#### **Edith Cowan University**

#### **Research Online**

Theses: Doctorates and Masters

**Theses** 

2015

## Women's experiences of pregnancy loss: An interpretative phenomenological analysis

Esther Lea Kint Edith Cowan University

Follow this and additional works at: https://ro.ecu.edu.au/theses



Part of the Psychology Commons

#### **Recommended Citation**

Kint, E. L. (2015). Women's experiences of pregnancy loss: An interpretative phenomenological analysis. https://ro.ecu.edu.au/theses/1723

This Thesis is posted at Research Online. https://ro.ecu.edu.au/theses/1723

## **Edith Cowan University Research Online**

Theses: Doctorates and Masters

Theses

2015

## Women's experiences of pregnancy loss: An interpretative phenomenological analysis

Esther Lea Kint Edith Cowan University

#### Recommended Citation

Kint, E. L. (2015). Women's experiences of pregnancy loss: An interpretative phenomenological analysis. Retrieved from http://ro.ecu.edu.au/theses/1723

This Thesis is posted at Research Online. http://ro.ecu.edu.au/theses/1723

# Edith Cowan University Copyright Warning

You may print or download ONE copy of this document for the purpose of your own research or study.

The University does not authorize you to copy, communicate or otherwise make available electronically to any other person any copyright material contained on this site.

You are reminded of the following:

- Copyright owners are entitled to take legal action against persons who infringe their copyright.
- A reproduction of material that is protected by copyright may be a copyright infringement. Where the reproduction of such material is done without attribution of authorship, with false attribution of authorship or the authorship is treated in a derogatory manner, this may be a breach of the author's moral rights contained in Part IX of the Copyright Act 1968 (Cth).
- Courts have the power to impose a wide range of civil and criminal sanctions for infringement of copyright, infringement of moral rights and other offences under the Copyright Act 1968 (Cth).
   Higher penalties may apply, and higher damages may be awarded, for offences and infringements involving the conversion of material into digital or electronic form.



Women's Experiences of Pregnancy Loss:

An Interpretative Phenomenological Analysis

Esther Lea Kint, BSc (Psych) Hons

Faculty of Health, Engineering and Science

Edith Cowan University

Western Australia

A thesis submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy

Date of Submission: 29<sup>th</sup> May 2015

### **USE OF THESIS**

Thal	Ico of	Thocic	statement	ic no	t inaluz	dod in	thic	vorcion	of tho	thocic
IIIE	72G 01	1116212	Statement	15 110	LIIIGIU	a <del>c</del> a III	เบบอ	VE121011	OI LITE	แบรงเจ.

#### **Abstract**

Over the past three decades, research has proliferated on the incidence of grief severity following pregnancy loss, with many research studies citing the existence of 'complicated' and 'unresolved' grief. It is argued that this emphasis on grief severity has overshadowed other aspects of the bereavement experience that might differ from grief as it has been defined. Understanding the experience of loss in pregnancy instead of categorising it, would allow for new and varied understandings of the meaning women attribute to their experience of losing a baby. Furthermore, paying attention to women's interpretations and understandings of pregnancy loss provides valuable insight into care that is perceived as meaningful and supportive.

Utilising interpretative phenomenological analysis (IPA), a qualitative research method, the current study explored the experience of pregnancy loss among nineteen bereaved women with a history of miscarriage or stillbirth. The findings revealed that bereaved women struggle with a unique, complex and pervasive bereavement experience, that is largely unacknowledged and misunderstood. Women conveyed a strong desire for others to acknowledge and validate their loss, and to facilitate rather than suppress their grief. In addition, women identified a need to remain connected to their deceased baby, and for others to recognise the profound and enduring nature of their grief. Perceptions of support were identified as a critical catalyst in determining women's bereavement experiences, and revealed both positive and negative attributions of professional and social support. In particular, women identified a need for increased public awareness of pregnancy loss, more sensitive and empathic care, continued support to facilitate contact with the baby, improved continuity of care to support grieving, and enhanced support in the subsequent pregnancy to assist with anxiety management. The implications of these findings for future research and practice are discussed.

The study provides a context within which women's experiences can not only be recognised as widespread and rational emotional processes following pregnancy loss, but that those suffering can also receive appropriate, specialised professional support and social acceptance by the wider community.

#### Statement of Confidentiality

Ethical clearance from the Edith Cowan University Ethics Committee was granted in March 2009. Ethical clearance from the Women and Newborn Health Service was granted in March 2010. Participant confidentiality was protected at all times, including all correspondence between myself and research supervisors. Pseudonyms for the bereaved participants and their family members are utilised throughout the thesis. All verbatim quotes were scrutinised for information that could render the participants identifiable, to ensure participants remained anonymous.

## The declaration page is not included in this version of the thesis

#### Acknowledgements

I would like to begin by conveying my heartfelt gratitude to the participants who took part in this research. My sincerest thanks and appreciation to all the mothers who were willing to share their stories of grief and loss. I feel forever privileged to have been a part of your journey, and your strength and resilience has inspired me greatly. I hope that I have done justice to your words and experiences, and that the newfound knowledge gained through this research will assist healthcare providers to improve bereavement support services for women like you.

I would also like to acknowledge and thank my amazing supervisory team. To my principal supervisor, Professor Lynne Cohen, thank you for your continued support, advice, humour and timely feedback. Your guidance was pivotal in the conceptualisation and early development of the project, and throughout the research process. To my associate supervisor, Belinda Jennings, thank you for your support, encouragement, and expert advice. Your knowledge and expertise in the field of perinatal loss was invaluable, and your feedback during the analysis and write up stages of the project ensured I was able to stay on track! You were able to recognise the project's worth, and I hope I have been able to do it justice. I admire your commitment towards ensuring women affected by pregnancy loss receive optimal care, and I look forward to continuing our professional relationship in the aftermath of this project.

Finally, I would like to thank my family and friends for their patience, understanding, and unwavering support whilst I completed this thesis. It was a long and arduous process, but you all showed empathy and encouraged me to persevere. It was well worth it.

#### **Table of Contents**

ABSTRACT	V
CHAPTER 1: INTRODUCTION	1
PREVALENCE AND CAUSES OF PREGNANCY LOSS	1
PSYCHOLOGICAL CONSEQUENCES OF PREGNANCY LOSS	2
THE UNIQUE NATURE OF PREGNANCY LOSS	3
IMPACT OF PREGNANCY LOSS ON THE SUBSEQUENT PREGNANCY	5
STATEMENT OF THE PROBLEM	6
THE PHENOMENOLOGICAL PERSPECTIVE	7
Husserl and Transcendental Phenomenology	9
Heidegger and Hermeneutic Phenomenology	10
Merleau-Ponty and Existential Phenomenology	11
Gadamer and Linguistic Phenomenology	11
Definitions	14
STRUCTURE OF THE THESIS	15
CHAPTER 2: LITERATURE REVIEW	19
Understandings of Grief and Loss	19
Historical Perspectives of Grief	20
Current Understandings of Grief	25
GRIEF AND PREGNANCY LOSS	27
Maternal Attachment	31
The association between gestation and attachment	35
The Impact of Partner Support	37
Recognising divergent grieving styles	39
PSYCHOLOGICAL DISTRESS AND PREGNANCY LOSS	41
Psychological Distress Following Miscarriage	42
Psychological Distress Following Stillbirth	43
Psychological Distress in the Subsequent Pregnancy	45
Pregnancy Loss Care	49
SUMMARY AND RATIONALE	55

CHAPTER 3: METHODOLOGY	59
RATIONALE FOR A QUALITATIVE APPROACH	59
Interpretative Phenomenological Analysis	60
Participant Recruitment	62
Ethical Considerations	65
Data Collection Procedures	70
Data Analysis	75
RESEARCH RIGOUR	81
Summary	85
CHAPTER 4: WOMEN'S EXPERIENCES OF BEREAVEMENT FOLLOWING PRI	EGNANCY
LOSS	87
EMERGENT THEMES	88
An Unexpected and Painful Reality	88
A Complex and Enduring Grief	100
An Undesirable and Rejecting Self	106
Maintaining Connections with the Baby	113
A Transformed Self	116
Summary	120
CHAPTER 5: UNDERSTANDING THE NATURE OF POSITIVE AND NEGATIVE	E SUPPORT
FOLLOWING PREGNANCY LOSS	123
EMERGENT THEMES	124
From Diagnosis to Birth: The Need for Sensitive and Empathic Care	125
After-Care: The Need for Improved and Continued Support	135
The Significance of Familial Support	
Advice for Others: How To Support My Grief	148
Seeking a Shared Grieving Experience	158
Summary	165
CHAPTER 6: THE SUBSEQUENT PREGNANCY	167
EMERGENT THEMES	168
Psychological Complications of Trying Again	168
Pregnant Again: The Dark Cloud of Anxiety	175
Coping with Anxiety During the Subsequent Pregnancy	182
The Subsequent Birth: A Bittersweet Reality	190
Summary	193

CHAPTER 7: DISCUSSION	195
GRIEF AND PREGNANCY LOSS: BEYOND THE DOMINANT DISCOURSE	196
Meaning Making and Investment In Pregnancy	197
Post-Trauma Distress	199
Reintegration Not Resolution of Grief	202
An Altered Sense of Self	204
PERCEPTIONS OF SUPPORT: A CRITICAL CATALYST	207
Caregiver Support: The Importance of Empathy, Guidance, and Respect	208
Interpersonal Support: Seeking A Shared Grieving Experience	217
Social Support: Issues of Avoidance and Minimisation	222
THE SUBSEQUENT PREGNANCY: THE NEED FOR GUIDANCE AND REASSURANCE	224
Is There A Right Time to Try Again?	224
The Difficult Task of Balancing Hope and Fear	229
Psychotherapy Treatment Initiatives	232
Summary	236
CHAPTER 8: CONCLUSIONS AND IMPLICATIONS	241
RESEARCH AIM AND DESIGN	241
SUMMARY AND CONCLUSIONS OF THE RESEARCH FINDINGS	242
RESEARCH IMPLICATIONS	245
Implications for Theory Development and Grief Classification	245
Implications for Policy Development	251
Implications for Future Research	269
STUDY LIMITATIONS	271
PERSONAL REFLECTIONS ON THE RESEARCH	274
REFERENCES	277
APPENDICES	305

Chapter One: Introduction 1

#### **Chapter 1: Introduction**

This chapter aims to emphasise the importance of further exploration of women's experiences of pregnancy loss. It focuses on providing an understanding of the reasons for the research and the choice of phenomenological enquiry as the methodological framework to explore this unique form of bereavement.

#### **Prevalence and Causes of Pregnancy Loss**

Pregnancy is a time in a woman's life that is generally associated with excitement and joy at the prospect of a new life being brought into the world. For more than 300 000 women in Australia each year, after nine months of anticipation the pregnancy experience concludes with the birth of a healthy newborn (Li, Zeki, Hilder, & Sullivan, 2011). However, for a large number of women, pregnancy does not proceed as expected and they experience a loss<sup>1</sup>. Every year in Australia, an estimated 50,000 pregnancies end in miscarriage or stillbirth (Evans, Lloyd, Considine, & Hancock, 2002).

In Australia, it is estimated that approximately 1 in 4 pregnancies  $(20 \text{ to } 25\%)^2$  end in miscarriage, a term which describes any spontaneous pregnancy loss occurring prior to 20 weeks gestation (Boyce, Condon, & Ellwood, 2002). In addition, approximately 1 in a 100 pregnancies result in stillbirth, defined as foetal death beyond 20 weeks gestation (Gee, 2013; Joyce & Tran, 2009; Laws, Abeywardana, Walker, & Sullivan, 2007). Recent perinatal mortality data in Western Australia indicate that between 2006 and 2010 there were 1076 stillbirths ( $\geq$  20 weeks gestation) during that period, or 7.1 per 1000 total births (Gee, 2013). No comprehensive statistical data exists for miscarriage ( $\leq$  20 weeks gestation), as this data is not reported or recorded (Herbert, Lucke, & Dobson, 2009).

<sup>&</sup>lt;sup>1</sup> The term 'pregnancy loss' in this study is used to refer to the spontaneous loss of a baby from conception to birth.

<sup>&</sup>lt;sup>2</sup> Statistical data  $\leq$  20 weeks gestation are not recorded in Australia, therefore miscarriage prevalence rates are only estimates.

Chapter One: Introduction 2

The most commonly cited causes of miscarriage are foetal chromosomal abnormalities, maternal hormonal and uterine factors, bacterial infections, and immunologic disorders (Kohn, Moffit, & Wilkins, 2013; Reagan & Rai, 2000; Yang, Stone, & Stewart, 2006). However, in approximately 50% of cases the cause of miscarriage is undeterminable (Kohn et al., 2013; Yang et al., 2006). The major causes of stillbirth are prematurity, congenital anomalies, growth restriction, complications of the placenta, cord and/or membranes, or other conditions originating in the perinatal period. Like miscarriage, however, the causes of many stillbirths remain unknown (Flenady et al., 2009; Gee, 2013).

Lifestyle factors such as maternal smoking, obesity, consuming alcohol during pregnancy, or exposure to other harmful toxins, have also been found to contribute to pregnancy loss (Ahluwalia, Grummer-Strawn, & Scanlon, 1997; Flenady et al., 2011; Gaizauskiene, Padaiga, Basys, Grigorjev, & Mizeriene, 2003; Kesmodel, Wisborg, Olsen, Henrikson, & Secher, 2002). In particular, there is growing evidence of a causal relationship between obesity and gestational complications (eg., gestational diabetes and hypertension). Likewise, first-time pregnancies have also been associated with emerging complications (e.g., preeclampsia and foetal growth restriction (Flenady et al., 2011). Another important risk factor is advanced maternal age (over 35 years), which has been associated with greater infertility rates and various adverse pregnancy outcomes (Andersen, Wohlfahrt, Christens, Olsen, & Melbye, 2000; Flenady et al., 2011; Fretts, Schmittidiel, McLean, Usher, & Goldman, 1995; Kenny, Lavender, McNamee, O'Neill, & Tracey, 2013; O'Leary, Bower, Knuiman, & Stanley, 2007; Valadan, Tanha, & Sepahi, 2011).

#### **Psychological Consequences of Pregnancy Loss**

Emotional reactions to pregnancy loss are often intense and many women experience a marked deterioration in health and psychological functioning (Cacciatore, 2010; Campbell-Jackson, & Horsch, 2014; Klier, Geller, & Neugebauer, 2000; Robinson, 2011; Swanson, 1999). Common grief reactions among women who experience pregnancy loss include: shock, numbness, sadness, confusion, sleeplessness, loss of appetite, guilt, anger and loneliness (DeFrain, 1991; Ewton, 1993; Madden, 1994; Wing, Clance, Burge-Callaway, & Armistead, 2001), together with marked reductions in their self-esteem and perceptions of being a biological failure (Hutti, 2005; Leon, 1992). With the loss of pregnancy comes the collapse of the woman's hopes and dreams, leaving her feeling intense emotional pain (Bangal, Sachdev, & Suryawansh, 2013; Brier, 2008; Cote-Arsenault & Mahlangu, 1999; Uren & Wastell, 2002).

In addition to profound and persistent grief reactions, research suggests that women who experience pregnancy loss are at increased risk of numerous psychological disorders. Elevated levels of anxiety have been reported among women who experience miscarriage and stillbirth (Cote-Arsenault & Marshall, 2000; Gaudet, Sejourne, Camborieux, Rogers, & Chabrol, 2010; Ockhuijsen, van den Hoogen, Boivin, Macklon, & de Boer, 2014). This anxiety has been found to be pervasive and enduring, continuing into the subsequent pregnancy and beyond (Brier, 2004; Cote-Arsenault & Donato, 2011; Geller, Kerns, & Klier, 2004). Research also indicates that women who experience pregnancy loss are at increased risk for depression and post-traumatic stress disorder (Blackmore et al., 2011; Gold & Johnson, 2014; Hughes, Turton, Hopper, & Evans. 2002).

#### The Unique Nature of Pregnancy Loss

Although death in any form is devastating to those bereaved, pregnancy loss is unique in several ways. For example, when a person dies, a piece of the past is lost and the bereaved individual grieves for this consciously known person and all that they represented in this world. Detachment<sup>3</sup> and identification<sup>4</sup> are central to the mourning

<sup>&</sup>lt;sup>3</sup> Detachment: to emotionally detach oneself from the deceased.

process, whereby memories are recalled and laid to rest, or preserved as a part of the self (Moscarello, 1989). Conversely, when a baby dies, a part of the future is lost and the bereaved mother grieves for what might have been and everything this child would come to represent (Bennett, Lee, Litz, & Maguen, 2005; Callister, 2006). Thus, the loss of a baby during pregnancy entails the loss of anticipated joy and motherhood, and the struggle to identify as a mother without the presence of a child (Bennett et al., 2005).

