandparents experiencing more than one type of loss. Eleven experienced a stillbirth, five experienced one or more miscarriages, and two experienced a medically indicated termination at 20 weeks or more. Grandparent ages ranged between 52 and 70 years (M = 59.4, SD = 4.4) and time since loss ranged between six months and four and a half years (M = 23.6 months, SD = 15.3). Table 1 provides a summary of participant characteristics.

Table 1

Summary of Participant Characteristics

Gender	Age	Cult. back ground	No. of Children	D/S	Type of Loss	Time Since Loss	No. of G/children Living (expected)
Female	70	Aust	2	D	MC x 2	19mths, 3 yrs	2
Female	N/A	Aust	3	S	SB term	6.5 mths	0
Female	57	Aust	3	D	1 twin SB, 1 died at birth 37 wks	15mths	6
Male	58	New Zealand	2	D	1 MITOP, previous MC's	2 yrs	1 (1)
Female	64	Aust	4	D	SB 30 wks	3 yrs	6

Gender	Age	Cult. back ground	No. of Children	D/S	Type of Loss	Time Since Loss	No. of G/children Living (expected)
Female	52	Maltese/ Aust	2	S	SB 27 wks, 2 x MC, 10 & 17 wks	16 mths	7
Female	59	Aust	2	D	SB term	4 yrs	3
Female	56	English	6	S	SB 33 wks	15 mths	4
Female	59	Aust	2	S	2 x MITOP post 22 wks	4.5 yrs, 6mths	2
Female	63	Aust	3	S	SB term	3.5 yrs	6
Female	61	Aust	2	D	SB 37 wks	6mths	1 (2)
Female	55	Aust	2	D	SB 23 weeks	13 mths	0
Female	56	Aust	3	S	SB term	12	4 (2)
Female	60	Aust	2	D x 2	MC x 3	17mths, 3yrs	4
Female	62	Aust	2	D	SB 22 wks	3 yrs	3

Note. SB=Stillbirth, MC=Miscarriage, MITOP = Medically Indicated Termination of Pregnancy, D = daughter, S = son, wks = weeks, mths = months, yrs = years, Aust = Australian

2.2 Procedure

The study was approved by the University of Adelaide Human Research Ethics Committee, approval number H-2018-070. To recruit grandparents, information and flyers

(Appendix A) were submitted to organisations where grandparents experiencing pregnancy loss might seek information and support, such as SANDS (Australia), the Stillbirth Foundation (Australia) and Perinatal Anxiety and Depression Australia (PANDA, Australia). In addition, community groups such as Rotary, Probus, local councils and church-based groups were also contacted as possible sources for recruitment. Potential participants were invited to contact the researchers by email or telephone, to express interest, and ask any questions. Participant Information Sheets were then emailed or posted to potential participants (Appendix B), and a Consent Form was emailed to interstate participants for signing and returning (Appendix C). For South Australian participants, a Consent Form was provided and completed immediately prior to the interview. Interview times and venues were arranged to be as convenient as possible for participants. Participants were advised that participation was voluntary, they were free to choose not to answer any question/s, and could withdraw from the study at any time until the end of data collection.

To allow for triangulation to improve validity of findings, attempts were made to recruit health professionals or support providers who had experience supporting grandparents who had experienced pregnancy loss, for example psychologists, counsellors, general practitioners and chaplains. Inclusion criteria for health professionals and support providers were that they were over 18 years of age, were fluent in English and had provided support in the previous 5 years. A broad definition of "support" was used in anticipation of the likelihood that healthcare professionals working directly with grandparents who had experienced pregnancy loss would be limited. To recruit support providers, information and flyers (Appendix A) were submitted to organisations where people providing counselling to bereaved parents or grandparents might be found, such as SANDS (Australia), the Stillbirth Foundation (Australia), PANDA (Australia), church-based community support organisations, the Midwives Board of Australia, the Independent Midwives Association, the Psychotherapy

and Counselling Federation of Australia, and the Australian Psychological Society website. In addition, the information was emailed to psychologists working in the perinatal field, and obstetric shared care general practitioners were contacted. Despite these efforts, only one private psychologist responded who had experience working with parents, but not grandparents. The psychologist did not feel they had any information to contribute, and therefore no formal interview was conducted.

The interviews took a semi-structured approach, with a series of open-ended questions developed based on previous studies concerning pregnancy loss (Obst & Due, 2017), and theoretical concepts discussed earlier in this thesis, for example those of disenfranchised grief (Basile & Thorsteinsson, 2015; Betz & Thorgren, 2006; Bonnette & Broom, 2011; Doka, 2002; McCreight, 2004). More specifically, questions focussed on experiences of grief, support needs, advice participants would give another grandparent experiencing pregnancy loss, advice they would like to have received, and whether the pregnancy loss had impacted on their relationship with their child. Demographic information was also collected. The interview schedule can be found in Appendix D.

In accordance with qualitative research practice (Braun & Clarke, 2006; Braun & Clarke, 2013), a pilot interview was conducted in May 2018 with a grandmother, to assess the appropriateness and clarity of the interview schedule. Small adjustments were made to the order of questions and an additional question relating to support during hospital procedures was added, as this was raised by the participant as important. This interview was included in the data set. Following reflection and review after each interview, additional questions or adjustments were considered, based upon information disclosed by participants, and added to the interview schedule if relevant to the aims of the research. This process was aided by the use of an audit trail (Appendix E). No additional questions were added after the fourth interview.

All interviews were conducted by the primary researcher (JL), with the first interview after the pilot also completed with an academic supervisor (MO). Demographic information was collected from the participants via email following the interview, if not already provided before or during the interview. A copy of the Participant Information Sheet, with support contact details included, and the SANDS Grandparent Leaflet were also forwarded to participants post-interview.

Interviews were completed between May and July 2018. The majority of interviews involved participants residing interstate, with 11 interviews conducted via telephone. One interview was conducted in a quiet public café, three in a private room at the university, and one in a private office at a participant's workplace. Interviews ranged between 27 minutes and 82 minutes, with an average length of 56 minutes. Data saturation (Guest, Bunce, & Johnson, 2006) was achieved by the tenth interview, however interviewing continued until all grandparents who had contacted the researcher prior to 31st of July were interviewed.

Interviews were transcribed verbatim using an orthographic approach, by the researcher, on a password locked computer (Braun & Clarke, 2013). Confidentiality and anonymity were maintained by allocating each participant a pseudonym, and removing any names and identifying features from the transcripts. Tracy's (2010) "Big-Tent" criteria for excellence in qualitative research were followed to enhance methodological rigour. As noted above, an audit trail was kept to facilitate data analysis, reflect on the quality of the interview process, and to enable decisions regarding interview schedule modifications. This also included records of all the interactions with the participants and support organisations, including emails and summaries of telephone calls, thereby enabling tracking of decisions regarding the research process and the organisation of the data. All participants were forwarded a copy of their interview transcript, allowing for 'member reflections' (Tracy, 2010). Six grandparents replied to this email. Four reported that they were satisfied with the

content, one requested minor changes, adding a brief postscript to the interview summarising her feelings about her grief following reflection upon the interview. The postscript was added to the transcript and included in the analysis.

Finally, it is important to engage in a process of self-reflexivity while conducting qualitative research. This process of engaging in honest and transparent self-awareness leads to more sincere research (Braun & Clarke, 2013; Tracy, 2010). The researcher (JL) is a middle-aged female, with three children and experience of pregnancy loss. Though any questions about the researcher were deferred until after completion of each interview, the researcher being close in age to participants may have influenced the way in which the grandparents interacted with the researcher, facilitating more open conversation across some question areas. However, this may have led to an assumption that certain experiences were understood by the researcher and therefore did not require further explanation. Reflection following each interview provided a reminder regarding the importance of the format of the interview schedule. The researcher also kept a diary of her thoughts and feelings following each interview, to ensure that through hearing participants stories of personal grief, and considering her own experiences, the researcher was better able to maintain consistency in her approach to all interviews. The researcher also used this to reflect on strategies to maintain a balance between reassurance and encouragement for participants disclosing their grief, and her ability to maintain objectivity. Many participants expressed gratitude for the opportunity to share their experiences, and for the opportunity to participate in research that may help others.