Unlike other child losses in which grief is retrospective and involves relinquishing shared experiences and memories, Leon (1996) noted that losing a child during pregnancy is a prospective loss and involves giving up the wishes, hopes and fantasies of one's ideal family. In addition, the mother's bond with her child has developed predominantly in utero, and she may feel extremely unjustified and invalidated in her grief (Peppers & Knapp, 1980), particularly if she feels that others may not perceive her baby as a 'real child' or legitimate loss. Adding to this sense of isolation, there may also be self-blame, shame, humiliation and guilt (Barr, 2004) as the mother may feel as though she is at fault for her pregnancy loss or that her body has betrayed her (Rosenfeld, 1991).

Contrary to other types of losses, pregnancy loss is unique in that it does not evoke the same sympathy and support aroused by other forms of death. The baby's existence as a 'real' being is often only affirmed by its parents who form a special attachment to their unborn baby (Malacrida, 1997). This response is further complicated by a society which celebrates birth at large, yet fails to acknowledge the grief and despair which ensues following a pregnancy loss (St John, Cooke, & Goopy, 2006). Thus, women may feel extremely alone and invalidated in their grief, as they must come to terms with the loss of a baby in a society where mourning expectations are ill-defined (Vance, Najman, Thearle, Embelton, Foster, & Boyle, 1995).

<sup>&</sup>lt;sup>4</sup> Identification: finding a place for the deceased in one's sense of self. See Fraley & Shaver (1999) and Bowlby (1980) for a detailed discussion of terms.

The consequence of denied loss for bereaved women is what Doka (1989) has referred to as "disenfranchised grief", a prevalent but socially unwarranted sense of grief. According to Doka (1989), women's feelings of loss become compounded by feelings of guilt, shame and alienation, by a society that unwittingly negates and often exacerbates grief feelings. Thus, neither the recognition of the loss nor the social rituals exist for women who experience pregnancy loss.

#### **Impact of Pregnancy Loss on the Subsequent Pregnancy**

Despite the many complexities that women face following a pregnancy loss, childbearing literature suggests that women express a strong desire to conceive again. Deciding to try to conceive again often triggers conflicting emotions, self-doubt, insecurity, and fear of a further loss (Cote-Arsenault & Marshall, 2000; Lamb, 2002). In addition, women often report contradictory advice in relation to how long they should wait before trying to conceive again following pregnancy loss (Lee, McKenzie-McHarg & Horsch, 2013). A range of factors appear to influence the decision to try again, including maternal age, fears of infertility, the presence of other living children, the intensity of the grief following the loss and the perceived 'emotional readiness' to conceive again (Armstrong, 2006; Lee et al., 2013).

Research examining the experience of subsequent pregnancy following pregnancy loss highlights the presence of ongoing and specific anxiety throughout the pregnancy (Armstrong & Hutti, 1998; Cote-Arsenault, 2003; Gaudet et al., 2010). Many women worry about the outcome of their subsequent pregnancy and describe feelings of having lost their innocence and the ability to enjoy of being pregnant (Nansel, Frederick, Doyle, & Zhang, 2005). To cope, women describe a tendency to 'hide' their subsequent pregnancy and keep their emotions guarded. Anxiety appears to be heightened around the anniversary of their baby's death, when women experience a

Chapter One: Introduction 6

resurgence of their grief as they recount the trauma of their previous loss (Cote-Arsenault & Donata, 2007).

Conflicting findings exist as to the effects of a subsequent pregnancy on the psychological distress of women who have experienced a previous loss. For example, Hughes, Turton, & Evans (1999) found elevated levels of depression, anxiety and post-traumatic stress in women who are pregnant following stillbirth compared to women with no history of pregnancy loss. Increased psychological distress was also reported in a later study by Turton, Hughes, Evans, & Fainman (2001), especially when conception occurs soon after loss. These researchers advocate that it may be advantageous for women to wait at least twelve months before trying to conceive. However, other studies have reported that a subsequent pregnancy can have a positive and mediating effect on psychological distress, primarily by decreasing women's grief, despair, and difficulty coping (Cuisiner, Janssen, de Graauw, Bakker & Hoogduin, 1996; Franche & Bulow, 1999; Lin & Lasker, 1996). Further research is needed to better understand the effects of pregnancy loss on the subsequent pregnancy, as little qualitative research exists. Furthermore, the limited qualitative data that does exist is primarily focused on stillbirth, and overlooks the experience of miscarriage.

#### **Statement of the Problem**

Despite the frequency of pregnancy loss, and the resultant psychological distress that ensues, insufficient research has been directed towards the experience of this vulnerable population. Few explicit definitions exist to describe the phenomenon, and inconsistency in conceptual meaning continues to impede theory development (Fenstermacher & Hupcey, 2013). Furthermore, the experience of pregnancy loss is one that remains uncomfortable for society. It is important to research such uncomfortable life experiences in order to increase understanding and potentially remove social boundaries that prohibit communication about these fundamental experiences.

Additionally, the manner in which the experience of pregnancy loss is identified and interpreted has the potential to positively impact bereavement support. This is not only important to assist women in the aftermath of pregnancy loss, but also in the subsequent pregnancy.

In order to explore women's experiences of pregnancy loss and derive women's interpretations of these lived experiences, the researcher adopted a phenomenological perspective of research enquiry. A description of the phenomenological perspective follows, together with a historical overview of phenomenology.

#### The Phenomenological Perspective

Philosophers such as Heidegger (1962) argued that all understanding is interpretative and arises out of our being in this world. Understanding and meaning of human phenomena is situated in time, space and body, and is developed through dialectical and contextual communications with those who are experts and those who have experienced the phenomenon of interest (Cresswell, 2009). As a psychologist, the researcher considered human realities as subjective and transformative, and understood mental constructions as socially and experientially based. This perspective is consistent with the constructivist paradigm, which posits that understandings are subjective and experiential, and that knowledge is never absolute (Fehring, 2002).

A researcher's worldview also influences their choice of methodology for a study. Constructivist/Interpretative approaches allow for research that aims for understanding of a human phenomenon, for research that is conducted in a natural setting, and for research which utilises the knowledge embedded in the experience (Fehring, 2002). Phenomenology is one such interpretative approach, which has provided the methodological structure for an increasing number of research studies within the behavioural sciences. It is a methodology to uncover "the meaning of a complex experience as it is lived by the person" (Burns & Grove, 2005, p. 27). As this

study was concerned with understanding the meaning of the lived experience of women who have experienced pregnancy loss, it was conducted from a phenomenological perspective. A discussion of the evolution of phenomenology, including its various modifications over the years, is necessary to provide justification for its adoption in the current study.

The word *phenomenon* comes from the greek word *phaenesthai*, meaning "to show itself", or "to appear" (Moustakas, 1994). Phenomenology therefore, focuses on people's perceptions of the world, or the perception of the "things in their appearing" (Langdridge, 2007, p. 11). Phenomenology is often defined in terms of the study of phenomena as people experience them, in his or her life (von Eckartsberg, 1998). As a methodology, the qualitative researcher seeks to elucidate individual experiences of phenomena, and interpretations are made from these lived experiences (Cresswell, 2009; Parry, 2004; Smith, Flowers, & Larkin, 2009).

Originally founded as a philosophy by Husserl (1857-1938), phenomenology began within the realms of consciousness and experience, but was later expanded by Heidegger (1889-1976) to include the human life world. Fuller (1990, pp. 29-30) captures the essence of phenomenology:

"Phenomenology is engaged in the project of bringing into the open (interpreting) and of faithfully portraying (describing) the total lifeworld structure of meaning events... How something happens in its lifeworld setting is essential to what it is. A meaning never exists in isolation but always in a lifeworld context of other meanings..." Thus, the phenomenologist seeks to elucidate the meaning of phenomena as they appear within the life-world of one's being (Barnacle, 2001). This means going beyond simply identifying and explaining shared meanings, but critically examining these meanings, in order to describe their core structure and character (Crotty, 1996; Karlsson, 1993).

The many perspectives of phenomenology locates it various forms in the positivist (Husserl), post-positivist (Merleau-Ponty), interpretivist (Heidegger) and constructivist (Gadamer) paradigms. Although the various forms share some commonalities, they also have distinct features. A brief historic review of phenomenology is provided in order to isolate key differences between traditional and contemporary phenomenology, and its subsequent adaptation as a methodological approach to explore the lived experience.

#### **Husserl and Transcendental Phenomenology**

Husserl (1857-1938) is considered the founder of phenomenology, as his work has permeated all subsequent phenomenological thought. A mathematician and philosopher, Husserl was influenced by descriptive psychology through his mentor Brentano. Husserl adopted Brentano's account of intentionality as the fundamental concept for understanding and categorising conscious acts and experiential mental practices (Moustakas, 1994). Intentionality is the principle that every mental act is related to some object and implies that all perceptions have meaning (Moran, 2000). As stated by van Manen, all thinking, whether it be imagining, remembering, or perceiving, is always thinking about something (1990). Therefore, consciousness intentionally constructs not only the experience, but also the meaning ascribed to the experience.

The transcendental nature of Husserl's thinking is reflected in his proposal of a phenomenological reduction, a method for transcending the life world to achieve contact with meaning. Husserl (1970) argued that the life world (*Lebenswelt*) is understood as what individuals experience pre-reflectively, without interpretation. Therefore, the method involves a suspension of perception and conceptualisation of the experience, and an attempt is made to understand the essential features of a phenomenon as freely and as unprejudiced as possible (Moustakas, 1994). In phenomenological research, this is achieved by a two-step process. First, through free

(imaginative) variation, which leads the researcher to a description of the essential structures (essence) of the phenomena (Polkinghorne, 1983). Essence is what makes a thing what it is, and without which it would not be so (van Manen, 1990). This is followed by intentional analysis, whereby the researcher focuses on the concrete experience itself and describes how the particular experience is constructed (Polkinghorne, 1983).

#### Heidegger and Hermeneutic Phenomenology

Like Husserl, Heidegger's hermeneutic phenomenology is concerned with the human experience as it is lived. However, he differs from Husserl in his views of how the lived experience is explored. Heidegger (1889-1976) challenged Husserl's construction of phenomenology as a purely descriptive philosophy. Instead, he referred to phenomenology as a concept and method which seeks to uncover understanding of the meaning of "Being" (*Dasein*), designating it as an interpretive, rather than descriptive process (Heidegger, 1962).

Published in 1927, Heidegger's work *Being in Time* proposes that consciousness is not separate from the world of human existence, and that human beings can only exist in the framework of an 'all-encompassing' world. Individual assumptions and interpretations are shaped by personal experiences, and influenced by time and place. Thus, individual perception is always an interpretative clarification of the world, it is never value neutral. Heidegger used the phrase "being in the world" to refer to the way human beings exist in the world and suggested that access to "being" is achieved through the hermeneutic process (Heidegger, 1962). The term hermeneutic, from Greek word *hermeneuo*, means to interpret. This interpretative approach, known as the 'hermeneutic circle', refers to the flow of understanding that takes place through being in the world. It is a circular process whereby the fore-structures of understanding are made explicit, then considered in terms of the whole of the understanding of something,

and then reconsidered in new ways. Thus, it refers to the back and forth movement between partial understandings and the more complete whole (Dowling, 2007).

#### **Merleau-Ponty and Existential Phenomenology**

Merleau-Ponty (1908-1961), a French philosopher, psychologist and existential phenomenologist, expanded on the work of Husserl and Heidegger. In his work, *Phenomenology of Perception*, he proposed that the goal of phenomenology is to discover the initial experience, which he labels the "primacy of perception" (Racher & Robinson, 2003). Like Husserl, Merleau-Ponty advocates phenomenological reduction in order to reach an original awareness (Racher & Robinson, 2003). However, in contrast to Husserl who believed that "all consciousness is conscious of something", Merleau-Ponty supposed that "all consciousness is perceptual consciousness" (van Manen, 2002). Merleau-Ponty believed that one's perception is influenced by both pre-reflective knowledge and one's being in the world.

The practicality of Merleau-Ponty's phenomenology is evident in the four existentials he considers to belong to the fundamental structure of the life world: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (communality) (Dowling, 2007). Consideration of these four existentialist facets provides methodological insight for the process of phenomenological questioning, reflecting and writing (van Manen, 2002).

#### Gadamer and Linguistic Phenomenology

Gadamer (1900-2002), a German philosopher and student of Heidegger, continued to develop hermeneutic phenomenology as a philosophical framework. In his version of phenomenology, Gadamer posited that understanding is derived from personal involvement by the researcher in a reciprocal process, that is intricately linked with one's being in the world (Spence, 2001). Interpretation permeates every activity, and is influenced by social and cultural contexts (Koch, 1999). Gadamer utilised the

term 'horizon' to account for this understanding, which assumes that perception is in a constant state of development.

Fleming, Gaidys and Robb (2003) developed a Gadamerian method for hermeneutic phenomenological research. They proposed five stages in the research process, which researchers can follow to guide their work. These include: (1) Deciding upon a research question, (2) Identifying pre-understandings, (3) Gaining understanding through dialogue with participants (4) Gaining understanding through dialogue with text, and (5), Establishing trustworthiness (Fleming et al., 2003).

Gadamer (1990) emphasised the importance of selecting the right questions to facilitate hermeneutical enquiry. Therefore, it is critical to ensure that the research question is appropriate to the phenomenon of interest, so that data obtained and conclusions drawn will be useful (stage one). In stage two, the authors propose that researchers engage with texts and colleagues to identify their prejudices, which may influence interpretation of the data. Periodic reviewing of prejudices and preunderstandings is considered to enable the researcher to enter the hermeneutic circle, and remain oriented to the phenomenon (Fleming et al., 2003). During stages three and four, the researcher remains actively immersed within the phenomenon of interest, through orientation with written and spoken dialogue. It is essential that the researcher interview the participants two or three times, because of changing horizons (i.e., the hermeneutic circle) that may affect interpretation. Gadamer takes the concept of the hermeneutic circle one step further and stipulates that researchers should ensure that feedback and further discussion take place with study participants (Fleming et al., 2003). As each individual's understanding is continually evolving, the participant and researcher work together to achieve a shared understanding. Therefore, the hermeneutic process becomes a dialogical method whereby the horizons of the researcher and participants merge, and a new understanding develops from this interaction.

In order to facilitate the process of understanding, the first series of interviews should be analysed before proceeding with the following. The process involves a series of steps that may occur concurrently or cyclically. All interview texts should be examined to reach an interpretation that reflects the fundamental meaning of the text as a whole. Sentences or sections should be examined for meanings that facilitate the identification of specific themes. Every sentence or section should be compared to the meaning of the text as a whole, until a shared meaning (between participant and researcher) is identified.

The establishment of trustworthiness completes the Gadamerian research process. The authors adhere to the criteria proposed by Lincoln and Guba (1985) and Clayton and Thorne (2000) to ensure auditability, credibility and confirmability of the research process. They advocate the clear documentation of the various deductive processes used during the different stages of analysis (auditability), the use of direct quotations from the text (credibility), and returning to participants for feedback and clarification (confirmability), during all stages of the research process (Fleming et al., 2003).

This review indicates that there are a variety of philosophical traditions that influence methodological approaches to phenomenological research. Numerous methodological approaches have been proposed for research within the fields of psychology and nursing, including; the descriptive phenomenology of Giorgio (1975; 2009) and Wertz (1983; 2005; 2011), van Manen's Hermeneutic Phenomenology (1990; 2002; 2014), and Smith's Interpretative Phenomenological Analysis (2004; 2007; 2009; 2011). In the current study, the methodological approach of Interpretative Phenomenological Analysis (IPA) was utilised to explore the lived structure of meaning for women who experienced pregnancy loss. The essence of this approach is discussed in Chapter Three.

#### **Definitions**

Some definitions of terms commonly used throughout the thesis are provided here for clarity. It is important to recognise that definitions of perinatal death are legally defined. The Perinatal Society of Australia and New Zealand (PSANZ) have developed a classification system for perinatal death, which is in use across Australia and some jurisdictions in New Zealand. The system ensures a streamlined approach for statistical and auditing purposes, as well as consistency across maternity care practices. In addition, legal definitions of perinatal death in Australia are collated in the National Health Data Dictionary (NHDD)(Australian Institute of Health and Welfare, 2012).

*Miscarriage*, also known as 'spontaneous abortion', is defined as the loss of a pregnancy from natural causes prior to the foetus achieving viability. Viability has been considered to be at least 20 weeks gestation, when the foetus has the capacity to survive outside the uterus. Therefore, miscarriage is defined as a pregnancy loss occurring before 20 weeks gestation, or of a foetus less than 400gm weight.

Stillbirth is defined as a foetal death occurring from 20 weeks' gestation, or of 400gm or more birth weight.

Care is needed when comparing Australian birth statistics with those from other countries that have different gestational ages included in the definitions of miscarriage and stillbirth. In many other countries, pregnancies must continue to 22, 24 or even 28 completed week's gestational age for a foetal death to be counted as a stillbirth. For example, the World Health Organisation (WHO) defines stillbirth as a baby born after 28 week's gestation.

In Australia, the term *Perinatal Loss* or *Perinatal Death* is used to refer to a foetal death from 20 week's gestation to 28 days after birth (Laws et al., 2007). Thus, it is a term that embodies only stillbirth and neonatal death. This definition differs from that recommended by the World Health Organisation which defines perinatal loss as the

loss of a pregnancy at any time from conception until 28 days after birth. To avoid confusion, the term 'perinatal' will be used to refer to both miscarriage and stillbirth, throughout this thesis.

The terms grief, mourning, and bereavement are often referred to synonymously when discussing loss, and are used interchangeably. However, there are slight differences in interpretation and it is important to understand these terms when exploring bereavement experiences.

*Grief* is defined as the process of psychological, social and somatic reactions to the perception of loss (Rando, 1984; Worden, 2009).

*Mourning* is defined as the public expression of grief. It is usually described as the process through which the bereaved individual works to undo the psychological bonds that bind them to the deceased (Rando, 1984; Worden, 2009).

Bereavement is defined as the state or condition of having experienced a loss, to which the individual must learn to adjust (Worden, 2009).

Whilst this study is interested in the bereavement *experience* of women who have endured a pregnancy loss, previous research indicates that the main attribute of perinatal bereavement is grief (Fenstermacher & Hupcey, 2013). Therefore, for the purposes of this study, it is assumed that grief will be a significant component of the bereavement experience.

#### **Structure of the Thesis**

The thesis is divided into eight chapters. The current chapter has clarified the rationale behind the research and has provided justification for the choice of phenomenological analysis as the methodological framework upon which to explore women's experiences of pregnancy loss.

The second chapter presents a detailed review of the bereavement literature specific to pregnancy loss. Considering the research orientation, the literature review

predominantly focuses on maternal grief and attachment theory, and the psychological effects of pregnancy loss pertaining to women. It includes a detailed discussion of the role of interpersonal and professional support in women's experiences, including the impact of partner support and the confines of current healthcare provision. A brief review of psychological distress in the subsequent pregnancy is also included to elucidate the enduring and complex nature of the grief experience. The review concludes with a rationale for the qualitative exploration of grief following pregnancy loss, with an emphasis on phenomenological enquiry to uncover how women cope and make sense of this unique bereavement experience.

Chapter Three outlines the research methodology. Justification is provided for the choice of qualitative research methodology and the use of interpretative phenomenological analysis to explore women's understandings of their pregnancy loss experiences. This is followed by a detailed account of the recruitment process, including a careful consideration of ethical matters pertaining to the research. Next, data collection procedures and the process of data analysis are outlined, with specific examples from the research. Finally, the measures taken to ensure research rigour are also discussed.

The findings are presented in chapters Four, Five, and Six. In chapter Four, women's bereavement experiences are described. The findings reveal that women who experience pregnancy loss endure significant emotional turmoil, which remains unrecognised and underappreciated. In particular, they experience marked anger, sadness, guilt, failure, shame, anxiety, self-blame, vulnerability and confusion, which appears pervasive and enduring. However, the experience of bereavement is also one of positive growth and enlightenment, and women describe becoming more empathic and appreciative individuals as a result of their bereavement experience.

In Chapter Five, women's experiences of positive and negative support are discussed. This chapter illustrates how women's grieving responses to pregnancy loss are often curtailed or ignored, as a result of society's lack of understanding over the psychological impact that their bereavement experience entails. This leads to experiences of isolation and abandonment, and dissatisfaction with caregiver support. Conversely, women felt respected and supported when others acknowledged their grief and conveyed empathy and sensitivity towards them. The impact of partner support was a crucial indicator of women's bereavement experiences, as was the ability to access support from women who shared a history of pregnancy bereavement.

In Chapter Six, women's experiences of subsequent pregnancy after loss are explored. This chapter focuses on the complex interplay of grief and anxiety in the subsequent pregnancy, and the challenges the women faced trying to simultaneously balance hope and fear. Although not initially part of the research aims per se, analysis revealed that women's experiences of anxiety in the subsequent pregnancy were a significant component of their bereavement experience. In order to cope with this anxiety, women engaged in numerous control behaviours and attempted to delay emotional bonding with their unborn child.

Chapter Seven presents a discussion of the research findings. The research findings are positioned in the context of existing literature and frameworks, and demonstrate how the current study contributes new information to existing research. In particular, the findings of the current study challenge what has previously been reported about the trajectory of grief following pregnancy loss, the negative impact of bereavement on the spousal relationship, and the timing of the subsequent pregnancy. In addition, the study has uncovered the need to consider meaning-making and investment in pregnancy as a crucial indicator of bereavement response, the potential disregard of

posttraumatic stress, the need to offer extended continuity of care, the incidence of posttraumatic growth, and the reintegration, rather than resolution, of grief.

Chapter Eight outlines the study's main conclusions, together with a discussion of the theoretical and practical implications that may be derived from the research. This chapter asserts that this research fills an identifiable gap in the literature, and makes significant contributions to understandings of perinatal bereavement for both theory and practice. It provides the reader with an understanding of the substantive domain and offers a framework for conducting future research.

### **Chapter 2: Literature Review**

This chapter presents a comprehensive overview of the grief and attachment literature, with a focus on perinatal grief and attachment. It includes a review of past and present understandings of grief, maternal attachment, the psychological consequences of pregnancy loss, anxiety in the subsequent pregnancy and the context of pregnancy loss care. The impact of partner support, together with gender differences in grieving styles are also discussed, as these have been shown to impact women's bereavement experiences. The review concludes with a chapter summary and rationale for the qualitative exploration of women's experiences of pregnancy loss.

## **Understandings of Grief and Loss**

Bereavement is ubiquitous in our existence. Nearly every human being at some point in his or her life will encounter the death of a significant other. It is assumed that most people will react with intense distress when they experience the loss of someone close to them. Therefore, the grief response is considered to be a normal and natural reaction to the loss of a loved one, a reaction that subsides over the passage of time (Stroebe, Hanson, Schut & Stroebe, 2008). Individuals are expected to adjust to the death of their loved one and return to a normal state of functioning.

The field of grief and bereavement has undergone a major transformation in terms of how the human experience of loss is understood. Long-held beliefs about the grief experience have been discarded, with research evidence failing to support early stage-based models, which construed grief as a predictable emotional trajectory. Modern theorists suggest grief is no longer conceptualised as a rigid or linear process leading from distress to 'recovery' (Hall, 2014). In addition, 'successful' grieving is no longer presumed to require a severance of attachment bonds. Instead, a gradual shift is occurring towards the potential healthy role of maintaining continued bonds with the deceased (Field, 2006; Klass, Silverman, & Nickman, 1996).

### **Historical Perspectives of Grief**

In order to understand current conceptualisations of grief and grief theory, it is necessary to provide a historical overview. The first major theoretical contribution which shaped professional intervention for nearly half a century, was provided by Freud in his book *Mourning and Melancholia* (1917/1957). Freud suggested that grief is a process to be worked through, whereby the bereaved must detach emotionally from the deceased and redirect this energy into other avenues of their lives. This psychic rearrangement involved three elements: (1) freeing the bereaved from bondage to the deceased; (2) readjustment to new life circumstances without the deceased; and (3) building of new relationships. Freud believed that this separation required the energetic process of acknowledging and expressing painful emotions such as guilt and anger. The view was held that if the bereaved failed to engage with or complete their grief work, the grief process would become complicated and increase the risk of mental and physical illness and compromise recovery. Consequently, Freud's work has been referred to by subsequent theorists to justify the concept of 'pathological mourning' (i.e. Archer, 1999; Stroebe, Hansson, Stoebe, & Schut, 2001).

In *Mourning and Melancholia*, Freud professed that 'mourning' and 'melancholia' are two distinct entities, because they are context-specific. He defined grief as a result of being bereaved as 'mourning', and grief as a result of other losses as 'melancholia' (Freud, 1917/1957). He asserted:

"In mourning we found that the inhibition and loss of interest are fully accounted for by the work of mourning in which the ego is absorbed. In melancholia, the unknown loss will result in a similar internal work and will therefore, be responsible for the melancholic inhibition. The difference is that the inhibition of the melancholic seems puzzling to us because we cannot see what it is that is absorbing him so entirely."

(p. 254).

Hence, Freud construed mourning as a normal but time-consuming response to bereavement, whereas melancholia had the potential to become pathological because it was a reaction that occurred outside of any explicable context (Granek, 2010). Another theorist, Abraham (1927) conceded with Freud, professing mourning and melancholia as two distinct conditions. However, whilst Freud focused on the redirection of cathartic energy following bereavement, Abraham (1927) focused on the integration of the deceased into oneself in order to heal from the loss. Abraham (1927) stated: "The process of mourning now brings with it the consolation: 'My loved one is not gone, for now, I carry it within myself and can never lose it" (p. 437).

Whilst Freud (1917/1957) and Abraham (1927) both conceptualised grief as a process to be worked through that never reaches completion, Deutsch (1937) proposed a different theory. In her essay, *The Absence of Grief*, Deutsch (1937) wrote that: "The process of mourning as a reaction to the real loss of a loved person must be carried to completion. As long as the early libidinal or aggressive attachments persist, the painful affect continues to flourish, or vice versa, the attachments are unresolved as long as the affective process of mourning has not been accomplished." (p. 21).

Deutsch's main assertion was that in order to become resolved, grief must be brought into consciousness because otherwise it will manifest in other ways (1937). This unmanifested energy, which she labelled 'absent' or 'repressed' grief, could result in the bereaved becoming psychologically unbalanced if they did not do their 'grief work' (1937). This interpretation remains crucial to contemporary psychological research on the notion of grief, as it suggests that unmanifested grief can be just as pathological as chronic grief (Granek, 2010).

While Freud (1856-1939) is generally conceived to be the first theorist to introduce the concept of grief into the realm of psychology, there were a few researchers who came before him. Burton (1577-1640) was the first theorist to define

the concept of grief in psychological terms, when he wrote about bereavement in his book *The Anatomy of Melancholy*, published after his death in 1651 (Archer, 1999). Burton understood grief as a form of 'transitory melancholy' that each individual must experience at some point in his or her lives in response to a melancholic event (such as loss and bereavement). However, he also emphasised the distinction between melancholy as a normal reaction to loss and melancholy as a disease whereby an individual is habitually melancholic in character (Burton, 1938). This notion of grief as a disease was evident in later publications on grief, such as the works of Benjamin Rush (1745-1813), who wrote about grief in his book *The Diseases of the Mind* (Rush, 1812). Rush described an array of emotional and physiological symptoms characteristic of grieving people such as fever, sighing, loss of memory, aphasia, and even the development of grey hair (Rush, 1812). Accordingly, Rush professed a number of interesting treatments thought to cure grief, including the use of opiates, crying, and in severe cases, bloodletting and purging (Rush, 1812).

Darwin (1809-1882) has also been acknowledged for his important contributions to grief theory. In his book, *The Expression of Emotions in Man and Animals*, Darwin described in detail the expressions of depression and grief in people as well as apes (Darwin & Ekman, 1998). Darwin also differentiated between an active, anxious form of grief, and a passive, more depressive form, which he claimed had different aetiologies (Darwin & Ekman, 1998). This propelled further work on the expressions and manifestations of grief, and Shand (1858-1936) is credited as the first researcher to conduct a comprehensive study of the psychology of grief. In his book, *The Foundations of Character*, Shand defined four types of grief reactions: active and aggressive; depressive and lethargic; suppressed; and hysterical and frantic (1920). Shand (1920) also discussed other influences on grief, including the need for social

support, the trauma associated with sudden death, and relationship bonds with the deceased.

To understand the transition of grief from a psychoanalytic construct to a psychiatric kind, it is necessary to refer to Lindemann's (1944) work on grief and mourning. Lindemann's (1944) publication Symptomatology and the Management of Acute Grief, was the first to present an empirical study of bereaved participants. By interviewing 101 participants who had been recently bereaved, Lindemann claimed to produce a methodologically sound and accurate portrayal of the grieving process, which offered a rationale for pathologising and treating grief (Lindemann, 1944). In his paper, he made a number of significant assumptions. Firstly, Lindemann (1944) asserted that grief was a psychological disorder, reporting that "grief is a definite syndrome with psychological and somatic symptomatology" (p. 141). Secondly, Lindemann (1944) delineated a list of specific grief symptoms and patterns of grief that he stated could differentiate normal grief from pathological grief. And thirdly, based on the notion that grief could be conceptualised as a disorder with a specific aetiology that could be predicted and treated, Lindemann (1944) advocated that it was the responsibility of professionals to do so. He professed that psychiatrists were experts in the field and therefore should be involved in assessment and monitoring of bereaved patients, to ensure they were doing their 'grief work' properly. This grief work involved detachment from the deceased, readjustment to the new environment without the deceased, and the formation of new attachment bonds (Lindemann, 1944). An individual who is said to be grieving normally must accomplish these tasks within the first few months or years following their loss. Disruption, avoidance, or any lengthy delay in the completion of these tasks is therefore construed as a pathological grief reaction according to Lindemann's theory.

In the decade or so following Lindemann's paper, several theorists reiterated or expanded on his ideas about grief work (see Brewster, 1950; Marris, 1958; Stern, Williams, & Prados, 1951 for example), but none appeared to have a profound impact on the field. It wasn't until the latter half of the twentieth century that the next major turning point for grief within the domain of psychology occurred. Numerous theories of grief were proposed, each with a focus on the processes, phases, or tasks of grief (Bowlby, 1961, 1980; Gorer, 1967; Hogan, Morse, & Tason, 1996; Kubler-Ross, 1969; Lazare, 1979; Parkes, 1965a,1965b, 1971; Rando, 1984; Shuchter & Zisook, 1986, 1993). Consistent with the notion of 'grief work', most of these theorists recognised grief as a distinctive pattern of yearning that eventually resolves after a period of several months or years upon 'working through' the grief. Apart from Rando (1993), who insisted that grief may never be 'completed', these theorists agree that pathological grief arises when the bereaved individual fails to relinquish attachment bonds with the deceased and therefore does not 'recover' within the 'expected' time frame.

The relinquishing of attachment bonds was also at the core of Bowlby's (1961, 1980), Bugen's (1977), and Worden's (1982,1991) grief theories. Parkes' clinical studies (1965a, 1965b; 1971) paralleled Lindemann's (1944) work by providing further justification for the pathologisation of grief and the use of psychology to treat it. Gorer (1967) and Lazare (1979) identified various behaviours representative of 'unresolved' grief, such as refusing to part with possessions of the deceased, and purchasing mementos to acknowledge the absence of the deceased on special occasions and anniversaries. The five stages of dying proposed by Elizabeth Kubler-Ross (denial, anger, bargaining, depression and acceptance)(1969) were also applied to grief and widely embraced by health professionals, despite the model being criticised for being methodologically flawed and lacking empirical validation (Corr, 1993).

## **Current Understandings of Grief**

Although earlier stage theories were useful in terms of predicting possible grief outcomes in response to bereavement, they eventually became unpopular because they were considered to be too rigid. Stage models do not address the multiplicity of physical, psychological, social and spiritual needs experienced by the bereaved, their families and intimate networks. Furthermore, they do not capture the complex and diverse nature of the grieving experience. Grief reactions are occurring within the larger context of the individual's life, thus these responses will not likely proceed in a linear fashion. Thus, coping with bereavement should not be understood as a discrete number of responses but as a set of coexisting reactions to a specific bereavement (Corr, 1993; Hall, 2014; Wortman & Silver, 2001).