2.3 Data Analysis

Data analysis was completed using Braun & Clarke's (2013) approach to Thematic Analysis (TA), from a realist ontological position. This position assumes that reality is

independent from human knowledge and corresponds with exactly what is present. Therefore, data was analysed as a reflection of participants lived experiences.

Thematic Analysis is a flexible systematic process, involving six major steps (Braun & Clarke, 2013). The first step, immersion and familiarisation with the data, involved transcription, multiple readings of the data, and identification of preliminary ideas. Following this, initial codes were generated by identifying features from across the data set relating to the research questions. The third step involved grouping the identified codes into possible themes. In the fourth step these potential themes were then reviewed extensively to ensure that the themes fit well to the data, and in relation to the aims of the research. The fifth step developed and named the most appropriate themes for the data set, and finally the most appropriate illustrative extracts were identified. Themes were then discussed with one of the student supervisors (CD) to ensure trustworthiness of the themes, and to ensure that the analysis was developed from a clear, coherent and meaningful platform.

Chapter 3: Results

3.1 Overview

Themes were allocated into three categories, reflecting the research aims outlined in Chapter 1. Specifically, these were Grief, Support, and Grandparent Needs. Within these categories there were five themes relating to grief, five themes relating to support, and three themes relating to grandparent needs for the future. Figure 1 summarises these findings.

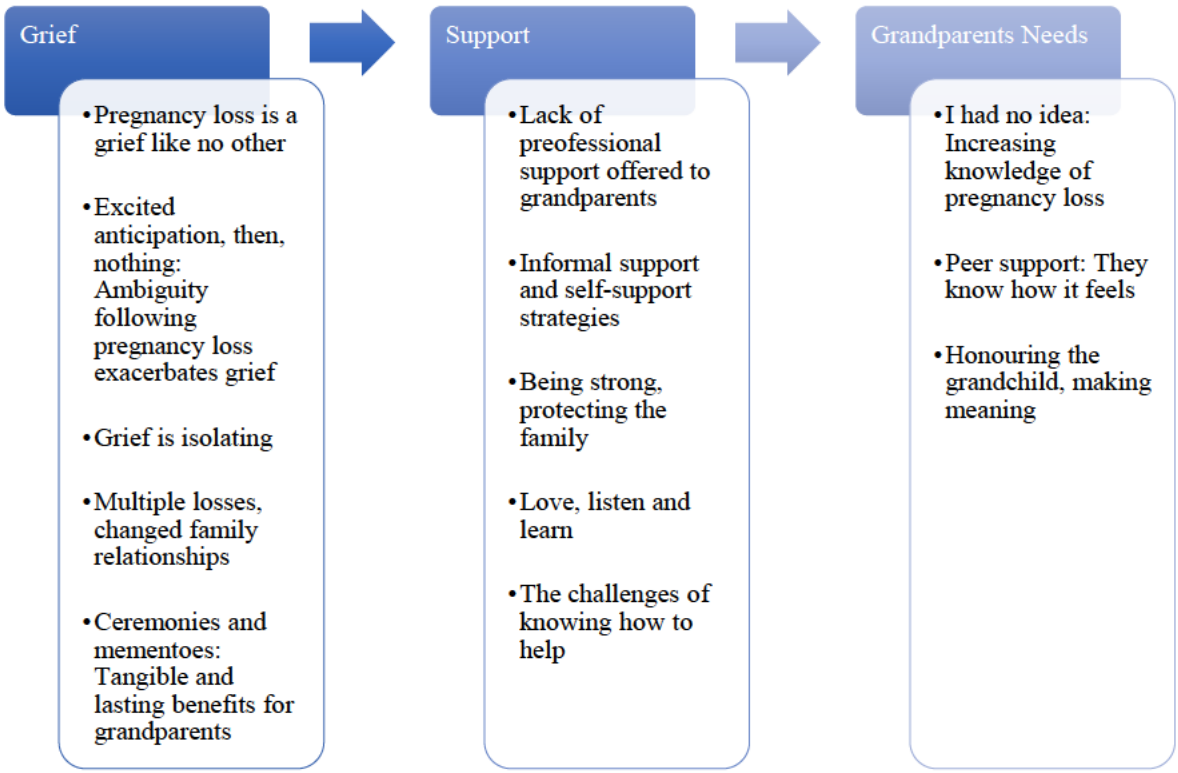

Figure 1. Thematic map

3.2 Grief

3.2.1 Pregnancy loss is a grief like no other

Participants commented that while the experience of their child's pregnancy loss and their own grief was different for everyone, participants felt it was a unique form of grief like no other they had experienced. In particular, participants highlighted that grief was inevitable for grandparents:

> "..I think every grandparents journey is totally different. Yes, we all go through the grief, but everybody does it in their own process, and you have no control over that unfortunately." ([redacted] Lines 67-69)

Shock and denial were typically expressed as the initial reactions to hearing about the loss of a grandchild. Grandparents described their grief at the loss of their grandchild as a grief like no other:

> "(Deep sigh) Look [interviewer] it just brought grief to another level. We've both lost parents. (Wife's) mum is still alive, but her dad's dead, and my parents are both dead, and we've lost other elderly friends and relatives, but the losing of little (granddaughter) that just ramped things up to a completely different level and yes, um, unbelievably difficult at the time. We are so glad we went and we are so glad we were part of it, but the sadness was just massive." ([redacted] Lines 70 -75)

All participants, regardless of time since the loss, experienced some emotional distress during the interviews. Grandparents explained that they learned to live their lives with the grief, to carry it with them:

> "Yes the grief is always, um it's always there, it never leaves you but the intensity is different at different times. […..] I don't know why but its um, sometimes it's still very raw and other times you can talk about it like now." ([redacted] Lines 305 - 308)

The intensity of this grief is reflected in an expressed desire to do anything to take away the pain of this loss for their child:

> "As I said I get, I didn't know what, I didn't know what to say or do, like as I said, I'll do anything I, if I, anything in my power to take it away, even if it meant, you know, if something dreadful happening to me I would have done it" ([redacted] Lines 606 – 608)

Many participants commented that following an initial period of intense grieving they realised they needed to make a choice to start functioning again. [redacted] expressed this:

> "Yeah and you just, well you know as time goes on its not totally consuming but it's always there and you just, yeah you have to accept it, and that life's going on. It's not life ending for you it was life ending for them, and they're still part of the family but you, yeah, you've still got to go on." (Lines 596-599)

3.2.2 Excited anticipation, then, nothing: Ambiguity following pregnancy loss exacerbates grief

The ambiguity of pregnancy loss added to the grief experienced. Grandparents spoke of the anticipation of the arrival of their grandchild, and the disbelief at their loss:

> "It was, it was as bad as it could be and I think I thought it just couldn't be real, it couldn't be real, because they were fine we saw them every day, we saw them and they were fine, because we would see the ultra sound, and then once a week she would have the big one and we could see them as clear as a bell so they were fine they were fine. But they weren't fine and yeah so, and that was sad." ([redacted] Lines 154-159)

In addition, the lack of opportunity to spend time with their grandchild, and lack of memories of time shared together, added to the ambiguity of the loss and resulting grief. In particular, participants highlighted that, after pregnancy loss, there was a perception that there was nothing to reflect on, laugh about or share with others:

> "Because they've never been there, you have them for a couple of hours, and you know what, you know you've gone through the pregnancy and then you have, you are supposed to have a bouncing baby crying, and you end up with, umm (daughter) has two baby boys that didn't breathe. Yeah, it's totally different. Because you haven't got ((pause)) you've lost them, but you've lost their whole life as well." ([redacted] Lines 668-672)

Where there was physical distance from their child, the ambiguity associated with grief and loss appeared to be more profound. Distance prevented grandparents having opportunities to hold their grandchild after birth, be present to help their child during any hospital interventions, or attend memorial events with their child. [redacted] shared the memories she has of her granddaughter:

> "No that's right there's just this sort of nothing-ness you know so I just thought well you know I was really affected you know and I thought why am I so affected I don't know why I am, um and I still miss her now. And I think you know um cos you know when she was born and they had her in the hospital they would text me and say you know she's got hair like her daddy you know and she's got and they would describe her and how beautiful she was, and that's all they have you know, you know that's all I have really." ([redacted] Lines 188-195)

It is also noteworthy that the presence and enjoyment experienced with other grandchildren, either prior to or following the loss(es), did not reduce the grief felt following pregnancy loss:

> "And the next child doesn't replace him, and I think that the other thing people need to remember that you can't just say when the next baby comes along, well you're over it because you're not, you know he's still in existence, he's still an entity he's still part of your life and you can't ignore him, and I think it's really hurtful to the parents. I mean we now talk openly about (grandson) um as family you know" ([redacted] Lines 558-563)

3.2.3 Grief is isolating

Many grandparents spoke of wanting to hide their grief from their child, in order to protect their child from added pain. This also extended to the community, where many grandparents felt uncomfortable talking about their loss, felt they could not discuss their grief, or felt unsupported when they did. As a result, grandparents became used to hiding their grief, or holding it within:

> "I think yes, it seems to be a taboo, an absolute you know taboo, it's the same as stillbirth, its ok, its ok to talk about um you know SIDS, oh 'my baby you know passed away' at whatever weeks or months {mm} you know that seems to be acceptable but as soon as you mention a stillbirth it's like 'woah, you know, we can't

> go there' […] It seems to be if you bring a child home its more accepted in society, if you lose that child you're given the free rein you can talk, but if you don't bring that child home, stillbirth, miscarriage, it doesn't matter when that miscarriage is, it's still a loss, you can't, it's a taboo" ([redacted] Lines 482-489)

As a result, grandparents who did not have close support found their grief to be very isolating:

> "That's what I think was the biggest thing as a grandparent the isolation, because the monumental grief that your children are going through you feel all of that but you're not really part of it, so you're there as a support person for them. But I don't believe that they actually see the impact on you either because of course it's their loss and it's horrific you know. I don't think um, it's very isolating particularly maybe being by yourself." ([redacted] Lines 106-111)

When grandparents did share with others, they spoke of being careful who they shared their loss with, rather than be confronted with unhelpful or distressing comments. This made the isolating aspect of pregnancy loss particularly insidious. For example:

> "But you need to be very choosy who you talk to, you know, some people don't understand it's too hurtful to talk about something that means a lot to you um you know to be rebutted really, yeah so, yeah be choosy about who you talk to about it." ([redacted] Lines 673-676)

However, grandparents acknowledged that internalising their grief was not always helpful for their wellbeing, and allowing themselves to express their grief was beneficial:

> "Just feel what you feel, don't try and not feel it like, ((pause)) I think ((pause)) the first time I held my son ((pause)) after, after we found out that (granddaughter) wasn't going to live, be delivered live was, ((pause)) crying together was pretty good

> […] so, you know cos I was like ((sigh)) going 'be strong be strong be strong'[..] and I'm glad I did." ([redacted] Lines 648-654)

3.2.4 Multiple losses, changed family relationships

The grief associated with pregnancy loss is not limited to the death of the grandchild. Participants in this study indicated that they also grieved for their child, and their child's experience of loss. For example:

> "It's like two lots of grief, because, but I don't want it to sound like it's as bad as um my daughter's loss, its different, it's a different grief, because you're grieving the loss of a grandchild, and you're also grieving for your daughter and her loss and it's like yeah you've been kicked in the guts twice instead of once…. but, yeah, I don't know how to explain how that feels, it's very, um its very uncontrollable. You're a mother and your supposed to take care of your children and make it right you know but you can't, you know, that feeling never goes away, whether they're grown up, or little kids that feelings with you for ever." ([redacted] Lines 541-548)

Grandparents whose child may have experienced difficulty conceiving, or may be limited by age, may lose hope of becoming a grandparent at all. As such, participants spoke of compounding impacts on grief related to a loss of hope and anticipation for grandchildren, and fear for future pregnancies:

> "I just think you know, as a family we're pretty strong, and you know, even though we're, you know it's been devastating ((pause)) so much loss, we're just looking forward to this little baby, not that we'll ever forget (granddaughter) cos she was beautiful, but um you know it's just something you've got to live with, so you know I dont think my daughter and son in law will have another one, I think this is it, it just puts so much strain on (daughters) body and her mental health and that I think that ion they get through this one and it's a healthy baby I think that will be it for them

> ((laughs)) you know, we'll just try and sort of have a, you know, happy family." ([redacted] Lines 624-631)

In addition to this, grandparents indicated that pregnancy loss frequently changed their relationship with their child in some way. Some felt they were closer, having been able to share such an experience. [redacted] shared:

> "It was a horrific part of our life but I guess the beauty of it was it brought the family very close together cos we were all there to support my son and his wife and um and I guess it makes all of the grandchildren even more valuable ((pause)) cos they're with us." (Lines 658-661)

However, some felt more distant and disconnected. This was particularly noticeable when there was physical distance from each other, and this changed relationship contributed to their grief:

> "When it first happened I just wanted to rush over straight away and they said no, just, there's nothing you can do just stay here, and I just felt like I wanted to do something but I couldn't. So, yeah I just feel she is distant, whereas before she was closer, you know, and he sort of, I don't know, they just both feel very distant now. And I never know what to say to them when I'm writing, cos I can't keep saying 'how are you?', and I don't know how to start a conversation now, and I just back off a lot, like a month or two will go by and you don't hear from them. So that's hard." ([redacted] Lines 307-313)

Some grandparents acknowledged that people behave in ways that are not typical of their usual behaviours when they are grieving, reflecting the complexities that arise with a shared grief. They stressed the importance of forgiveness, and not taking things personally:

> "(Daughter) was quite distressed or angry actually, that's what I'm looking for, she would get quite angry if I got too distressed, she didn't wish to share her grief, she

> wanted to hold on to it and for it be her grief and for her to be, and she apologised one day um she had yelled at me and said, err, that I needed help they weren't my babies, and I needed to pull myself together. And then she said 'mum I can't believe I said that I'm so sorry' so she was quite, um, she needed to lash out um, and I was the person to lash out to I suppose. That's right that's probably more what it was, err she needed to be cruel to someone because of her own pain? Yes." ([redacted] Lines 404-412)

3.2.5 Ceremonies and mementoes: Tangible, with lasting benefits for grandparents

Grandparents stressed the importance and ongoing value of being involved in memory making and spending time with the baby where possible:

> "Yeah yes definitely yes {mm} yes um because really that's the only memory you've got isn't it {yes} and that's the hardest thing um there's no memories there's nothing to remember." ([redacted] Lines 180-182)

Mementoes of the baby, such as photos, emblems, and foot and hand prints, or planting trees and having teddy bears made, provided tangible evidence of and a focus for grief, and were an important way of coping with the loss. [redacted] said:

> "I ended up planting a tree for him, so I watch that growing, an apple tree, and that sort of helps and I go out and talk to that sometimes and watch that grow, sort of thing. It's not really the same but it's just something, you know. The way its stops the sadness. […] I don't know I just thought it would help me cos, it's a, it's a living sort of thing, you know, and you can see it get taller, and produce apples ((laugh)) yeah, yeah so I just talk to that every now and then." (Lines 164-167, 174-177)

And [redacted]

> "Its tangible. And (daughter) had two photos done for us in little frames, so there's one of (wife) holding (granddaughter) and one of me holding (granddaughter)." (Lines 354-355)

In addition to this, grandparents stressed that the grandchild that died was equally as important as their other grandchildren. Mementoes, remembering dates such as birthdays, and talking about the child, kept the baby 'alive' in the family, was a way of honouring the child and demonstrated that they mattered to the family:

> "We often talk about (granddaughter). (Granddaughter) remains an active part of our family and even little (grandson) he's only coming up 4, and he knows who (granddaughter) was. And they've got a little, for want of a better word, they've got a little shrine in their house {mm}, and it's got pictures, and it's got um, little ornaments and stuff, and it's all to do with (granddaughter). So (granddaughter) continues to be part of our lives." ([redacted] lines 193-199)

3.3 Support

3.3.1 Lack of professional support offered to grandparents

Some participants experienced negative encounters with hospital staff prior to the pregnancy loss, and then a lack of support afterwards. Some spoke of frustration or anger at medical services, who they felt failed to address their child's concerns about the pregnancy adequately, or were unable to prevent the loss of the baby. While accepting that miscarriage might not be preventable, many felt that with current medical knowledge and equipment, had their child's concerns been addressed, stillbirth could have been prevented, adding to the grief experienced:

> "Yeah its um I think what still sticks with me the most is that she'd been in 5 days before to the hospital with reduced movements ,and she'd been on the, not a scan but the monitor and that for at least an hour a half and the midwife deemed that there'd

> been a bit of movement but enough to warrant her going home again and you know I think in hindsight I think we should have made more of a fuss of it or something but um you do trust midwives and […] they were too dismissive of the mother." ([redacted] Lines 20-25)

Support from hospital staff during and following the loss of babies was lacking. While many grandparents found hospital staff to be kind, only one grandparent, whose family had a relationship with the hospital, was directly supported. In all other cases, no support was offered to grandparents, and no information or education provided:

> "Ok, yes, if there was someone at the hospital I probably would have welcomed hearing from them before we left. We basically just walked out the door later that morning, um, but, had there been someone there who could have taken us aside and had a bit of a chat and made suggestions about how we could move forward that might have been useful." ([redacted] Lines 464-467)

Very few grandparents sought any form of professional support. While some stated that they would have sought this help if they felt that they needed it, many did not know where to source such support:

> "None ((pause)) none. Other than some friends, but even then you know they would call I mean there was no professional support available, not even at the hospital like there was no um ((pause)) no there was no support available. The only thing that we found was, as I said, I googled other people's stories and got some solace from that […] Yeah so there wasn't any support other than what we looked for ourselves, none offered, it was just a matter of deal with it as best you can." ([redacted] Lines 330-333, 339-340)

Others found a lack of understanding and their grief minimised. One participant, after seeking support from her general practitioner commented:

> "No, not really, I think I went in there not, I think I went in there for support and maybe I didn't ask the right questions or whether I didn't um ((pause)) say it in the right way but no he just sort of said to me um 'oh well he said, you'll be there for them, that daughter, you know, you been through it, you'll be right, you'll be right', and I thought ok but I do remember thinking I would have liked to talk about it. I've been through it but I haven't been through my daughters' loss." ([redacted] Lines 349-354)

A small number grandparents had access to professional healthcare informally through their work or incidentally through social networks, and found this to be helpful:

> "Um my sister being a palliative care nurse knew a lot of little things that, you know, and she just took over, and um, yes ((sigh)) um helped me out with things like that. Um you know you've gotta do this and you've gotta do that, and just guided me really so that I was fortunate to have that." ([redacted] Lines 331-334)

3.3.2 Informal support and self-support strategies

Common sources of support were extended family, friends, and church communities. Participants indicated that they valued strong social support and opportunities to talk about their loss. [redacted] commented that:

> "My husband comes from a massive family his mother was one of sixteen, they all live here, um they've all got, so he's got something like seventy first cousins of which fifty live locally [..] so you know and this was the first set of twins in that family so there was a lot of people our age looking forward to them being born so it was the first set of twins in both sides … like we got bombarded with people consoling us, I was amazed, actually I was pretty floored I was pretty humbled. But up there we didn't know anybody so it was a different situation, it was a different situation there to here […]." (Lines 421-429)

Those grandparents that did not have such a strong social support network felt very isolated, in an already isolating experience:

> "I feel like other losses I've had I've been (pause) I've had a lot of people to share that loss with {yes}. I don't think, that hasn't been the same for (granddaughter) I don't think other people have grieved with me, I think other people have felt sympathetic, um, and (pause) yeah, but I don't think they have felt the grief, so while I've had a few people to share it with it hasn't been like, other losses I've had." ([redacted] Lines 608-613)

Having faith provided some comfort to grandparents, while the church community provided support as well, demonstrating the benefit of community networks:

> "Yes without a doubt. Lots of prayers were said, and questions asked but I think that was something that helped, definitely. Yes, that's what I, I do feel sorry for people that don't have that faith or don't have some belief in a life after or whatever." ([redacted] Lines 418-420)

Those that were still employed found work to be a useful distraction, helping them to focus on something else and start functioning again in their normal lives. This made their grief easier to carry. Most grandparents in paid employment at the time found their employers and fellow staff to be supportive and this was highly valued:

> "Oh they were wonderful, they were absolutely wonderful. I was with, I worked in a library in a […] girls school just up the road from where I'm living, and, um, I couldn't have asked for any more from anybody." ([redacted] Lines 450-452)

Many grandparents found that there was little time to care for themselves in the weeks following their loss. However, time out to care for themselves, away from their child and others, to grieve in their own way, became necessary and important for long-term wellbeing:

> "I've decided to give myself the day before, the day we found out the news that she wouldn't be born alive. I've given that to myself as my stay at home, eat pizza and do nothing day, don't get out of bed if that's what I want to do you know ((laugh)). …so I'm just going to be taking the day off every year, that's just going to be my day to remember her and be a bit miserable. And then next day it's her birthday and then I can be on top of it for the kids you know they need me, I'll be ready." ([redacted] Lines 681-686)

Also perceived as important to wellbeing was the ability to honour their grandchild, by increasing community awareness, fundraising or providing support to others. This will be explained further in section 3.4.

3.3.3 Being strong, protecting their family

Grandparents expressed the need to be strong, to support as well as protect their child from added stress:

> "I thought I just wanted to bundle them up and protect them from everything so they didn't have to face anybody or see anybody or, it was probably wrong because that didn't happen do you know what I mean, they saw people and they still had to function." ([redacted] Lines 258-261)

Grandparents also expressed frustration at the comments people directed to their child regarding the loss, and while understanding they are well intentioned, wanted to shield their child from insensitivity. As explained by [redacted]

> "Then someone else said to (daughter) people always try to have sayings, you know, there will be a silver lining you know. There's always all these platitudes that because people can't understand, they put a positive spin on it, and thats just, there are a whole, there is a whole list of things people could say that are crap ((laughs)) but

> people will do it you know, because that's just human nature that, they try to put a positive spin on everything that's negative." (Lines 412 - 417)

As previously noted, many attempted to hide the extent of their own grief, only expressing its depth when away from their child. However, others commented that sharing their grief with their child built connection and understanding between them:

> "I think he saw how much (grandson) mattered to everyone, and so it was appropriate to grieve the loss, you know it was, I mean we tried to minimise (laugh) to minimise the impact on him as much as we could but he needed to know that we were sharing this grief and this journey with him. I think that's important. But no, I think cos I guess for him it acknowledged for him that (grandson) was there that we, you know, we were missing him and that we missed him that he existed and he was important and enough a part of our life to grieve for." ([redacted] Lines 627-631)

3.3.4 Love, listen and learn

Grandparents indicated very strongly that their child's needs took priority over their own and that they supported in whatever way was needed. Grandparents consistently commented that the best way to help their child was to "just be there". This included being present, allowing their child to express themselves and translating their learning into meaningful action. These concepts were summarised by [redacted]

> "That's all I could say. Love with all your heart, learn every day, that you can say and do something a little different, and listen, listen so hard that your ears nearly fall off." (Lines 649-650)

Grandparents indicated that it was important that their child knew that their love and care was ongoing and that their grandchild would always be remembered and loved:

> "Because you're so, you just want that feeling of love and caring and nurturing to go on, and its going on, you don't have to worry about it, ((laughs)) its going on. But you