Recent grief models have emphasised the importance of acknowledging the individuality of the grief experience. Stage theories have been rejected in favour of more phasal conceptualisations that recognise that there may be qualitatively distinct paths through bereavement. Two of the most influential grief theories are the Dual-Process Model proposed by Stroebe and Schut (1999); and the Task-Based Model developed by Worden (2009). Originally, the Two-Track Model of Bereavement was proposed by Rubin (1999), which focuses both on the bereaved's functioning and the quality and nature of the continuing attachment bond. Around the same time, Stroebe and Schut (1999) introduced their Dual Process Model of coping with bereavement, whereby the bereaved individual oscillates between loss oriented (e.g., grief work, focusing on the deceased) and restoration oriented affiliations (e.g., distraction from grief, avoidance, investment in new roles and relationships). Both these models are distinctive from stage/process models of grief as they assume that coping with bereavement involves a complex regulatory process of confrontation and avoidance, rather than an eventual detachment from the deceased and recovery from grief.

Furthermore, the model suggests that the focus of coping may differ from one moment to another, from one individual to another, and across cultures.

A model of grief proposed by Worden (2002, 2009) involved four tasks that must be accomplished for 'successful' adjustment following bereavement. These included: accepting the loss, experiencing the pain of grief, adjusting to the environment without the deceased, and maintaining attachment bonds with the deceased in the midst of embarking on a new life (Worden, 2009). Worden also identifies seven mediating factors that are critical to appreciate in order to understand the bereaved's experience. These include: (1) who the person who died was; (2) the nature of the attachment to the deceased; (3) how the person died; (4) historical antecedents; (5) personality variables; (6) social mediators; and (7) concurrent stressors. These determinants include many of the risk and protective factors identified by the research literature and provide an important context for appreciating the idiosyncratic nature of the grief experience.

Issues such as the strength and nature of the attachment to the deceased, the meaning of the relationship with the deceased, the availability of social support, and the degree of conflict and ambivalence with the deceased are important considerations.

This shift in interpretation considers the broader context of grief responses and is advantageous as it minimises the pathologisation of distress when someone does not conform to typical grief manifestations. Unrealistic assumptions held by many healthcare professionals and society has been associated with increased feelings of distress for the bereaved, and an isolated grieving experience (Doka, 2002). Consequently, whilst it is important for healthcare professionals to identify pathological responses in order to provide effective treatment, this goal should not preclude the recognition of alternative experiences of adjusting to loss.

## **Grief and Pregnancy Loss**

There is general consistency within the literature that compared to other types of bereavement, the loss of a child is associated with a grief experience that is particularly long-lasting, complicated, and severe (Archer, 2001; Hunt & Greeff, 2011; Leahy, 1992; Noelen-Hoeksema & Larson, 1999; Sanders, 1980; Stroebe & Schut, 2001). Whilst existing grief literature can provide a foundation for understanding the experience of pregnancy loss, pregnancy loss is a unique experience that is remarkably distinct from other child losses. Women who experience pregnancy loss are mourning the loss of the 'hoped-for' child, and the wishes and fantasies of what might have been (Dagleish, 2004). This is different from mourning the loss of a child that has lived in this world; who has formed a personality. In addition, it means that attachment and identification processes (previously assumed to be essential mechanisms for mourning) are not possible. For example, there are no memories of the deceased upon which to lay to rest (detachment), and therefore, these memories are unable to be preserved as part of the self (identification). The only memories that may be used in the process of detachment are those created by coming into contact with the deceased baby (i.e., seeing, touching, and holding the stillborn baby). Furthermore, for women who experience a miscarriage, interaction with their baby is not often possible.

The nature of pregnancy loss bereavement is characteristically different from other child losses, as pregnancy loss occurs in utero (within the mother's womb). This reality may serve to complicate the mourning process, as unlike other losses, the mother is unable to grieve for a tangible being. Indeed, researchers have characterised pregnancy loss as an ambiguous loss, stemming from the concurrent physical absence of and psychological presence of the baby (Boss, 2004; Cacciatore, DeFrain, & Jones, 2008). This sense of ambiguity has the potential to become further complicated by society's dismissal and invalidation of such a short-lived or "unborn" life (Lang,

Fleiszer, Duhame, Sword, Gilbert, & Corsini-Munt, 2011). Without the physical presence of the baby, many people find it difficult to comprehend how the grief for a child who has not lived in this world completely, can be so prolific and severe (Rubin & Malkinson, 2001). Consequently, pregnancy loss is generally viewed as a less traumatic and intense experience than the death of an older child or adult that has existed in this world known to others, and is often disregarded. Further, there are no implicit or explicit rules for mourning the death of a child that has died in-utero. Thus, pregnancy loss is often met with silence and confusion, as parents, siblings, friends, colleagues, and the wider social community are often uncertain of how to respond.

Lang and MacLean (2007) signify that it is a combination of society's lack of knowledge about the physical, emotional, and social impact of pregnancy loss, together with their sense of discomfort with bereavement in general, that leaves them unsure as to how to attend to the bereaved. Doka (1989) used the term 'disenfranchised grief', to refer to the grief that individuals experience "when they incur a loss that is not or cannot be openly acknowledged, publically mourned, or socially supported" (p. 4). Such dismissal of grief can have an enormous impact on the coping capacities of women who experience pregnancy loss (Boss, 2004;Lang, Edwards, & Benzies, 2005). It has been shown that women's grief reactions to pregnancy loss are intensified by their perception that their grief is not understood or recognised by others (Lang et al., 2011).

Manifestations of grief vary widely, thus cultural and religious variables may affect how a woman responds to the loss of her baby (Callister, 2006; Chichester, 2005; Van, 2003). Most cultures place a great value on having children, which can increase the significance and pain of pregnancy loss (Chichester, 2005). Likewise, many women view the attainment of motherhood as a significant life goal. Failing to meet this societal norm can affect the intensity of guilt and shame a woman feels, when she is unable to fulfil her maternal role of bearing a healthy child. Variations in cultural and

religious practices may also influence how a woman ascribes meaning to her loss, engages in memorial practices, and how she will seek personal and professional support (Callister, 2006; Chichester, 2005; Van & Meleis, 2003).

The reported societal pressure to move on from a pregnancy loss is a related issue. Individual accounts of women's experiences of loss suggest that the length of time considered socially appropriate to grieve a pregnancy loss is relatively brief (Frost, Bradley, Levitas, Smith, & Garcia, 2007). Women are expected to recover from their loss in a fairly short time frame, and insensitive comments such as "don't worry, you can always have another one" or "it's only a miscarriage" are prevalent (Frost et al., 2007). These comments only serve to minimise and deny the grief experience, reducing the baby to an outcome that can be easily replicated (Adolfsson, Larsson, Wijma, & Bertero, 2004).

Several qualitative studies on women's experiences of miscarriage have confirmed the existence of denied grief feelings (Abboud & Liamputtong, 2003; Adolfsson et al., 2004; Letherby, 1993; Madden, 1994). Adolfsson et al. (2004) used interpretive phenomenology to identify and describe thirteen women's experiences of miscarriage. Their analysis revealed one major theme (guilt and emptiness), and five subthemes (feeling emotionally split, bodily sensation, loss, grief and abandonment), which the authors felt depicted the essence of women's experiences. In particular, women blamed themselves for the miscarriage and experienced a deep sense of emptiness following the loss of their baby. The women wanted these grief feelings recognised and were upset by society's tendency to trivialise the loss. Similarly, in a study investigating women's perceptions of miscarriage, Letherby (1993) reported that women felt they were "not supposed" to be upset. They felt that others did not consider their baby to be a real person, compounding their feelings of shame and isolation. Similar findings have also been reported in qualitative studies that focus on women's

experiences of late pregnancy loss (DeFrain, Martens, Stork, & Stork, 1991), where self-blame, guilt, hardship and the necessity for adequate support systems embodies women's experiences.

The mourning process is further complicated by the presence of what Rando (1986) calls "secondary losses". In addition to the loss of a child, women who experience pregnancy loss also experience a variety of secondary losses, which may intensify the grief experience. For example, in a study exploring ten women's experiences of pregnancy loss, Conway and Valentine (1988) identified five secondary losses. In addition to the loss of the baby, these losses included: loss of pregnancy, loss of parenthood, loss of control, loss of relationships, and loss of self-image. In the study, women who had experienced various types of reproductive loss explained that the loss of pregnancy included the loss of the "experiences" of pregnancy, including childbirth and breastfeeding. Related to this is the loss of parenthood, which represents the loss of the parenting role and a delay in progression of the family life cycle. Both men and women alike expressed this as a significant loss. Loss of control over their reproductive capacities was another important loss, and many women reported feeling betrayed by their body. Loss of relationships primarily referred to the impact of loss on the couple's sexual intimacy. As sexual intimacy was previously associated with the creation of new life, intimacy after loss may serve as a traumatic reminder and may therefore be avoided (Lang, Goulet, & Amsel, 2004). Other relationships may also be affected; particularly those with family and friends who have young children whose presence may serve as a painful reminder (den Hartog, 2014). Thus, withdrawal from others with children and feelings of jealousy may ensue. Further, a pregnancy loss may have a profound effect on the mother's self-identity. The loss of an anticipated baby also entails the loss of motherhood, a major life goal for many women (Lovell, 1983; Hsu, Tseng, Banks & Kuo, 2004). Not achieving this goal may inflict a profound sense of personal failure and

guilt, whereby women may feel inadequate as a woman, wife, and mother for failing to bring a pregnancy to a complete and healthy outcome (Bangal et al., 2013; Frost & Condon, 1996).

### **Maternal Attachment**

The experience of grief is strongly influenced by the perceived strength of the attachment bond. The attachment style of the individual, together with the attachment bond, will ultimately affect the grief experienced (Bowlby, 1969; Worden, 2002). Likewise, it has also been suggested that the mother's degree of physical and emotional attachment to her baby is influenced by the personal meaning she attributes to the pregnancy (Braun & Berg, 1994; Uren & Wastell, 2002). Thus, the amount of time and energy spent trying to conceive, whether the pregnancy was planned or unplanned, the age of the mother, the state of the couple's relationship, a first pregnancy, previous pregnancy losses and the time of loss (i.e., early versus late pregnancy loss), will all have some bearing on how the mother reacts to her loss (e.g. Bennett et al., 2005; Letherby, 1993; Robinson, Baker, & Nackerud, 1999; Uren & Wastell, 2002). Consequently, the degree of prenatal attachment experienced by the mother impacts significantly on her emotional experience of loss (Boyce et al., 2002; Condon, 1993; Frost & Condon, 1996; Laxton-Kane & Slade, 2002).

The first to develop a framework for understanding the basic principles of neonatal attachment<sup>5</sup> was Bowlby (1969), a pioneer in early theories of attachment and loss. Bowlby (1969) spoke in great depth about the formation and maintenance of attachment bonds between mother and infant and how these attachment bonds are emotionally significant. Although Bowlby considered attachment between mother and baby as a continuous process, he was primarily concerned with attachment bonds that occurred after birth. The phenomenon of prenatal attachment between the mother and

<sup>&</sup>lt;sup>5</sup> See Bowlby (1969) for a comprehensive discussion of neonatal attachment.

the foetus was initially explored by Rubin, a nurse researcher who concluded that the immediate bond between a mother and her newborn infant was a direct consequence of prenatal processes (Rubin, 1975). Rubin identified four specific tasks that pregnant women navigate before childbirth: (1) seeking safe passage for self and the baby, (2) ensuring that the baby is accepted by significant others, (3), 'binding-in' (a term Rubin thought more descriptive than 'attachment') and (4) giving of herself. These tasks formed a framework for her conceptualisation of the psychological experience of pregnancy and, although she did not use the term "attachment," Rubin states: "By the end of the second trimester, the pregnant woman becomes so aware of the child within her and attaches so much value to him that she possesses something very dear, very important to her, something that gives her considerable pleasure and pride" (1975, p. 145).

Around the same time, a perinatal epidemiologist in Australia interviewed first-time expectant mothers across the duration of their pregnancy, and found that women's conceptualisations of their baby as a 'real being' increased over the passage of time (Lumley, 1972). The introduction of ultrasound during pregnancy inspired her to examine the impact on maternal bonding of a visual image of the foetus. Lumley (1980) interviewed thirty primiparous women and findings suggested that as early as the first trimester, one-third of the women already conceptualised their baby as a real individual. Women in this study conveyed that they would mourn their loss if they were to miscarry, and also indicated that they would be willing to change their behaviours to protect their developing baby. Lumley's findings (1980) support the notion that this early view of the foetus enhances a mother's ability to differentiate it as a 'little person'. After 'quickening' (an old fashioned term for feeling foetal movement), all but two of the participant mothers identified their foetus as a real baby.

Lumley's subsequent study was one of the first empirical longitudinal studies of prenatal attachment. In an attempt to capture first-time mothers attitudes towards their baby, Lumley (1982) interviewed primiparous women at five points in time during and after pregnancy. In this study, attachment was conceptualised as being a point at which mothers thought of their babies as a "real person" (Lumley, 1982). Lumley reported this phenomenon in 30% of her study participants in the first trimester, 63% in the second trimester, and in 92% in the third trimester. The study confirmed her previous results, suggesting that the experience of foetal movement enhances prenatal attachment among pregnant women.

Expanding on the work of previous researchers, Leifer (1977) was interested in psychological functioning and maturational changes during the course of pregnancy. Study participants were nineteen first-time pregnant women, who completed questionnaires and were interviewed during each trimester of their pregnancies and again shortly after their baby's birth. Results indicated that psychological stability was correlated with stronger attachment patterns, with higher functioning women developing a more intense emotional attachment to their baby. Like her predecessors, Leifer concluded that the emotional bond begins early in pregnancy and intensifies with quickening. Thus, attachment does not begin at birth, but during pregnancy.

Recent advances in technology have meant that the physical and psychological processes that facilitate a mother's sense of attachment to her baby are now occurring at earlier stages of gestation. For example, the first images of an ultrasound are now readily occurring as early as ten weeks, providing women an opportunity to visually bond with their baby and deepen attachment from the first trimester (Righetti, Dell'Avanzo, Grigio, & Nicolini, 2005; Robinson et al., 1999). Similarly, the introduction of three-dimensional and even four-dimensional ultrasound images allows high-quality visualisation of the baby in real time. Although there is limited evidence

that new 3D and 4D technology increases attachment (Alhusen, 2008), studies measuring maternal foetal attachment prior to the performance of any type of ultrasound have delivered evidence that maternal foetal attachment increased upon having an ultrasound (Honemeyer & Kurjak, 2014; Righetti et al., 2005). Thus, the option and ability to view the baby at an earlier point in pregnancy likely contributes to the maternal-foetal relationship developing at a much earlier point in foetal development.

The developing concept of prenatal attachment led to further research efforts to theoretically define the construct. Cranley (1979) is credited with the first theoretically based definition, which she construed from the findings of her doctoral thesis. She defined maternal-foetal attachment as: "The extent to which women engage in behaviours that represent an affiliation and interaction with their unborn child" (Cranley, 1981, p. 282). In 1981, Cranley developed the first multidimensional tool for measuring maternal foetal attachment. The Maternal-Foetal Attachment Scale (MFAS) includes 24-items organised into six behavioural domains. These include: role taking, differentiation of self from the foetus, interaction with the foetus, attributing characteristics to the foetus, giving of self, and nesting (Cranley, 1981). Due to lack of statistical reliability, nesting was subsequently eliminated, reducing the instrument to five subscales.

Since the scale's implementation, two additional psychometric scales have been developed to quantify maternal foetal attachment (see Condon, 1993 and Muller, 1993). The Prenatal Attachment Inventory (PAI) was developed by Muller (1993) to measure the strength of affection that develops between a mother and her growing foetus. The goal was to provide an additional tool, which focused on affiliation, rather than on the behaviours emphasised in the MFAS. In the same year, Condon (1993) developed the Maternal Antenatal Attachment Scale (MAAS). Condon believed that existing instruments inadequately discriminated attitudes towards the baby from attitudes

towards the state of pregnancy and motherhood. Thus, his nineteen-item scale focused exclusively on thoughts and feelings about the baby and ignored feelings about pregnancy or the maternal role. Two factors were generated, quality (affective experiences reported by the mother) and intensity (the amount of time the mother spent thinking about or interacting with the baby). Of these instruments, Cranley's MFAS and Condon's MAAS are the most commonly used measures (Laxton-Kane & Slade, 2002).

Maternal foetal attachment as measured by these scales has been consistently found to increase with gestational age, particularly after quickening (Condon, 1993; Cranley, 1981; Grace, 1989; Muller, 1993). Thus, their evidence supports the notion that maternal foetal attachment may be strengthened by experiences that provide greater reality of the growing foetus within the womb.

### The association between gestation and attachment

The correlation between attachment intensity and foetal movement has led several researchers to draw parallels between grief intensity and gestational age (Cuisinier, Kuijpers, Hoogduin, de Grauuw, & Janssen, 1993; Frost & Condon, 1996; Goldbach, Dunn, Toedter, & Lasker, 1991; Lasker & Toedter, 2000). However, published literature concerning gestational influences on women's experiences of loss has resulted in much discrepancy. Some studies have argued that gestational age is a significant determinant of women's grief reactions following pregnancy loss. Utilising the Perinatal Grief Scale (PGS) to measure grief responses, Goldbach et al. (1991) found that women who experienced a late pregnancy loss reported higher levels of grief than those who experienced an early pregnancy loss. The authors attributed the outcome to increased bonding, suggesting that longer gestation strengthens attachment and ultimately augmented grief. Similarly, in a study combining both quantitative (the PGS) and qualitative (open-ended questionnaire) measures of assessment, Cuisinier et al. (1993) explored 143 women's experiences of miscarriage or stillbirth. Their findings

revealed that grief intensity was greatest among women who had experienced a stillbirth.

Other research suggests that there are no significant differences between grief and gestational age for women who lose their baby. In studies comparing women's responses to miscarriages and stillbirth, and studies investigating women's reactions to miscarriage, researchers found that grief intensity was irrespective of gestational age, because significant attachment occurred early on in the pregnancy (Jackman, McGee, & Turner, 1991; Prettyman, Cordle, & Cook, 1993; Thomas & Striegel, 1994). Using the General Health Questionnaire, Jackman et al. (1991) measured levels of psychological distress among 27 women who had experienced a first trimester miscarriage. The results indicated that a high percentage of women (44%) had significantly elevated levels of depression and anxiety several months after loss. Thus, their grief was comparable to women who experienced a late gestational pregnancy loss. Similarly, Peppers and Knapp (1980) in their study of perinatal loss found no significant differences in grief intensity among women who had experienced miscarriage, stillbirth and neonatal death. This indicates that other factors must also contribute to a mother's sense of attachment to her baby during pregnancy, other than gestational influences alone.

Several researchers have concurred with this interpretation, reporting that gestational age does have an impact on women's grief responses following pregnancy loss, but that other factors also moderate the grief experience (Cote-Arsenault & Mahlangu, 1999; Moulder, 1994; Robinson et al., 1999; Uren & Wastell, 2002). These factors include: the nature of the relationship between the mother and her baby, the specific needs and wishes the mother associates with the relationship, the meaning the mother attributes to her lost pregnancy, the way the mother deals with emotional challenges and her experience of social support (Bangal et al., 2013; Brier, 2008). For example, two women who miscarry at the same gestational age can react very

differently. How they react depends on their sense of attachment to the baby and how they define their experience of loss. It is therefore not a given that every woman will become attached to her baby in the same way at a particular stage of her pregnancy, as attachment to an unborn baby may occur at different stages for each individual (Cote-Arsenault & Mahlangu, 1999; Uren & Wastell, 2002). For instance, some women may develop a strong level of attachment upon confirmation of the pregnancy, whereas for others, the emotional attachment may not develop until the abdomen is visible (Bennett et al., 2005).

While there is much discrepancy within the literature as to the effect of gestational age on the grief experience, there is general agreement that the nature and intensity of grieving is different when loss occurs late in pregnancy than when it occurs during the early stages (Goldbach et al., 1991; Kersting & Wagner, 2012; Lasker & Toedter, 2000). Researchers have suggested that for women who lose a baby early in pregnancy, the baby is primarily represented by fantasies and illusions (Theut, Pederson, Zaslow, Cain, Rabinovich, & Morishisa, 1989). On the other hand, for women who lose a baby late in pregnancy the baby has achieved more reality and the deeper level of attachment is thought to contribute to more intensive grief (Theut et al., 1989). However, research dictates that the painful experiences of women who have experienced miscarriage cannot be ignored and further research is required to ascertain the influence of gestation on perinatal attachment.

### The Impact of Partner Support

While the bereavement experience is influenced by numerous factors, one of the most significant is the level of support one receives following bereavement (Cacciatore, Schnebly, & Froen, 2009; Dyregrov & Dyregrov, 2008; Egan & Arnold, 2003; Hutti, 2005; Kavanaugh et al., 2004; Kohn et al., 2013). An important consideration when exploring women's experiences of pregnancy loss is the influence of partner support on

the mother's grieving experience. Perceived partner support has been found to be a protective factor against lasting grief and distress, and has been found to lead to better relationship outcomes (Buchi et al., 2009). For some couples, getting through the loss affirms the strength of their relationship and their ability to endure difficult times. As a result, their emotional bond may be strengthened and they may feel closer as a couple (Saflund, Avelin, Erlandsson, Wredlin, & Radestad, 2013; Cacciatore, DeFrain, Jones, & Jones, 2008; Toller & Braithwaite, 2009). For others, pregnancy loss may be a difficult journey where they struggle to understand the other's experience or way of coping with loss. The differences in the individual experience of each partner can lead to isolation and may cause the couple to question the future of their relationship (Lang et al., 2011; Wing et al., 2001).

The risk of a relationship breakdown following pregnancy loss has been explored in several studies, with conflicting findings. Some studies have found that relationships have a higher risk of dissolving following a miscarriage or stillbirth (Gold, Sen & Hayward, 2010; Shreffler, Hill & Cacciatore, 2012). Gold et al. (2010) explored relationship outcomes among married and cohabiting women who either experienced pregnancy loss or live birth (N = 3707 mothers). They found that relationships had a significantly greater risk of ending when they experienced a miscarriage or stillbirth, compared with women whose pregnancies ended in live birth. Similarly, Shreffler et al. (2012) examined the risk of divorce among married couples who experienced pregnancy loss (N = 3461), and found that women who experienced miscarriage or stillbirth had greater odds of divorce than women who did not experience loss.

Although there is a lack of research on the nature of the relationship between pregnancy loss and marital dissolution, it may be assumed that pregnancy loss is a significant source of additional distress that may negatively impact relationships, which are already vulnerable. For example, couples with an unstable relationship before the pregnancy

loss may find it more difficult to cope and sustain their relationship after a miscarriage or stillbirth (Gold et al. 2010).

Other research contradicts these findings, advocating that pregnancy loss acts as a protective factor in that it encourages couple cohesion. For example, a study by Cacciatore, DeFrain, Jones, & Jones (2008) found that fewer than 10% of couples who experienced a stillbirth considered divorce. Similarly, DeFrain, Millspaugh, and Xie (1996) found that only 11% of couples who experienced miscarriage reported that their marriage was weakened by the event, compared to 60% who said it was strengthened. A recent study by Saflund and colleagues on parental grief and relationships after stillbirth also supports these findings (Saflund et al., 2013). They found that mothers and fathers reported increased feelings of closeness after the experience of loss and that these feelings deepened over the course of a year (Saflund et al., 2013). The researchers attributed this emotional closeness to each partners respect and tolerance of each other's grieving.

## **Recognising divergent grieving styles**

It is widely acknowledged that men and women grieve differently (Cacciatore, DeFrain, Jones, & Jones, 2008; Martin & Doka, 2000; Peppers & Knapp, 1980; Stroebe & Schut, 1999, 2010). The Dual Process Model (DPM) of grief (Stroebe & Schut, 1999, 2010) suggests that women are frequently more loss-orientated, expressing feelings and distress about the loss, whereas men are more restoration-oriented, engaging in practical tasks and problem-solving behaviour (Stroebe & Schut, 2001). Martin and Doka (2000) labelled these two styles of grieving intuitive and instrumental. According to Martin and Doka (2000), women are predominantly associated with an intuitive grieving style as they are typically more expressive of their emotions and release their emotional pain through sharing. Men are typically associated with an instrumental grieving style, as

they tend to channel their grief energy into actions and look for solutions (Cacciatore et al., 2008; Martin & Doka, 2000).

Whilst stereotypical, it is important to acknowledge how such gender stereotypes may influence societal expectations and assumptions of parental grief following pregnancy loss. For example, McCreight (2004) found that men often feel marginalised and conflicted in their role as a grieving father and supportive partner. Although they experience grief feelings of anger, fear, self-blame and pain, they feel the need to remain strong for their partner and family (McCreight, 2004). These findings are consistent with other research findings on men's grief responses following pregnancy loss. In O'Neil's (1998) study on fathers' grief following stillbirth, one father reflected on his experience and stated: "it was clear my role needed to be one of strength and support...my grief was not a priority" (p. 33). O'Leary and Thorwick's (2006) phenomenological research on fathers' experiences of pregnancy loss also reported societal pressure to be strong and an unwillingness to show anxiety and fear in order to protect their partners. Similarly, Murphy's (1998) phenomenological study on the experience of early miscarriage from a male perspective noted how men felt the need to suppress feelings of sadness, loss and anger in order to support their partner. It is clear that men feel an overwhelming responsibility and need to portray unwavering strength, at the expense of addressing their own grief. They put their emotional needs aside in order to support and comfort their partner.

To carry such an immense burden in a time of grief may not only lead to a false sense of coping but may also highlight inconsistencies in grieving styles between the couple. Grieving mothers may feel that their partners have recovered from their loss or do not care about the baby as much as they do, leading to isolation and tension within the relationship (Lang et al., 2011; Wing et al., 2001). However, when mothers feel supported and understood in their grief experience, research suggests that they tend to

feel closer to their spouse and cope more successfully with their grief (Saflund et al., 2013; Cacciatore et al., 2008; Toller & Braithwaite, 2009). This occurs irrespective of differences in grieving styles between the mother and father and suggests that understanding and acceptance of one another's grieving style is important to facilitate healthy coping.

### **Psychological Distress and Pregnancy Loss**

Bereavement reactions are often intense, complex, and pervasive following pregnancy loss (Cacciatore, 2010; Campbell-Jackson, & Horsch, 2014; Robinson, 2011). Common grief reactions include: anger, shock, denial, sadness, disbelief, disappointment, confusion, guilt, numbness, sleeping disturbances, loss of appetite, social withdrawal and feelings of 'empty arms' (Adeyemi, Mosaku, Ajeniguja, Fatoye, Makinde, & Ola, 2008; Brownlee & Oikonen, 2004; Murphy, Sheylin, & Elklit, 2014). Differentiating a 'normal' grief response from a depressive reaction remains increasingly difficult, given that perinatal bereavement research suggests that intense grief reactions are common for at least six months post-loss and may often endure past twelve months post-loss (Swanson, 1999). By definition, pathological grief involves chronic, absent or distorted grief, psychiatric symptoms, or intense grieving beyond the first year of loss that significantly affects the long-term psychological functioning of the individual (Burns & Covington, 2006). Whilst it is important that such pathological grief reactions are identified and not simply dismissed as normal grief (so that appropriate treatment to minimise adverse longer-term health outcomes can be administered), it is equally important to understand the full range of psychological consequences following pregnancy loss so that normal grieving is not pathologised. Thus, further research within this understudied area is warranted, so that more definitive conclusions can be drawn.

## **Psychological Distress Following Miscarriage**

The existence of depression and anxiety in women who have experienced miscarriage has been confirmed by several studies (Beutel, 1995; Neugebauer et al., 1997). Using the Diagnostic Interview Schedule (DIS; Robins, Helzer, Croughan, Ratcliff, 1981), Neugebauer and colleagues (1997) assessed psychological distress in 229 women at two weeks, six weeks and six months following an early miscarriage. Using a comparison sample of women who had not been pregnant in the last year, the researchers found that women who miscarried were at significantly increased risk of a major depressive episode at six months following loss. The risk was greater for childless women but did not vary significantly by history of reproductive loss, maternal age, time of gestation, or attitude toward the pregnancy.

Similar results were reported by Beutel et al. (1995), who compared depressive symptoms of women who had miscarried to those of pregnant women and control groups overtime (at one to two days, six months and twelve months post-loss). The researchers documented elevated depression scores in miscarrying women immediately following loss as compared to comparison groups. However, at six and twelve months post-loss this effect was only apparent between the miscarrying cohort and the control group, suggesting that the experience of pregnancy may moderate women's psychological distress.

Anxiety symptomatology following miscarriage has also been researched and studies have consistently found an increase in anxiety responses that may persist for up to six months following loss (Brier, 2004; Geller et al., 2004). For example, Tharpar and Tharpar (1992) found significantly elevated levels of anxiety among women who miscarried, at twenty-four hours and six-weeks post-loss as compared to pregnant women. In addition, the researchers found that the risk increased among childless women, women who had experienced a previous loss and women who had not planned

their pregnancy, suggesting that other factors may also contribute to anxiety responses following miscarriage.

Lee, Slade, & Lygo (1996) extended the timeline for anxiety responses and reported significant increases in anxiety among women who miscarried compared to control groups at four-months post-loss. This finding was supported by Janssen, Cuisinier, Hoogduin, & de Graauw (1996), who also reported elevated levels of anxiety in women who miscarried compared to women who delivered a healthy baby. This effect was evident at six-months post-loss, with differences in anxiety dissipating by the twelve and eighteen-month follow-up.

Considerably less research has been devoted to the incidence of specific anxiety disorders following miscarriage. In a study examining the risk of Obsessive-Compulsive Disorder (OCD), Panic Disorder, or Phobic Disorder, Geller, Klier, & Neugebauer (2002) found that miscarriage is a significant risk factor for OCD, with a relative risk of 8.0, compared to community samples. However, miscarriage presented no increased risk for panic disorder or phobic disorders, compared to women who had not been pregnant in the last year. Similarly, there is limited evidence of acute stress disorder (ASD) or Post-Traumatic Stress Disorder (PTSD) following miscarriage (Bowles et al., 2000; Geller et al., 2004).

#### **Psychological Distress Following Stillbirth**

Women who experience stillbirth are three times more likely to be at risk of developing depressive symptoms than women who experience a live birth (Blackmore et al., 2011; Grekin & O'Hara, 2014; Hughes et al., 1999). In addition, women are at even greater risk for experiencing post-traumatic stress, with a recent study indicating that women who experience stillbirth are more than five times more likely to develop post-traumatic symptomatology compared to women who experience a live-birth (Gold & Johnson, 2014). For some women, these symptoms of distress are pervasive and

enduring, persisting for many years after loss. For example, Hughes and colleagues (1999; Turton et al., 2009) seminal research on the effects of stillbirth led them to conclude that approximately 20% of women who experience a stillbirth have long-lasting depression and a further 20% develop post-traumatic stress disorder (Hughes et al., 2002).

A correlation has been found between persisting PTSD symptoms and the earlier experience of holding a stillborn baby, which remains the subject of much controversy. Whilst research suggests that women who have the opportunity to see and hold their stillborn baby report this experience as extremely valuable (Cacciatore, 2010; Radestad & Christoffersen, 2008; Schott, Henley, & Kohner, 2007), findings also suggest that increased contact with the stillborn baby is associated with increased psychological distress (Hughes et al., 2002; Turton, Evans, & Hughes, 2009). In their influential qualitative study of the long-term psychosocial sequelae of stillbirth, Turton et al. (2009) found that mothers who held their stillborn infant were more likely to be depressed and have higher symptoms of PTSD in their third trimester of the subsequent pregnancy and at one year post-loss, compared to mothers who did not hold their baby. These symptoms of PTSD were still present at seven years post-loss (Turton et al., 2009).

Other research contests the findings of Turton and colleagues and advocates that contact with the stillborn baby acts to reduce, rather than increase, psychological distress (Cacciatore, Radestad, & Froen, 2008; Cacciatore, 2010; Radestad & Christoffersen, 2008; Schott et al., 2007). Cacciatore et al. (2008) found that mothers who had seen and held their stillborn babies had lower rates of anxiety and depression, unless they were pregnant. The women in their study reported that having visual memories and the opportunity to create tangible tokens of remembrance assisted them to come to terms with their baby's death. Furthermore, several women revealed that

they might have expressed regret had they not chosen to engage in this emotionally validating experience. This finding is supported by Radestad, Steineck, Nordin and Sjogren (1996), who found that mothers who wished they had spent more time with their stillborn babies exhibited more anxiety and depressive symptoms.