> don't want (grandson) to be forgotten as a grandmother but you want (daughter and son in law) to always be remembered, you know." ([redacted] Lines 710-714)

In addition, grandparents indicated that listening to their child, not necessarily giving advice or solutions, and enabling their child to express their grief and needs, formed an important component of support that they could offer. As [redacted] explains:

> "To listen ((pause)) stand by and listen and not, not offer advice ((pause)) just to be there to be a physical presence I mean we used to make a point like when my daughter in law she would take herself off I mean we never saw her for a couple of months but we would always make a point of calling in to see (son) or calling him on the phone um popping in with meals be a physical presence there, talk about what's happened, mention the baby, try not to dissolve into tears yourself." (Lines 523-528)

Finally, listening also presented opportunities for both grandparent and child to learn from and understand each other better. Grandparents felt that this reciprocal learning facilitated grieving for both themselves and their child, as well as helping their child re-engage with the world, navigate difficult situations and feel supported:

> "So we were close, but now we're, we understand each other now, we have a rapport now, we were a mother and daughter before now we're like ((pause)) we're shared experience people. I was physically there the whole time, um so it was a shared experience with her husband, but there are things that she feels that she says to me and I say to her now that I wouldn't have done had we not had this experience, we're much more open with each other, that's probably what's it is we're much more tolerant with each other and we're much more open with each other {mm} so yes {yeah} um so that's positive." ([redacted] Lines 550-556)

3.3.5 The challenges of knowing how to help

Grandparents expressed their grief at not being able to control the situation or make things better for their child, particularly in relation to addressing their grief. Grandparents felt helpless in the face of such grief:

> "Yeah, I felt, my role as a dad, and a grandad, but as a dad my role is to love my kids, and protect them, and to make things better when things go wrong, and I was torn that this was a situation I had no control over. I couldn't fix this, I could not make this better for (daughter and son in law) and that really broke my heart as well. I don't think I was failing in my role, but I was disappointed that I couldn't make things better, on this occasion." ([redacted] Lines 87-91)

With a lack of formal guidance regarding how to help their child, participants relied on instincts and knowledge of their child to inform their support. However almost all grandparents expressed a lack confidence regarding how to best support their child:

> "I think the hardest thing you know is when your kids are hurt, you just don't know what to do in that situation you know it's totally out of your control you know I mean, you know I had no idea how to deal with that you know ([redacted] Lines 361-363)[…]maybe for grandparents perhaps that need a bit of guidance you know um what to say and what to do, and how to be how to think I mean some people just don't know and they stay away." ([redacted] Lines 610-613)

Furthermore, some decisions were made, actions taken and comments said or unsaid that were later regretted. Grandparents wished they could take back things done with good intention, but which they subsequently realised were hurtful or unsupportive. This emphasises the importance for grandparents to be forgiven, and forgive themselves:

> "..How to cope with the decisions that you make at the time you know. I thought you know, you know in your heart of hearts that you made the best decisions you could

> under the circumstances at that time, you know that you maybe should have a different decision, but at that time it was the best decision that you could make. Um but having someone that's been through it and you say to them look, I know this probably wasn't, what did you do, you know like, how did you cope, how do you cope with the decisions that you made?" ([redacted] Lines 177- 184)

Grandparents wished there was someone they could talk to who could advise them on how to help their child:

> "Um, and I wish there was places out there where you could talk to people, just to grandparents, and say 'oh my god, what did you do?' and 'what did you do when you found your daughter in the foetal position on the bottom of the shower {oh}, and couldn't get her out?'. Or 'what did you do when you felt that their marriage was suffering so badly that you didn't think they were going to survive?', 'How did you help your son or your daughter, what should have I done, what could I have done?' , 'what can you do down the track'." ([redacted] Lines 109-115)

Grandparents who could not "just be there" due to physical distance struggled to know how to help their child, felt more helplessness and increasing disconnection as a result. This appeared to be more pronounced for parents of sons, who found communication more challenging from a distance, and therefore had less guidance regarding how to support:

> "Yeah at the time, exactly, that's right, so and when it's something you haven't come across before, and you no experience in um, you know and you're not really getting a lot of communication about what you should be doing from the person involved, for me (coughs) I just thought well if I don't want to go and be in the way well (coughs) and well maybe I could have been more help but I don't know how?" ([redacted] Lines 471-476)

Even more challenging than knowing how to support their own child was knowing how to support their son or daughter-in-law if their parents were physically or emotionally distant:

> "But then, he hasn't got a relationship with his parents, so (husband) and I were trying to be parents to him as well. And, um, it's a very different thing nurturing your child through a stillborn, as to nurturing their partner through it as well, and particularly a male [….]You know, you switch from how you think you should be handling your daughter, can someone please tell me how to handle my son in law. That's where you struggle, you so need help. You so need help. Someone just be, just a lifeline." ([redacted] Lines 206-213)

3.4 Grandparent Needs

3.4.1 I had no idea: Increasing knowledge of pregnancy loss

Many grandparents were shocked at the rate of pregnancy loss in Australia. Many participants, particularly those whose children had experienced stillbirth rather than miscarriage, were unaware of the incidence rates and felt they would have been better prepared to support their child had they been more aware of the possibility of such a loss. Participants indicated that this highlighted the point that there is a broad lack of understanding and education in the wider community:

> "Um I've had kids, I've had six kids, I've never had a problem with pregnancy and I was, I never once heard anyone mention anything about still birth. I think it's something I thought that was something back in the dark ages and the midwife couldn't get there in time you know and I was actually, so I was actually shocked that um that how common it is, you know." ([redacted] Lines 82-87)

Some felt that raising awareness would also increase community understanding of pregnancy loss, resulting in less disenfranchisement:

> "We put in our church newsletter and people like who might have been 60 or 70 came up to us and said 'I had a stillbirth and nothing was, nothing, it was we didn't even see the baby it was just taken away', so I guess um that surprised, the extent of it surprised me, the numbers just blew me away and that its been happening for 60-70 years and people still didn't talk. We had close friends, like close friends and the conversations never come up {mm} and so I guess we were trying to be more open because we thought no this is a conversation that needs to be had, um you know and I think some people, you know it was, yeah I think that's what surprised me most, the extent of stillbirths in Australia {yes} um and the fact that we don't seem to have improved that situation in that time." ([redacted] Lines 259-272)

In addition, while participants indicated that they preferred the focus of support to be on their child/ren when such a loss occurs, they expressed frustration at the lack of information made available to them at the time of the loss, resulting in more difficulty supporting both their child and themselves:

> "These people that help the kids are just, they're wonderful, wonderful people, you know. But there should be something just for grandparents, you know. Just to say help me help my child." ([redacted] Lines 371-374)

Staff providing brochures to grandparents directly or via their child was seen as a simple and easy to provide resource, which could also be available in doctors' surgeries and community areas such as libraries:

> "Yeah, you know have leaflet stands and even those sorts of things, um, can be left in libraries and places like that as well. But probably um, doctors' offices, but I think if it can be, there needs to be some sort of, I don't know whether there is or not, a pack given to people when they go through it, even if they go through it later, and ' oh

here's a brochure I can give to mum', cos they don't consider at the time" ([redacted] Lines 71-77)

3.4.2 Peer support: They know how it feels

Many grandparents indicated that talking to other people who had been through the same experience and therefore knew how they felt would be the most helpful. This could be in small groups or one-on-one. Of importance was that this be separate to parent groups:

"I thought it's a shame that there's not an opportunity for even those same groups of people to have um a grandparents group linked to that in some way. Not meet with them you know like people are very private […], I don't um want to go with my children and see go through what they go through but I think a separate group um for grandparents where they can talk to another grandparent has experienced the same thing, um that that would be so beneficial." ([redacted] Lines 134- 41)

Online or telephone peer support for geographically isolated people could also fill this need. Online forums were not widely used, however could be helpful if participation was encouraged:

"Maybe we're all as bad as each other, maybe we're waiting for somebody to say, 'ok how's everyone going, how's everyone's day today' and start a conversation. Maybe I should just do that. […] I don't think, I don't think there's a great deal of members on there, there not a lot of people in it, but maybe that's what it takes, just someone to say 'hey how's your day been, I've had a shit day' or something." ([redacted] Lines 599 – 602, 616-618)

3.4.3 Honouring the grandchildren, making meaning

Finally, grandparents found that participating in activities to raise awareness was helpful to them, was something they could control, and was a way of honouring their grandchild and ensuring that their life mattered:

> "Yes, well the walk seems to help me, and even just talking to you seems to help me. Just to, um, just to do, I don't know, just go out and do fundraising and volunteering and just um, celebrate their life and not forget their life, you know. Cos he was on the planet for a brief time, so, um, yeah just um, and, and remember when he was born. Well we all lit candles, cos there was ah, it was a day where it was world support for stillborn babies so at a certain time we all lit a candle. Lighting a candle helps and doing all these positive things and not forgetting about him. Just remembering that he was here, so yeah. If that sort of makes sense?" ([redacted] Lines 376-383)

Grandparents did this in various ways, including fundraising, participating in research, supporting others, and marking national and international awareness days. The choice of method gave them some control in an otherwise uncontrollable situation:

> "I was more interested, you know, if there was an awareness group or a fund raising, um, and I guess I was angry as well thinking why didn't I know about this ((cough)). And that's why now you know I do what I can and and have stalls at fetes and I will talk to people, and the number of people who have come up to me and shared their stories that they haven't been able to share with anyone else." ([redacted] Lines 240-245)

Chapter 4: Discussion

4.1 Overview

This study explored grandparents' experiences when their child loses a baby during pregnancy. Thematic analysis of semi-structured interviews identified three categories of themes: grief, support, and grandparent needs. Within these, five themes related to grief, five to support and three to grandparent needs were identified. Each of these themes will be addressed, along with implications for further research and practice.

Grandparents described their experiences of pregnancy loss in terms that identified this as an ambiguous and compounded loss, where disenfranchisement of grief led to feelings of isolation and powerlessness. For first time grandparents, the symbolic loss of the role of grandparent was an additional grief to bear. The grief experienced is influenced by individual differences and circumstances (Addis & Mahalik, 2003; Callister, 2006; Doka & Martin, 1998; O'Leary et al., 2011; Rosenblatt, 2017) with styles of grieving, personality, spirituality, family relationships, and the extent of prior losses all contributing to grandparents' progression through grief. No difference in intensity of grief was identified between types of loss, and the methodology employed did not provide scope to measure this objectively. Furthermore, grandparents did not identify any health issues that were attributed to the loss of their grandchild beyond short- term sleep disturbances. This finding stands in contrast to the literature pertaining to the health and wellbeing of grandparents following the death of a grandchild (Youngblut et al, 2015), and may represent a point of difference between this and other types of losses.

Theories of grieving propose that grievers move through a series of steps to process loss. Worden (2008) describes four tasks of grieving, and each presents challenges for grandparents experiencing pregnancy loss of a grandchild. Firstly, accepting the reality of the loss is difficult when the loss is ambiguous, where there is nothing tangible to represent the baby. Next, working through the pain of grief is challenging when there are limited supports to validate grief, and other family members needs to consider. Following this, adjustment to an environment where the deceased is missing presents challenges, when attachment is based on expectations of a life to be shared. Finally, finding an enduring attachment to the deceased is difficult when there are no lifetime memories shared. When a loss is ambiguous and disenfranchised, the process of moving through such steps can be incomplete, delaying or stalling the grieving process. This is exacerbated when non-supportive behaviours are

encountered (eg., minimisation, unhelpful advice, encouragement of rapid recovery) thereby making the grieving process more complicated. (Attig, 2004; Betz & Thorngren, 2006; Callister, 2006; Rycroft & Perlesz, 2001).

Grandparents also identified ongoing changes in family relationships as a significant consequence of the loss of their grandchild. This reinforces findings of studies relating to parents and the impact of differences in grieving style upon the relationship between fathers and mothers, and upon extended families following pregnancy loss (McCreight, 2004; Obst & Due, 2017; O'Leary et al., 2011). Family rules and norms influence how a family grieves and makes sense of such a non-normative loss that may not have been experienced before. Family members may lack the language to discuss ambiguous loss, and difficulty expressing their grief, differ in their views or emotions, or have a mismatch of grieving patterns (Betz & Thorngren, 2006; O'Leary et al., 2011; Rosenblatt, 2017; Rycroft and Perlesz, 2001). This study reinforces the importance of recognition and validation of the loss across extended family relationships, to facilitate grieving and maintain or strengthen relationships.

White et al. (2008) argue that listening and being present is as important as 'doing' during times of grief. Grandparents described this as 'being there', or 'love', and consistently described these behaviours as important. Where families grew closer, grandparents described the loss as an opportunity to listen, and to learn more about each other. Thereby, family disruption and regrets could be overcome, and healing progress. Grandparents that were geographically distant to their child had more difficulty maintaining open communication and faced additional challenges in being able to love, and to listen and learn.

Rituals to acknowledge ambiguous losses are not well established in western cultures, however such rituals are important to guide grieving (Callister, 2006; Doka, 2002; Mortell, 2015; Rycroft & Perlesz, 2001). Therefore, the death of an unborn baby presented challenges for some grandparents in balancing societal expectations of mourning, respecting their child's

wishes, and spending time with their grandchild. Creating memories and memorabilia is recognised as being helpful for parents following pregnancy loss (Callister, 2006), and is included in the PSANZ guidelines. While previous literature pertaining to parents' psychological outcomes after holding their baby revealed mixed findings (Hennegan, Henderson & Redshaw, 2015), participants who were given the opportunity to hold their grandchild indicated that this was helpful and valued. Furthermore, grandparents recognised the importance of keeping the grandchild present in the family, which is congruent with Worden's (2008) fourth task of grieving. Grandparents appear to have a fundamental role in facilitating rituals and connection for the extended family, and feel a responsibility to ensure these are established and maintained. This finding reinforces similar findings by O'Leary et al (2011), form the parents perspective, who expressed the importance of this recognition, and look to grandparents to continue to acknowledge the baby that died.

The study also confirmed that grandparents provide support to their child in a variety of ways following pregnancy loss, with support being largely unidirectional, from parent to child. However, the lack of individual and community awareness regarding the frequency of pregnancy loss, together with the lack of information provided to grandparents, and the subsequent changes in family interactions brought about by loss and grief, meant grandparents were left to rely on their parental instincts and life experiences to help their family. Furthermore, with generational changes in practices and expectations, grandparents that had experienced losses themselves, while understanding how such a loss felt, did not find this knowledge addressed the added complexities associated with being the grandparent.

Formal supports for grandparents were inadequate. However, those that received grief counselling and advice informally through social and employment networks found this beneficial, suggesting that skilled grief support services may be of value. As grandparents received most support from their social network, those without strong networks found

themselves isolated in their grief, and therefore possibly in greater need of professional support services. Of note, unlike previous research findings based on fathers' experiences of pregnancy loss (Obst & Due, 2017), most grandparents in paid employment received strong support from their workplace, which was very highly valued by participants. The reasons for this difference are unclear, but perhaps reflect gender, the type of employment environments, and a recognition of the need for grief support as evidenced by already established systems within the workplace.

Grandparents indicated that peer support would be helpful, with peers perceived to be better able to relate to the feelings experienced than professional support providers. This is reinforced by grief theorists such as Doka (2002) who argue that peer support validates and normalises such grief. Furthermore, central to the path through grief is the opportunity to make meaning of the loss, and talking and sharing is essential to this process (Attig, 2004; Betz & Thorngren, 2006; Callister, 2006; Worden, 2008). Peer support provides such an opportunity while avoiding the risk of burdening other family members. Moreover many grandparents described a sense of purpose gained from participating in activities such as fundraising and awareness days. As well as educating and raising community awareness, this was empowering, and gave opportunities to create a positive legacy that gave meaning and purpose to the life of their grandchild.