These conflicting findings within the research suggest that whilst visual and tactile contact with a stillborn baby generates vivid images that may later become distressing for some mothers, creating memories by seeing and holding the stillborn baby is also valuable to support women's grieving and appease psychological distress (Koopmans, Wilson, Cacciatore, & Flenady, 2013; Schott et al, 2007).

# **Psychological Distress in the Subsequent Pregnancy**

The significant psychological morbidity associated with pregnancy loss has also led researchers to focus on maternal outcomes in the subsequent pregnancy, as the majority of women who experience pregnancy loss will fall pregnant again within the first year of loss (Cote-Arsenault & Marshall, 2000; Gaudet et al., 2010). Existing research reveals that women who experience pregnancy loss consistently exhibit elevated rates of anxiety and depression during the subsequent pregnancy (Cote-Arsenault, 2003; DeBackere, Hill, & Kavanaugh, 2008; Franche & Mikail, 1999; Hughes et al., 1999). In addition, some research has shown that depression and anxiety following pregnancy loss may persist even after the birth of a subsequent (live-born) child (Blackmore et al., 2011; Surkan, Radestad, Cnattinggius, Steinbeck, & Dickman, 2008). This is important because increased anxiety during pregnancy has not only been linked to poorer obstetric and maternal outcomes (DiPietro, Novak, Costigan, Atella, & Reussing, 2006; Van den Bergh, Mulder, Mennes, & Glover, 2005), but also interferes with the intensity of attachment during pregnancy and may affect the quality of attachment to the subsequent child (Gaudet et al., 2010; Heller & Zeanah, 1999; Hughes et al., 2002).

The experience of the subsequent pregnancy has been described as anxiety laden, characterised by an imminent fear of recurrence together with co-existing high levels of grief (Armstrong, 2006; Cote-Arsenault, & Dombeck, 2001; Gaudet et al., 2010; Hughes et al., 1999). Fear and insecurity dominate the pregnancy experience, with women displaying marked hypervigilence and a constant preoccupation with needing to have everything under control (Cote-Arsenault et al., 2011). Although such distress occurs irrespective of gestational age at time of loss, research findings demonstrate a positive correlation between advanced gestation and elevated levels of distress in the subsequent pregnancy (Bergner, Beyer, Klapp, & Rachfuss, 2008; Lee et al., 2013; Cote-Arsenault & Mahlangu, 1999; Gaudet et al., 2010). This is likely attributable to anticipatory anxiety about the outcome (i.e., pregnancy loss or live birth), that is prolonged for women who have experienced a stillbirth. Indeed, researchers have reported that pregnancy anxiety lessens considerably after the first trimester among women who experienced a previous miscarriage (Andersson, Nilsson, & Adolfsson, 2012; Ockhuijsen et al., 2014), as these women have surpassed the point of their previous loss. However among women who experienced a prior stillbirth, anxiety often persists until the live birth of the subsequent child, as there is no 'safe' point (Cote-Arsenault & Dombeck, 2001; Gaudet et al., 2010).

Although research into pregnancy after miscarriage is limited, available literature suggests that the duration of grief decreases with a shorter conception period (Brier, 2008). However, grief and anxiety has been reported to continue into the subsequent pregnancy irrespective of the time period between pregnancy loss and conception, and woman with a history of miscarriage have been found to display greater anxiety than women who have never experienced pregnancy loss (Geller et al., 2004; Tsartsara & Johnson, 2006).

Women with a history of miscarriage are uncertain whether another miscarriage will occur, and may adopt a variety of coping strategies to help them cope (Andersson et al., 2012; Ockhuijsen et al., 2014; Tsartsara & Johnson, 2006). In a qualitative study of 16 pregnant women with a history of miscarriage, Andersson et al. (2012) found that women distanced themselves emotionally from the pregnancy, were preoccupied with pregnancy symptoms, displayed reassurance-seeking behaviour, and sought professional and social support, in order to cope with the uncertainty they were feeling. Similar coping responses have been identified in a recent qualitative study by Ockhuijsen et al. (2014), who explored 24 women's experiences of pregnancy after miscarriage. Their analyses revealed an overarching theme of balancing loss of control with searching for control during the subsequent pregnancy (Ockhuijsen, et al., 2014). Although the women realised there was little they could do to influence their pregnancy outcome, they actively engaged in behaviours to increase their sense of control. The commonality of this future-oriented coping strategy following miscarriage suggests that women engage in control-seeking behaviours to increase their feelings of control and avoid the disappointment of a potentially negative outcome (Carroll, Sweeney & Shepperd, 2006; Ockhuijsen et al., 2014; Shepperd, Findley-Klein, Kwavnick, Walker & Perez, 2000).

Similar findings have also been documented within the stillbirth literature, with the term 'emotional cushioning' used to describe the coping response used by women to cope with the anxiety, uncertainty, and sense of vulnerability experienced in the subsequent pregnancy (Cote-Arsenault & Donato, 2011). The experience is one of balancing hope for a positive outcome, and fear of a negative one, whereby women avoid emotional investment in their pregnancy until they have a greater certainty of success or hold their healthy baby in their arms (Cote-Arsenault & Freije, 2004; O'Leary & Thorwick, 2008). Emotional cushioning can be a conscious or subconscious process, which serves to protect the mother from the pain of another loss. Women have

been found to engage in emotional cushioning behaviours; such as hiding their pregnancy from family and friends, avoiding talking to and interaction with their baby and postponing physical preparations such as completion of the nursery or holding a baby shower (Cote-Arsenault & Marshall, 2000; Cote-Arsenault & Donato, 2007; 2011; O'Leary & Thorwick, 2008).

In a mixed methods study of sixty-three pregnant women who had previously experienced perinatal loss, Cote-Arsenault & Donato (2011) found that emotional cushioning was positively associated with pregnancy anxiety. Women who experienced anxiety and worry used emotional cushioning to control their worry and gain confidence. In this manner, emotional cushioning was appraised as a proactive coping strategy to help pregnant women reduce their anxiety and increase their feeling of control during a period of such uncertainty (Ockhuijsen et al., 2013; Cote-Arsenault & Marshall, 2000). However, because emotional cushioning may be construed as 'avoiding' prenatal attachment, future research is needed to determine the impact of such strategies on bonding, attachment, and parenting of the subsequent child (Ockhuijsen et al., 2013).

A lack of consensus exists in the literature as to the role and consequences of a new pregnancy on the perinatal grief process. Some studies suggest that the subsequent pregnancy can provide a mediating effect, resulting in a decrease of grief symptoms and less guilt and depression, as the new pregnancy instils a sense of hope and purpose (Cuisinier et al., 1996; Lin & Lasker, 1996; Theut, Zaslow, Rabinovich, Bartko, & Morishisha, 1990). Other researchers have argued against this assertion, citing that such perceived 'benefits' might interfere with the grieving process (Cote-Arsenault & Dombeck, 2001; Field, 2006; Hughes et al., 1999). These researchers postulate that when women conceive another baby without being emotionally ready, pregnancy acts as a way to avoid the pain and this may ultimately result in greater psychological

distress. For example, Hughes et al. (1999) found that women whose previous pregnancy ended in stillbirth were significantly more depressed in the third trimester of the subsequent pregnancy and experienced higher anxiety if conception occurred within a year after stillbirth, compared with conception occurring later. Further evidence to support the contention that the subsequent pregnancy may complicate the grieving process has been provided by other researchers (e.g., Franche & Bulow, 1999; Cote-Arsenault & Dombeck, 2001; O'Leary, 2003), who have proposed that the subsequent pregnancy may reactivate painful emotions. However, this reality may also be construed as a normal part of the grieving process and care should be taken to ensure 'normal' grieving behaviours are not confused with 'pathological' reactions (O'Leary, 2003).

## **Pregnancy Loss Care**

Prior to the 1970s, pregnancy loss was not considered to be a meaningful event by the medical community (Komaromy, Layne, & Earle, 2013), thus there was little acknowledgment of the phenomenon of perinatal bereavement. Pregnancy loss was seen as an event that was unfortunate but not worthy of a grief reaction, and women were encouraged to simply "try again" and move on with their lives (Leon, 1992). This denied grief response is interesting considering evidence to the contrary. Personal transcriptions of women from as early as the nineteenth century indicate that pregnancy loss resulted in significant emotional distress. For example, Judith Leavitt's book on early childbearing in America (1986) contains raw and painful accounts of women's pregnancy loss experiences. Furthermore, women's perceptions of themselves as 'mothers' to children living and deceased are prevalent, and are strikingly similar to current depictions of pregnancy loss that refer to 'angel babies' (Komaromy et al., 2012).

The emotional pain of pregnancy loss has also been expressed in early paintings (e.g., "The Empty Cradle", 1847) and poetry, confirming the existence of grief feelings.

This is significant because it demonstrates that women seem to have loved, cherished, and mourned the babies that they lost in much the same way as they do now. Yet, women were not encouraged to acknowledge or express their grief, and postnatal care practices to assist women in processing their grief were non-existent (Reagan, 2003).

The first documented empirical evidence that women experience significant mourning following pregnancy loss was publicised in 1970, the seminal work of Kennell and colleagues (1970). The study reported that the length and intensity of mourning following pregnancy loss was proportionate to the mother's sense of attachment to her baby (Kennell, Slyter, & Klaus, 1970). Following this publication, interest in perinatal bereavement increased, as evident by the surge of perinatal literature generated in the 1980s (Cranley, 1981; Kirkley-Best & Kellner, 1982; Lumley, 1982; Peppers & Knapp, 1980; Theut et al, 1989; Toedter Lasker, & Alhadeff, 1988). Three major factors appear to have contributed to the recognition of perinatal bereavement as a 'real' phenomenon. These include; the emergence of attachment theory to understand maternal bonding during pregnancy (Rubin, 1975; Peppers & Knapp, 1980); changing social conditions which acknowledged the suffering of women following pregnancy loss (Toedter, Lasker, & Janssen, 2001); and technological advances in neonatal care (Hughes & Riches, 2003).

This shift in understanding had a pivotal influence on hospital care practices and changed the way professionals recognised and responded to perinatal bereavement.

Instead of treating pregnancy loss as an insignificant event, unworthy of a grief reaction, healthcare providers are now encouraged to provide bereavement care that recognises and facilitates mourning<sup>6</sup>. In Australia, it has now become common practice for nursing and midwifery staff to acknowledge and respond to grief following pregnancy loss; encourage parents to see, hold, and take photos of their stillborn baby; and support

 $<sup>^{6}</sup>$  The author acknowledges cross-cultural variations in pregnancy loss care.

parents in arranging funeral and memorial services. Similarly, increasing recognition of grief following pregnancy loss has meant that healthcare providers are more likely to consider the value of specific components of care. In Australia, extra care is now taken in certain maternity hospitals to ensure that mothers are not exposed to additional psychological distress, such as crying babies on a maternity ward. The importance of psychological support is also emphasised, and women who experience pregnancy loss are provided with brochures on support and counselling services, and referral if needed, before they leave the hospital.

In Australia, there are multiple avenues of bereavement support services, but only a couple that are specific to pregnancy loss. One of these support services is SANDS, which provides support to bereaved parents and families who have suffered the death of a baby at anytime from conception through to 28 days after birth. This includes miscarriage, stillbirth, neonatal death, ectopic pregnancy, and medically advised termination. Established in 1988, SANDS WA offers telephone, online, and group support to women who have experienced pregnancy loss. In addition, the organisation is responsible for the development of the successful book "Your Baby Has Died", first published by SANDS Victoria in 1986. Funding difficulties in the nineties led to the organisation being merged with SIDS and Kids WA, who offer targeted and specific services to families who have experienced the sudden and unexpected death of a baby or child, during birth, pregnancy or infancy, irrespective of the cause.

Despite the growing recognition of the impact of pregnancy loss and the resultant shift in care practices<sup>7</sup>, women continue to report that their healthcare is not sufficiently meeting their needs (Evans et al., 2002; Lindgren, Malm & Radestad, 2014; Pullen, Golden & Cacciatore, 2012; Trulsson & Radestad, 2004). Reports of dissatisfaction with medical care following miscarriage are common (Evans et al, 2002;

<sup>&</sup>lt;sup>7</sup> The researcher acknowledges the universal and cultural variations in care practices.

Geller, Psaros, & Kornfield, 2010; Wong, Crawford, Gask, & Grinyer, 2003). In particular, there is a discrepancy between women's needs and the respective attitudes and responses of their primary healthcare providers. Women emphasise the lack of emotional support and sensitivity they receive following miscarriage, and report a need to have their loss recognised and their thoughts and feelings validated (Evans, 212; Corbet-Owen, & Kruger, 2001; Mills, Ricklesford, Cooke, Heazell, Whitworth, & Lavender, 2014; Stratton & Lloyd, 2008). In addition, women require enhanced primary care and more specific information regarding the implications of their miscarriage (Corbet-Owen & Kruger, 2001; Sejourne, Callahan, & Chabrol, 2010; Stratton & Lloyd, 2008; Wong, Crawfrod, Gask, & Grinyer, 2003). Despite the frequency and psychological impact of miscarriage, they are less often associated with support services than stillbirth (Kong, Lok, Lam, Yip, & Chung, 2010).

Disregard of the emotionality of loss has also been reported among women who experience stillbirth, who have criticised healthcare providers for their treatment of loss as a medical 'outcome' rather than the loss of a human being (Cote-Arsenault, Donato, & Earl, 2006; Mills et al., 2014). Dismissive attitudes to fears and concerns and inappropriate comments by health practitioners are commonly reported (Caelli, Downie, & Letendre, 2002; Downe, Schmidt, & Kingdon, & Heazell, 2013). In a recent comprehensive review, Peters, Riitano, Lisy, Jordan, Pearson and Aromataris (2014) found that a number of issues exist around sensitivity, clarity of information, validation of emotions and decision-making, that influence women's experiences of care. In particular, women need more guidance as to whether or not to see and hold their stillborn baby and the consequences (positive and negative) of this decision. Likewise, women need more information and guidance as to what to expect during labour and birth and sufficient time to process this information. The researchers also noted the importance of individualising care. Whilst some mothers may appreciate the delay

between diagnosis and induction, others may find this extended waiting period meaningless and distressing (Peters et al., 2014). Dissatisfaction with continuity of care was also emphasised in the review, with the need for additional support once the mother leaves the hospital. Women report that they need healthcare providers to spend extra time elucidating the common psychological reactions following pregnancy loss, so that they are better prepared for the emotional upset following miscarriage or stillbirth (Bangal et al. 2013; Brier, 2008; Peters et al., 2014). Further, the decision to try to conceive again following stillbirth often triggers conflicting emotions and insecurities, and mothers would appear to benefit from further guidance and support to address their concerns (Lee et al., 2013). These findings are important because perceived professional support is associated with improved maternal mental health following pregnancy loss (Crawley, Lomax, & Ayers, 2013).

Implications of women's perceptions of care suggest that the delivery of sensitive and high-quality care by health care professionals may substantially reduce their psychological distress following pregnancy loss. Specifically, more genuine and personalised care, that acknowledges the emotionality of the loss, would likely improve women's perceptions of care (Downe et al., 2013; Kelley & Trinidad, 2012). This includes the provision of clear, factual and comprehensible information, communicated in a warm and sensitive manner, in order to improve support and reduce confusion about what to expect (Pullen et al., 2012; Trulsson & Radestad, 2004). Despite the growing recognition of the impact of pregnancy loss, women still report that their feelings remain unacknowledged by their primary healthcare providers (Pullen et al., 2012). Some researchers have therefore advocated for bereavement support training to educate healthcare providers on how to provide sensitive and culturally appropriate care to women who have experienced loss (Mills et al., 2014; Peters et al., 2014).

In terms of psychological interventions following pregnancy loss, these are rarely used in routine clinical care and are lacking empirical validation (Geller et al., 2010). Only a few randomised controlled studies exist and most have focused on addressing depression following pregnancy loss rather than grief (Lake, Johnson, Murphy & Knuppel, 1987; Nikcevic, Kuczmierczyk, & Nicolaides, 2007; Swanson, Chen, Graham, Wojnar, & Petras, 2009). In a randomised controlled trial, Nikcevi et al., (2007) explored the influence of medical and psychological interventions on women's psychological distress following miscarriage. They found psychological intervention superior to medical treatment, in terms of reducing grief and worry. Swanson et al. (2009) conducted a randomised controlled trial to explore the efficacy of couplefocused interventions on grief and depression following miscarriage. They compared the effects of four conditions (self-care, three counselling sessions with a nurse, combined nurse care and self-care, and a no treatment control) and found the nurse counselling condition the most effective in reducing women's depression. Neugebauer et al. (2007) reported similar benefits of counselling in their study that explored the effects of a telephone-administered counselling intervention on women's depression following miscarriage. Findings revealed that interpersonal counselling significantly reduced women's depressive symptoms, but a small sample size (N = 17) limits the generalisability of these findings.

In recent years, the Internet has emerged as a useful source of information and support and a wealth of Internet-based mental health services now exist. In particular, Internet-based cognitive-behavioural treatments for depression, anxiety, and posttraumatic stress have been evaluated, with positive results (Andersson & Cuijpers, 2009; Kersting, Kroker, Schlicht, Baust, & Wagner, 2011; Kersting et al., 2013). In a randomised controlled trial, Kersting et al. (2011) examined the efficacy of an Internet-based cognitive behavioural therapy program for mothers who experienced pregnancy

loss. Participants (N = 83 women) were randomly assigned to either five weeks of Internet therapy or a waitlist control condition. The program consisted of three phases (self-confrontation, cognitive restructuring and social sharing), in which women wrote a total of ten assignments. Each assignment lasted forty-five minutes and was followed by therapeutic feedback. Preliminary findings revealed that women who had undertaken the therapy showed significant improvement in posttraumatic stress, grief, depression and overall mental health after treatment and at three-month follow-up compared to controls. This result was confirmed in a later study by Kersting and colleagues (Kersting et al., 2013), who reported significant reductions in posttraumatic stress disorder symptoms, grief, depression and anxiety. Furthermore, these symptom reductions were maintained at three-month and twelve-month follow-ups. Such positive results are promising and indicate the efficacy of a low-cost Internet-based intervention to reduce psychological distress following pregnancy loss. However, the authors noted the high rate of attrition in the study, with only 45% of participants completing the twelve-month follow up. This may have biased the results and additional research is needed as to the role of therapeutic support in reducing attrition rates and improving treatment outcomes.

#### **Summary and Rationale**

To date, although there is a considerable amount of research documenting the incidence of grief associated with pregnancy loss, there is insufficient research focusing on the pregnancy loss experience of women to drive evidence-based care. The current study attempts to address this gap in the literature by exploring the following question: "How do women experience pregnancy loss following a miscarriage or stillbirth?" Through eliciting information from women's personal experiences, it is anticipated that a greater understanding may be derived upon which to inform care.

This review has highlighted that pregnancy loss involves a complex and disenfranchised grieving experience, whereby the significance of loss is not recognised or understood by society at large. Such dismissal of grief will likely impact the coping capacities of women who experience pregnancy loss (Boss, 2004; Lang, Edwards, & Benzies, 2005), as grief that is not recognised cannot be socially supported. Social support has been identified as one of the most crucial predictors of grief response (Kavanaugh et al., 2004). Considering that there is good evidence that pregnancy loss results in marked psychological distress for many women, it is important to ensure that women are adequately supported. Consequently, further information is required to uncover the nature of the grieving experience, to determine how women cope with their experience of loss and access support.

The act of seeing and holding a stillborn baby remains contentious. Whilst positive association in the research has resulted in the current drive for healthcare providers to encourage this form of contact to facilitate grieving (Cacciatore, 2010; Radestad, & Christoffersen, 2008; Schott et al., 2007), this practice requires further justification. Some findings have reported that seeing, holding and spending time with the stillborn baby may result in later psychological distress (Hughes et al., 2002). Therefore, further information is required as to the value of encouraging contact with the deceased baby following stillbirth, and whether or not the experience results in increased psychological distress.

The inherent difficulty in differentiating between normal and pathological manifestations of grief highlights a further clinical disparity. Although the literature recognises the pervasive and enduring nature of perinatal grief, such manifestations continue to be labelled as 'pathological' or 'complicated' (Kersting & Wagner, 2012). Further research is required to phenomenologically differentiate between 'normal' and 'pathological' variations of grief following pregnancy loss, so that normal grief is not

inadvertently pathologised. The literature is also conflicted as to the function of 'continuing bonds' following pregnancy loss. Some literature has described that maintaining connections with the deceased is necessary for 'successful' adjustment following loss (Field & Filanosky, 2009; Klass et al., 1996; Sormanti & August, 1997), whilst other research indicates that 'continuing bonds' predict greater grief intensity (Boerner & Heckhausen, 2003; Stroebe et al., 2012; Stroebe & Schut, 2005). Further information is also required as to whether women who experience pregnancy loss describe resolution or recovery from grief (consistent with early stage theories of grief, i.e., Lindemann, 1944), or reintegration of grief (consistent with current models, i.e., Worden, 2009), and whether these coping responses facilitate 'successful' adjustment.

The literature shows a lack of consensus regarding the 'right' time to attempt conception and/or the potentially damaging effects of a subsequent pregnancy that occurs 'too soon'. Women are currently advised to wait until they feel 'emotionally ready', or adhere to a specific time-frame until their grief is 'resolved' (Lee et al., 2013). Furthermore, there remains discrepancy between whether early conception in the subsequent pregnancy creates additional psychological distress (Cote-Arsenault & Dombeck, 2001; Field, 2006; Hughes et al., 1999; Lee et al., 2013) or whether it acts as a mechanism for healing (Cuisinier et al., 1996; Lin & Lasker, 1996; Theut et al, 1990).

Finally, although healthcare practices have changed considerably over the years, the research indicates that pregnancy loss care is still not meeting women's expectations (Evans et al., 2002). Women continue to report dissatisfaction with caregiver attitudes, the manner in which information is expressed, and continuity of support (Pullen et al., 2012; Trulsson & Radestad, 2004). In addition, women who experience pregnancy loss are at risk of suffering from a number of detrimental psychological effects including depression (Adeyemei et al., 2008), anxiety (Radestad, 2001), posttraumatic stress disorder (Kelley & Trinidad, 2012) and this risk of psychological distress is pervasive

(Gaudet et at., 2010). Consequently, further research is required to ascertain the support needs of women following pregnancy loss, in order to provide more effective care.

In summary, it is evident that more detailed information pertaining to the individual experience of loss is required. With this knowledge, it is anticipated that healthcare providers can work to develop more effective interventions to assist in the bereavement process for women who experience pregnancy loss.

# **Chapter 3: Methodology**

This chapter outlines the methods and procedures used to conduct the study.

Justification for the use of a qualitative phenomenological approach is provided, beginning with a rationale for qualitative inquiry. A discussion and critique of Interpretative Phenomenological Analysis (IPA) follows, as an effective methodology to discover the meaning of women's lived experiences of pregnancy loss. Data collection and analysis procedures are outlined, including ethical considerations to ensure scientific rigour.

# Rationale for a Qualitative Approach

A review of the literature reveals that much of the previous research has been quantitative in nature with an overall lack of qualitative inquiry pertaining to women's experiences of bereavement following pregnancy loss. Whilst quantitative methodology is useful for uncovering a relationship between specified known variables, this methodology does not reveal new processes or explain the nature of the relationship between the known variables (Denzin & Lincoln, 2005; Hennink, Hutter, & Bailey, 2011). Thus, statistical quantitative data may be useful to isolate the extent of women's grief following pregnancy loss, but it does not explain the 'how' of the bereavement experience in its entirety.

Qualitative research provides an alternative paradigm for bereavement research, in that it seeks to build an understanding of phenomena. The aim of qualitative research is to describe and better understand the "quality and texture of experience" (Willig, 2008, p. 9), rather than generalise to a broader population and predict outcomes. Qualitative methodology has the potential to produce rich and descriptive data that facilitates understanding of the meanings and interpretations that individuals give to their experiences. With this knowledge, it may be possible to broaden and deepen an understanding of bereavement. This is imperative to inform theoretical understandings on grief and

bereavement, which can then be tested and refined using more quantitative methods (Neimeyer & Hogan, 2001).

Given the complexity of the phenomenon, and the importance of the participants' processes of meaning making (Brocki & Wearden, 2006), a qualitative research approach was determined to be the most appropriate for the current study. The qualitative method of interpretative phenomenological analysis (IPA) was utilised to capture the rich, detailed descriptions of how participants endure and come to make sense of the lived experience of pregnancy loss. IPA was selected for its emphasis on systematically exploring personal meaning-making with an idiographic focus, which allows the researcher to compare the perceptions and understandings of individual participants sharing the phenomenon of interest (Smith et al., 2009).

# **Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA) is a qualitative methodology that shares theoretical ground with phenomenological psychology, hermeneutics, social constructionism, discourse analysis, and social cognition research (Eatough & Smith, 2008; Larkin, Watts, & Clifton, 2006; Smith & Osborn, 2003). The method has been employed frequently in health psychology research, given its amenability to uncovering subjective experiences of illness and other life experiences (Johnson, Burrows & Williamson, 2004; Eatough & Smith, 2008). More recently, IPA research has expanded to include clinical, counselling and social psychology domains, where researchers are interested in in-depth exploration of participants' personal and social worlds (Brocki & Wearden, 2006; Reid, Flowers & Larkin, 2005). It is compatible with psychological inquiry as it emphasises the thought processes involved in participants' experiences (Smith & Osborn, 2003).

The process of IPA involves two complementary analyses – phenomenological and interpretative. The phenomenological analysis requires the researcher to understand and 'give voice' to the participants, whilst the interpretative analysis requires the researcher to contextualise and 'make sense' of this information from a psychological perspective (Pringle, Drummond, McLafferty, & Hendry, 2011; Wagstaff & Williams, 2014). A two-stage interpretative process, or a 'double hermeneutic' is involved, where participants are trying to make sense of their world and the researcher is simultaneously trying to make sense of the participant's interpretations (Smith et al., 2009; Smith, 2004).

To achieve this, IPA studies typically use small samples, semi-structured interviews, and an inductive and reflexive approach (Wagstaff & Williams, 2014). The approach is inductive because it draws meanings from the data rather than imposing predefined constructs on them, and reflexive because researchers are encouraged to continually monitor their responses and critically examine the process throughout (Larkin et al., 2006; Reid et al., 2005). IPA is also idiographic in nature, in that its emphasis is on the particular (Smith et al., 2009). Using in-depth analysis, the focus is on understanding how particular experiential phenomena (i.e., an event, process or relationship) has been understood from the personal perspectives of those who have experienced it (Smith et al., 2009).

The current study is concerned with understanding the personal meaning that women attribute to their experiences of pregnancy loss. IPA appears well suited to this particular research orientation, in that it concerns itself with a detailed understanding of the human lived experience (Parry, 2004; Snelgrove, 2014). The aim of the study is to explore, describe and interpret how women make sense of their lived experience of pregnancy loss, in order to gain an unprejudiced description of the essence of this experience.

# **Participant Recruitment**

This study was conducted at a tertiary referral hospital in Western Australia, which contains an established Perinatal Loss Service. This service was established to provide information and ongoing support to women and their families who experience pregnancy loss. All families who have experienced pregnancy loss within the hospital are offered comprehensive multidisciplinary care. The team is comprised of an obstetrician, maternal foetal medicine specialist, midwife, neonatal paediatrician, perinatal pathologist, pastoral care representative, social worker, psychologist, and other specialists as required.

Participants were selectively recruited through the clinic in order to attain a uniform sample, who had access to pregnancy loss support services that the hospital provides. Criteria for inclusion in the study encompassed that bereaved women were at least 18 years old, English speaking, and had experienced a spontaneous loss. Women also needed to reside in the Perth Metropolitan area to ensure they were able to participate in face-to-face interviews with the researcher. Women who had experienced an elective pregnancy loss (such as an abortion or termination for foetal anomaly), or a multiple pregnancy with survival of one or more babies were excluded from participating as these specific types of losses were beyond the scope of this study.

Ethical clearance was obtained from the Edith Cowan University (ECU) Human Research Ethics Committee and the KEMH Research Ethics Committees. The Midwife Coordinator of the Perinatal Loss Service at KEMH was responsible for recruiting prospective participants via hospital records. Prospective participants who met selection criteria received a detailed information letter that outlined the nature and rationale of the study (Appendix A). A return form (Appendix B), where the participant could indicate whether or not they wanted to participate in the study, was supplied with the information

letter. Prospective participants were also given the option to request further information to inform their decision if required. This form was returned to the midwife coordinator prior to the patients discharge from hospital, with the contact details of those willing to participate forwarded to the researcher. This approach ensured that privacy was protected and that only participants willing to be involved in the study were accessed for participation.

Women who indicated on a return form that they were either interested in participating in the study or wanted further information, were contacted via telephone by the researcher. During the initial conversation the researcher introduced herself, explained the nature of the study, and answered any questions or the participants had regarding the study. The researcher's intention to audio-record the interviews and collect data over three stages was also clarified. Following this discussion, a mutually convenient time and place for the first interview was scheduled.

Care was taken to ensure that telephone contact was made no sooner than four weeks post-loss, and that initial interviews were scheduled no later than six-weeks post-loss. This time frame was applied in order to respect the nature of women's grieving, as well as identify respondents who had experienced a recent loss. Furthermore, this point in time complied with ethical guidelines which suggest that bereaved informants should not be contacted for research within the first month after a loss to avoid any undue distress (Cook, 2001; Rosenblatt, 1995).

Bereaved women were purposively sampled according to the gestational cohort within which their loss occurred, in order to gain a comprehensive description of the loss experience and permit a detailed comparison between early losses (miscarriage) and late-term losses (stillbirth). Purposive sampling is utilised in qualitative research to identify

participants that will present an in-depth account of an experience (i.e., pregnancy loss), so that generalisations can be made as to the meanings and interpretations of the experiences (Liamputtong & Ezzy, 2005). It facilitates data richness, enabling the researcher to acquire a thorough understanding of the phenomena under investigation.

These sampling and recruitment techniques resulted in 19 participants who were willing to be part of the research study. Of these 19 women, five did not complete the study but their interview data was still included. This is because qualitative investigation aims for depth and breadth, there is no need for scale or estimates of statistical significance. The resultant distribution sample consisted of five women who experienced a miscarriage (3 in the first trimester, 2 in the second trimester) and fourteen women who experienced a stillbirth (7 in the second trimester, and 7 in the third trimester). Such a sample size is deemed adequate for the purposes of interpretative phenomenological analysis (Smith et al., 2009), and allows for a richer depth of analysis that might otherwise be inhibited with a larger sample (Smith, Jarman, & Osborne, 1999). Furthermore, in the current study recruitment was only curtailed once the data reached 'saturation' point. Saturation occurs when no new information is provided by participants, at which point 'saturation' of the data is reached and no new participants are required (Richards, 2005).

Bereaved participants ranged in age from 20 years to 36 years (Mean = 29.53 SD = 5.03), and resided within the Perth metropolitan area in Western Australia. The majority of women were in either de facto or marital relationships at the time of the loss, and one participant was single. There was considerable diversity in the formal education and current occupations of the participants. Several had university degrees, some were students, some were stay-at-home mothers, and others worked in retail, hospitality, or administration.

Demographic data revealed that the women interviewed came from various cultural

backgrounds and religious affiliations. Country of birth included Australia, Czech Republic, England, Germany, Holland, Iraq and South Africa. Religious groups the women were affiliated with included Anglican, Christian, Catholic, Jehovah Witness, and Muslim, whilst others were atheists. In addition, participants were asked about their history of previous losses as well as if they had any other living children. For the majority of participants this was a first time loss, with four participants having endured a previous loss. Nine women had another child or children at the time of loss, with ten women having no living children. The majority of respondents (n = 14) conceived again within the interview period, and experienced a subsequent pregnancy. (See Appendix F for an outlay of the demographic data).