4.2 Strengths of the Study

This study provides an important contribution to the literature that the current body of research has not yet addressed – no studies have been previously conducted specifically concerning grandparents and pregnancy loss. The choice of methodology facilitated the greatest strength of this study; interviewing grandparents directly about their experiences of pregnancy loss. In addition to developing an understanding of grandparents' experiences of pregnancy loss, valuable insight was gained regarding the nature of grief and support needs,

vital to informing future support strategies. Furthermore, nationwide recruitment enabled a diverse participant sample, capturing experiences from a variety of health settings and a range of communities. Moreover, the inclusion of participants who experienced different types of pregnancy loss reinforced findings from previous literature that the extent of grief is independent of the type of loss (McCreight, 2008). Though most grandparents experienced a stillbirth (11 of 15), the similarities in participants experiences across the sample increases confidence that these findings are relevant to a wide range of grandparents experiencing pregnancy loss. Finally, the high number of participants for this type of methodology adds depth to the data and enhances the trustworthiness of the findings. This study provides a strong basis upon which future research can build.

4.3 Limitations and Future Directions

The most significant limitation of this study is the involvement of only one grandfather. This may be reflective of gender differences in expression of grief and available support networks (Doka & Martin, 1998; Obst & Due, 2017; Wagner et al 2018). Perceived barriers to involvement including greater disenfranchisement of grandfathers' grief, or the requirement to be interviewed, may have also deterred grandfathers. Therefore, grandfathers' experiences cannot be adequately understood from these findings. Anecdotally, participants in this study suggested that grandfathers were as distressed as grandmothers, and therefore further research that prioritises involvement from grandfathers would be valuable.

Furthermore, a lack of cultural diversity among participants may reflect the English language competency required, but possibly also cultural differences in support experiences and expression of grief with respect to pregnancy loss. Rosenblatt (2017) argues that there are strong cultural differences in ways of grieving. Identifying such differences, and the influence of these on families and healing, may be beneficial for the wider population and inform strategies for acknowledging and grieving such losses.

Moreover, the study may have attracted participants who are particularly motivated to add to knowledge and awareness of this experience, or grandparents who have found this particularly challenging, and therefore may not be reflective of the experiences of most grandparents. In addition, most participants were directed to the study by family members with established links to support organisations. Research that identifies more isolated grandparents would provide a more comprehensive understanding of grandparent experiences. Furthermore, due to the ambiguity and disenfranchisement of such a loss, grandparents may not have identified their experience as relevant for the study. These points should be taken into consideration when transferring these findings to other populations until further research builds upon the body of knowledge.

The inability to triangulate the data with that of health professionals and support providers reinforces the findings that few grandparents received professional support. The support provider who contacted the researcher indicated that they had no direct experience with grandparents and this was re-iterated informally by the support organisations who assisted with recruitment for the study. Research including support providers would help determine effects on family relationships, and identify further support needs. In addition, piloting and evaluating a support program for grandparents based upon the needs outlined in this study, would identify strengths and variations needed in support programs in order to refine and consolidate strategies. Furthermore, this would raise awareness of grandparent grief following pregnancy loss, reducing disenfranchisement in the wider community. As grandparents identify this as a grief that does not go away, and the current study was limited to losses within the previous five years, of further interest would be investigation of the longer-term impact of pregnancy loss on grandparents and their families, including family relationships, facilitators and barriers to healing, and any subsequent health issues.

4.4 Implications

4.4.1 Theoretical implications

As the first study of its kind, this research has significant implications. Firstly, it makes an important contribution to the body of knowledge in this area that is currently lacking. This study identifies the types of loss and grief grandparents experience following pregnancy loss, and the severity and consequences of those losses. In doing so, this research also strengthens previous findings relating to ambiguous and compound loss, and disenfranchised grief (Betz & Thorngren, 2006; Callister, 2006; Lang et al., 2011; Rycroft & Perlesz, 2001; O'Leary et al., 2011; Worden, 2008). While increasing understanding of the challenges that grandparents face when the loss of a grandchild occurs, the study provides a preliminary theoretical basis upon which to investigate further aspects of this experience, including how individual, situational and relational differences contribute to this experience. The study also adds to the body of research informing care protocols for parents and grandparents following pregnancy loss.

4.4.2 Practical implications

This study identified the nature and extent of grandparents' support for their families following pregnancy loss. Recognising these contributions has implications for healthcare professionals and support providers working with parents to identify support deficits and create opportunities to build strong family relationships. Furthermore, speaking with grandparents directly identified the types of challenges grandparents face and potential solutions to these challenges. The research also identified gaps in support systems and provide a basis from which to develop support frameworks, including peer support networks, and ways to facilitate access to such support. Peer support programs that specifically cater for grandparents would provide a much-needed opportunity to talk and share. Furthermore, such support should be available long-term, as the role peers play in providing support may change

as the grieving process progresses. This support could be provided as small group and/or one-to-one formats, thereby catering to diverse needs. In addition, flexible delivery options such as telephone or on-line formats would allow access for isolated grandparents. This study also identified the need to raise awareness and educate the community regarding the incidence of pregnancy loss, and the need to acknowledge and to give voice to those experiencing such losses. This can be achieved through inclusion of grandparents in awareness days and fundraising opportunities, helping to reduce ambiguity and disenfranchisement, and facilitate meaning making. The findings also highlighted possible changes to hospital procedures to ensure that grandparents are provided with information and included in memory-making activities where possible, reflecting the importance to the grieving process of maintaining a connection with the baby. Moreover, information brochures could be made available in health facilities such as doctors surgeries, and community areas such as libraries, to increase the accessibility of these resources and raise awareness.

4.5 Conclusions

This research found the loss of a grandchild during pregnancy was an overwhelming and isolating experience for grandparents; a loss like no other. However, the lack of support available for grandparents, with a simultaneous desire to support their own child, leaves many grandparents lacking confidence in knowing how to support their child, and struggling to access skilled support for their own grief. Relying on their pre-existing relationship and knowledge of their child, grandparents indicated that what was needed most was for them to be there, to love their child, to listen to them, and to learn. Acknowledgement of what has been lost is fundamental to healing for those experiencing ambiguous loss and disenfranchised grief, and to make meaning of such a loss. Therefore, in turn, grandparents need this same support from their community after they lose a grandchild to pregnancy loss; for us to love them, to listen, and to learn.

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Appendix A

School of Psychology
The University of Adelaide

PARTICIPANTS NEEDED

We are seeking participants to take part in a research study of

Grandparents' Experiences of Support Following Pregnancy Loss

As a participant in this study, you will be asked to take part in an interview with the researcher, at your convenience, to describe your experiences of support following your child experiencing pregnancy loss.

To be eligible, this loss must have occurred between 6 months and 5 years ago. Grandmothers and grandfathers are welcome to participate, whether you have a son or a daughter who experienced this loss.

Your participation would involve one session, lasting approximately one hour. Your identity and information will remain confidential and you will not be identified in any publication resulting from this study.

You may not receive any direct benefit from this study, but your participation may help discover the ways to best support grandparents in the future.

For more information about this research study, or to volunteer, please contact:

[redacted]

The study has been reviewed and approved by the Human Research Ethics Committee, [redacted] The University of Adelaide.

School of Psychology
The University of Adelaide

PARTICIPANTS NEEDED

We are seeking participants to take part in a research study of

Grandparents' Experiences of Support Following Pregnancy Loss

As a participant: in this study, you will be asked to take part in an interview with the researcher, at your convenience, to describe your experiences, as a health care worker or support provider for grandparents (or parents, where the impact if the loss upon grandparents has been discussed) following pregnancy loss.

Your participation: would involve one session, lasting approximately one hour. Your identity and information will remain confidential and you will not be identified in any publication resulting from this study.

To be eligible: you must be over 18, and be experienced in providing formal or informal support for families who have experienced an unexpected pregnancy loss in the last 5 years.

You may not receive any direct benefit from this study, but your participation may help discover ways to best support grandparents experiencing pregnancy loss in the future.