## **Ethical Considerations**

Participant vulnerability. Ethical clearance from Edith Cowan University Human Research Ethics Committee was granted in March 2009. Ethical clearance from King Edward Memorial Hospital Ethics Committee was granted in March 2010. The delay for ethical clearance was due to circumstances beyond the researchers control – the study was subject to review by the hospital board on numerous occasions and lengthy delays were experienced as a result. Namely, the committee raised ongoing concerns that the interview process may be distressing for some participants. This assumption is not uncommon, and research indicates that ethics boards often flag qualitative data collection in bereavement research as 'concerning' or 'potentially harmful' for prospective participants (Dyregrov, 2004; Hadjistavropoulos & Smythe, 2001). Further, there has been a tendency to conceptualise the bereaved as vulnerable and in need of protection in the research process (Hadjistavropoulos & Smythe, 2001). However, previous research indicates that the nature of qualitative interviews in bereavement research is typically more helpful than distressing

for participants (Buckle, Dwyer & Jackson, 2010). There is increasing evidence to support the notion that participants in bereavement research find the research interview to be therapeutic and meaningful (Birch & Miller, 2000; Buckle et al., 2010; Hyneson, Aroni, Bauld & Sawyer, 2006). Although tears are often present during the course of interviews, this has not been viewed as a risk or negative outcome by researchers or participants (Hyneson et al., 2006; Rosenblatt, 1995). Instead, it seems that participants are grateful to have had the opportunity to engage with an interested other who was willing to listen to their experiences (Birch & Miller, 2000; Buckle et al., 2010).

Nevertheless, given that bereaved participants are considered a vulnerable population, consideration needs to be given towards potential benefits and risks. Two of the most fundamental ethical principles applicable to research are beneficence and nonmaleficence, which are based on the premise 'to do good' and above all 'to do no harm' (Allan 2010). Beneficence refers to the moral obligation researchers have to act in the best interests of others, whilst non-maleficence means to act in a manner which avoids potential harm (Allan, 2010). Thus, researchers engaging in research that may be potentially harmful must only do so if the benefits of the research are assumed to outweigh the potential risks involved (Allan, 2010). In assessing the potential adverse effects for research participants, it was acknowledged that talking about personal experiences of loss may arouse intense emotional responses within participants (Kavanagh & Ayres, 1998; Walker, 2007).

Therefore, it was necessary to ensure that precautionary measures were put in place to promote the safety and wellbeing of all participants.

Following each interview, the researcher checked to see how the participant was feeling and whether or not they wished to be referred to an appropriate support service (Holloway & Wheeler, 1995). Information pamphlets detailing support services were

provided to all participants should they wish to talk further about any issues that may have arisen. Prior to data collection, arrangements were also made with the PLS Midwife Coordinator to provide referral to specialist support services if required.

When collecting data on a vulnerable population, it is also important to ensure that the researcher engages in preparatory work before commencing interviews (Dickson-Swift, James, Kippen, & Liamputtong, 2006). As such, the researcher attended a two-day griefcounselling workshop in July 2009, held by the Bonnie Babes Foundation. The purpose of attending this workshop was to isolate what is currently known and espoused about pregnancy loss and associated grief. In addition, the researcher met with a representative from SANDS WA, to learn more about the support groups available to women and parents who experience pregnancy loss. Being a psychologist, the researcher was aware of the need and possessed the skills to engage in empathic and sensitive interviewing. She was also aware of the need to maintain her role as a researcher, that is, not to assume the role of a therapist or grief counsellor. It is important to make a distinction between therapist and researcher, particularly in relation to bereavement research. Although the researcher should attempt to be a supportive and empathic listener, at no stage should the boundaries be crossed (Dickson-Swift et al., 2006). It is the researcher's responsibility to maintain a sense of professional detachment, by distancing themselves and ensuring that a safe boundary exists between themselves and the participant (Dickson-Swift et al., 2006). The researcher should not engage in a therapeutic relationship with the participant as the goal of the interview is to gain knowledge, not to provide therapy, and doing so would conflict with the research goals (Kvale, 1996).

It is notable that engaging in cathartic disclosure in research interviews can often be quite therapeutic in itself, even though therapy is not the purpose. This benefit has been

conveyed by researchers and participants alike (Holloway & Wheeler, 1995), and was evident in the current study. Several women expressed their gratitude following interview proceedings, commenting that "it felt good" to tell their story and "to have someone listen". It is possible that this potential therapeutic effect may have inadvertently biased the results of the study, in terms of affecting women's grief. However, cathartic effects are common in qualitative bereavement research (Holloway & Wheeler, 1995), and must be considered within the broader context of grief responses.

Informed consent. Additional ethical considerations include facilitating the process of informed consent, as well as maintaining participant confidentiality and anonymity. Informed consent means that participants need to have adequate information regarding the nature of the research, and need to be thoroughly informed regarding its purpose and procedures (Byrne, 2001). Participants must be fully capable of comprehending this information, and with this knowledge, they are then in a position to consent or decline to participate in the research voluntarily (Walker, 2007). The process is embedded within the principal of respect for autonomy and includes providing participants with information about the risks and benefits of the research (Holloway & Wheeler, 2002).

In qualitative bereavement research, ethical concerns have been raised about the nature of the interview process, with some researchers suggesting that it complicates the process of informed consent (Buckle et al., 2010; Hadjistavropoulos, & Smythe, 2001; Walker, 2007). For example, Hadjistavropoulos and Smythe (2001) argue that participants cannot provide true informed consent because they are not aware of how the interview will unfold. To address this concern, researchers are advised to continually inform participants of their right to withdraw from the study at any time (Walker, 2007). Similarly, the researcher must continue to monitor and assess when the anticipated or collected data may

induce stress for participants, as it is not always possible to predict all the risks at the outset of the study (Byrne, 2001). Particularly in phenomenological research where the researcher engages in in-depth interviewing, it cannot be known prior to data collection what type of information the interview will uncover (Walker, 2007). Certain information may be disclosed that the participant is not comfortable revealing or including in the study's findings. Hence, the process of informed consent is an ongoing negotiation and the researcher needs to remain sensitive to factors that may influence the participants decision to decline to participate or withdraw from the study (Cook, 1995). Ultimately, the researcher must do all that they can to protect their participants and reduce the potential for psychological harm (Byrne, 2001).

In the current study, all participants were provided with detailed information specifying the nature and purpose of the study, and the benefits and potential risks. This occurred both verbally (on the phone and prior to each interview) and in writing (information letter, see Appendix A). In accordance with ethical requirements, research participants were also asked to acknowledge their informed consent on a consent form prior to data collection. Both the researcher and the participant signed this consent form on the day of the initial interview (see Appendix C). In addition, the option to withdraw from the study at any time was reiterated throughout the research process. Participants were asked for their informed consent at the beginning and end of each interview.

Confidentiality and anonymity. A further ethical consideration relates to the researcher's responsibility to provide assurances of confidentiality and anonymity (McHaffie, 2000). The confidentiality and anonymity of participants were protected at all times, including all correspondence between the researcher and her supervisors. For example, all interviews were conducted in a secluded room located at either the hospital or

the participant's personal residence to ensure privacy. All participant contact information was stored in a locked cabinet in the researcher's office to protect their identity. Transcribed data and data files relating to the research were stored on the researcher's personal hard-drive and were password protected, thus were only accessible by the researcher. Upon transcription, all participants and their family members were assigned pseudonyms which were utilised throughout this thesis (Walker, 2007). Quotes used in the thesis were also scrutinised for information that could possibly render the participant identifiable (Parkes, 1995). Audiotapes were subsequently erased following transcription. Following completion of the study, interview transcripts were stored in a locked filing cabinet in the School of Psychology and Social Science at ECU for the preservation period of five years. These ethical considerations are in accordance with the Human Research Ethics Committee (HREC) guidelines at ECU and KEMH.

**Self-care.** Due to the sensitive nature of the proposed study, another ethical consideration is the psychological and emotional well-being of the researcher (Dickson-Swift, James, Kippen, & Liamputtong, 2008). Engaging in sensitive research may create an emotionally draining experience for the researcher, and consequently, several authors have argued that supportive and precautionary measures outside of supervision must be put into place (Dickson-Swift et al., 2008; Dunn, 1991; Hubbard, Backett-Milburn, & Kemmer, 2001). As such, the researcher participated in formal debriefing sessions with a Clinical Psychologist from the Edith Cowan University Psychological Services Centre, as required, for the duration of the study.

# **Data Collection Procedures**

**Interview guide.** An interview guide (Appendix D) consisting of suggested questions and prompts was utilised to provide direction to the interviews (Smith et al., 2009). The format was semi-structured, and intended to provide avenues for exploration of the women's loss experiences. Topics included: pregnancy, the mother's feelings of attachment to her baby, the day of the loss itself, and the experience of support received. The wording and order of the questions derived from the guide were not fixed, and were constructed according to the flow of the interview content (Smith et al., 2009). Care was taken to ensure the participant could express their personal story in any way they wished, with the researcher asking for further clarification or encouraging the participant to elaborate if required. Specific questions were based on Smith et al.'s (2009) question types. For example, some questions were descriptive (e.g., "Tell me more about what you mean by that"), others asked about feelings (e.g., "and how did you feel about that?"), or opinions (e.g., "Did you find that useful?" or "What would you have done differently?"). Many questions also began with "tell me about your experience of..." to ensure that the question was not leading in any way or making assumptions. At the conclusion of the interview, questions such as "is there anything else you would like to add that we haven't talked about?" were asked to ensure the participant had ample opportunity to share her experience to the fullest.

A prominent feature of the in-depth interview is the use of verbal and non-verbal probes, which encourage the participant to elaborate on their description of an experience which requires clarification (Sorrell & Redmond, 1995; Smith et al., 2009). Verbal probes in particular, can be useful when participants are asked to retell part of their stories to illicit further information (Liamputtong & Ezzy, 2005). Furthermore, they can help the interviewer to maintain a certain level of consistency over subject matter (Berg, 2001). Non-verbal probes, such as periods of silence, can be used to set the tone of the interview or enable the interviewer to capture hidden meanings embedded in the silence (Kvale,

1996; Sorrell & Redmond, 1995). During the interview process, the researcher engaged in the use of verbal probes as necessary, including, "can you provide me with an example?" and "can you tell me a bit more about that?" In addition, she was sensitive to periods of silence, and was sympathetic to their emotional pain.

Interview process. The majority of participants elected to conduct the interviews at their own home. This appeared to be the most comfortable setting for these women, and several conveyed their preference to avoid the hospital because there were "too many memories there". The few women who did choose the hospital setting did so for reasons of privacy or ease of location. Interviews ranged from one to three hours duration. During the longer interviews, time was also spent with the women honouring their baby's memory. Many of the women chose to share their personal keepsakes with the researcher, such as photographs, footprints, handprints, toys, paintings, poetry and journal entries.

Prior to the commencement of the first interview, the researcher formally introduced herself to the participant, thanked them for kindly agreeing to participate in the study, and reiterated the purpose of the research and voluntary nature of participation. The option to withdraw from the interview at any time and to not answer any questions they did not feel comfortable answering was made explicit, both verbally and in writing (Cook, 1995). Participants were also assured that there were no right or wrong answers and that they could request the recorder to be switched off at any time throughout the interview (Parkes, 1995). As soon as the researcher was confident that the participant fully understood the interview procedures, written consent to participate in the research and interview process was obtained (Appendix C).

The formal interview commenced with the researcher asking some general questions about the participant, in order to establish rapport between the participant and the

researcher. Spending some time getting to know the participant helps to create a less threatening environment by encouraging the participant to talk freely over topics of interest, and also sets the tone for the interview (Berg, 2001; Smith, 1995; Sullivan, 1998). During this time, some of the participants chose to ask the researcher why she had an interest in women's experiences of pregnancy loss, and whether or not she had suffered a pregnancy loss herself. To answer these questions the researcher disclosed that she knew several women who experienced a pregnancy loss, but had not experienced one herself. At this point, the researcher also acknowledged that she in no way understood what it felt like to lose a baby, but that she had great empathy for women who experience such a loss and wanted to know more about what could be done to assist women who endure this experience.

The interview progressed with a number of demographic questions, leading to more detailed open-ended questions relating to the participants' experiences following their loss. When required, probes were used to encourage participants to elaborate on their thoughts and feelings concerning a particular issue. At times, some participants became quite emotional and teary when talking about the day of their loss. This was an expected occurrence and the researcher allowed the participant to continue to share their story through the tears. However, the researcher did pause periodically to check if the women were okay and still willing to continue with the interview. All elected to continue. Participants were also asked periodically if they would like to take a short break, which some participants did.

Tape recording each interview provided an accurate record of the conversation and also meant that the researcher could pay attention to the participant without excessive note taking. The only notes taken were key words used to formulate new questions based on

participant responses, or ideas of prominent themes or insights gained during the interview. In addition, note taking assisted transcription and facilitated later analysis and interpretation. Personal notes were expanded on immediately after the interview, and reflections on the interview process were also noted in a journal. Using a journal for selfreflection is beneficial in phenomenological enquiry, as it enables the researcher to record and reflect on any deeper understandings, frustrations, surprises and questions that arise as the study evolves (Munhall, 2007).

Upon completion of the formal interview, participants were thanked for their participation and debriefed. Engaging in a debriefing session with participants is important when conducting bereavement research as it allows the participant to talk freely over certain issues and feelings that may have arisen during the interview process (Alty & Rodham, 1998). The practice is beneficial to both participant and researcher as it provides the opportunity for participants to voice concerns they perhaps did not feel comfortable discussing with the tape recorder on, and the researcher benefits from this new information (Kvale, 1996). Furthermore, the debriefing process ensures the participants' wellbeing is directly attended to as it enables the researcher to reiterate the purpose of the research and clarify any concerns. In some cases, participants may feel a little anxious because they have been so open about their experiences, and it is the researcher's role to reaffirm the nature of confidentiality and relieve such tensions (Kvale, 1996). Finally, debriefing is important after the interview because it enables the researcher to assess whether or not the participant has become troubled or distressed during the interview or requires therapeutic referral (Alty & Rodham, 1998).

Following debriefing after the first interview, the procedure for follow-up interviews and the researcher's intention to maintain contact with the participant was

discussed. The participant was reminded that participation in the research involved a three-stage interview process, which occurred over the course of a year. The researcher discussed her intention to conduct the second interview approximately 6 months after the first, and asked for the participant's consent. It was explained to the participant that they would be contacted at a later stage to negotiate a date for the second interview. The same process occurred for the third interview, which was scheduled approximately 13-18 months after loss. This time-frame was chosen to assess women's experiences of loss over time, but also to avoid the relapse in grief reactions which is common around the first anniversary of a loss (Hynson et al., 2006).

Care was taken to ensure that the voluntary nature of participation was affirmed throughout the data collection phase, and participants were assured each time that they were under no obligation to continue their involvement in the study. Maintaining contact with participants not only served an ethical purpose, but also helped to build rapport between the participant and the researcher.

### **Data Analysis**

The use of computer-assisted qualitative data analysis software (CAQDAS) was originally considered to assist with data management and analysis, but after much deliberation was not deemed suitable. Despite the widespread adoption of CAQDAS, and the increasing sophistication of packages, many critics assert that such programs are not necessary and may in fact impede data analysis (Clarke, 2009; Patton, 2002; St. John & Johnson, 2000). Similarly, some critics have advocated that that the researcher's insight and intuition should never be replaced by a computerised system that may prevent adequate engagement with and immersion in the data (Banner & Albarran, 2009). CAQDAS users run the risk of becoming preoccupied with creating codes that are needlessly detailed at the

expense of generating meanings (Banner & Albarrran, 2009; St. John & Johnson, 2000). In this sense, the researcher may become estranged and distracted by the process and may overlook the philosophical aspects of qualitative research that are so pertinent to data analysis (Banner & Albarrran, 2009). Hence, whilst CAQDAS provides a useful tool for managing and sorting qualitative data, methodological concerns over the software appear to outweigh the benefits.

Given that Smith et al. (2009) made no specific recommendations or suggestions in this respect, it would seem that the choice of whether or not to utilise computer assisted software in phenomenological analysis lies with the researcher. Considering that various researchers have argued against the use of such tools (i.e., Banner & Albarran, 2009; Clarke, 2009; Leech & Onwuegbzie, 2011; Patton, 2002; Popay, Rogers, & Williams, 1998; St. John & Johnson, 2000), the researcher decided against the use of CAQDAS for the current study, and used manual coding.

Consistent with the interpretative phenomenological framework selected, the analytical procedure was guided by the work of Smith et al. (2009). This process involved a deep engagement with each interview transcript, in order to yield specific themes that represented the shared experiences of participants. All interviews were transcribed verbatim to ensure data authenticity, and were transcribed personally by the researcher. This decision not only ensured participant confidentiality and anonymity, but also enabled the researcher to become completely immersed in the recorded data. Interviews were transcribed within a few days