For more information about this research study, or to volunteer for this study, please contact:

[redacted]

The study has been reviewed and approved by the Human Research Ethics Committee, [redacted] The University of Adelaide.

Appendix B

GRANDPARENT PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Grandparents experiences of support following pregnancy loss

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-070

PRINCIPAL INVESTIGATOR: Dr Clemence Due and Dr Melissa Oxlad

STUDENT RESEARCHER: Ms Jane Lockton

STUDENT'S DEGREE: Bachelor of Psychological Science (Honours)

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This project aims to increase understanding around grandparent's experiences of pregnancy loss and support received and given following pregnancy loss (including miscarriage and stillbirth).

Who is undertaking the project?

This project is being conducted by Ms Jane Lockton, forming the basis of her Honours degree in Psychology, under the supervision of Dr Clemence Due and Dr Melissa Oxlad.

Why am I being invited to participate?

This research will explore the perceptions of grandparents and healthcare professionals about pregnancy loss, and the support provided to and given by grandparents following a pregnancy loss. We are looking to speak to any grandparent whose son or daughter has experienced an unexpected pregnancy loss (including miscarriage and stillbirth) between 6 months and 5 years ago, and who is fluent in English.

What am I being invited to do?

If you consent to participate, you will be able to participate in an interview about your experience of, and perceptions towards, support following a pregnancy loss. Interviews can take place at the University of Adelaide (North Terrace Campus), over the telephone, or an alternative public area at a time that is convenient to you. The interview will be audio recorded, so that an anonymous transcription can be made of the interview.

How much time will my involvement in the project take?

Each interview is anticipated to take approximately 1 hour of your time.

Are there any risks associated with participating in this project?

Due to the sensitive nature of the topic being discussed, you may experience some emotional distress during the interview. However, every effort will be made to minimise this possibility, and you will be provided with a comprehensive list of supports that you may wish to access following the interview. These include contact details for support and telephone helplines, online forums, and local organisations relevant to pregnancy loss. You can also view these supports at the end of this information sheet. You can also choose not to answer questions, or to end the interview at any time.

What are the potential benefits of the research project?
This research will help to inform support organisations and healthcare professionals about how to best provide support to grandparents and their families following pregnancy loss. Although you will not receive any financial compensation from your involvement in the study, your participation in an interview will provide valuable insights that will help to benefit grandparents and their families in the future following a pregnancy loss.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time until the start of the data analysis phase.

What will happen to my information?

The information from this research will contribute towards an Honours thesis. Your name and any identifying information will remain confidential and will be removed from any publications or reports that arise from the data. Confidential interview transcripts will be made from the audio recordings, however only the named researchers above will have access to the interview transcripts, for the purposes of analysis.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

Who do I contact if I have questions about the project?

[redacted]

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-070). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028
Email: hrec@adelaide.edu.au
Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000
Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

Please contact Jane (email: jane.lockton@student.adelaide.edu.au). You will then receive a consent form and be able to arrange a time for an interview.

Yours sincerely,

Ms Jane Lockton, Dr Clemence Due and Dr Melissa Oxlad

Support Resources

To talk to someone right away:

- SANDS – Stillborn and Neonatal Death Support
  Available 24/7: 1300 072 637
- SIDS and Kids Bereavement Support
  Available 24/7: 1300 799 656
- Stillbirth Foundation
  02 9557 9070 (9am to 4pm Monday to Friday)
- PANDA – Post and Antenatal Depression Association
  Available 10am-5pm, Monday-Friday: 1300 726 306

- Pregnancy Birth & Baby Helpline
  Available 24/7: 1800 882 436
- Lifeline
  Available 24/7: 13 11 14
- Beyond Blue
  Available 24/7: 1300 224 636

Organisations offering support for pregnancy loss:

- SANDS - Stillborn and Neonatal Death Support: Provides group support, one to one support, online support and telephone support to all bereaved parents and families. *http://www.sands.org.au/*
- Sids and Kids (SA): Dedicated to saving the lives of babies and supporting bereaved families through counselling, peer support and memorial services. *http://www.sidssa.org/*
- PANDA – Post and Antenatal Depression Association: PANDA's telephone information, suppo rt
  and referral service is staffed by trained volunteers, professional counsellors and supervising

  staff. *http://www.panda.org.au/*

Appendix C

Human Research Ethics Committee (HREC)

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	**Grandparents experiences of support following pregnancy loss**
Ethics Approval Number:	[redacted]

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me. (Delete for health professionals)

4. Although I understand the purpose of the research project is to improve the quality of health/medical care, it has also been explained that my involvement may not be of any benefit to me.

5. I agree to participate in the activities as outlined in the participant information sheet.

6. I agree to be:
   ☐ Audio recorded

7. I understand that participation in this project is completely voluntary and I am free to withdraw from the project at any time from the start of the study until the start of the data analysis phase.

   I have been informed that the information gained in the project may be published in a thesis.

   I have been informed that in the published materials I will not be identified and my personal results will not be divulged.

8. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.

9. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: _____ Signature: _____

Date: _____

Researcher/Witness to complete:

I have described the nature of the research to

_____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____ Position: _____

Date: _____

Appendix D

Interview Schedule – Version 2

Grandparents:

1. Could you share a little bit about your experiences of your daughters/sons pregnancy loss? (and self if applicable)

   Prompts:
   -How long ago did your daughter/son experience pregnancy loss?
   -How did you feel when you heard?
   -Have you experienced more than one pregnancy loss as a grandparent? Can you tell me about each pregnancy loss you have experienced as a grandparent?
   -What was the length of gestation of your daughters/sons pregnancy at the time of the loss?
   -Do you have any other grandchildren?
   -Have you experienced your own pregnancy loss?
   -If relevant: How do you think having experienced your own pregnancy loss may have influenced your ability to provide support to your daughter/son?
   If relevant: How do you think having experienced your own pregnancy loss may have influenced the support you required as a grandparent experiencing a pregnancy loss?
2. Do you live near your child, or are you in close contact with your child?
3. How did you envisage your role as a grandparent?
4. What are your experiences of providing support for your daughter/son?

   -What support have you provided your child?
   -How confident were you knowing how to help?
   -Were there any challenges you faced giving support?
   -What was the most difficult aspect of supporting your child?
5. Can you tell me about the support/s you received at the time of the loss of your grandchild?

   -Only if relevant: What supports did you receive at the time of your own loss?
   -Only if relevant: How did the support you experienced for your own loss compare to the support you received when you experienced a pregnancy loss as a grandparent?
6. In your role as a grandparent, did you receive any kind of support from the hospital staff? If there were any hospital interventions – same question?
7. What sort of support did you receive from family, friends, or work colleagues when you experienced the loss of your grandchild?
8. Have you ever sought any support from a professional? (e.g., counsellor, psychologist, support agency, etc.)
9. Were you satisfied with the support you received?
10. What type of support are you still receiving now?

    -Professional, online support groups, family, friends, etc.
11. Was there anything that you felt prevented you from seeking support?
12. If not already mentioned, ask about mementos or memorials
13. What other types of supports do you think would have been useful to you during that time/would you like to have received?

14. Have you experienced any physical health issues since the loss?
15. Do you think that your relationship with your child has changed?
16. If you had the ability to talk to directly to SANDS or the Stillbirth Foundation about what would be most helpful for grandparents, what would you want them to know?
17. If you could give one piece of advice to another parent trying to support their child after a pregnancy loss what would it be?
18. If you could give one piece of advice to another grandparent about support for themselves after the loss of a grandchild what would it be?
19. Is there anything else you would like to tell us?

Demographic Questions:
- What is your age?
- Gender?
- Cultural background?

Appendix E

Post Interview Summary Sheet

Participant:

Date:
Time start:
Time finish:

Reflection on location/environment:

Participant details: Self presentation, reactions

Reflection on the Interaction:

Changes required to the interview schedule:

General interview difficulties:

Potential emerging themes:

Analysis points relating to the literature:

Questions to ask in subsequent interviews: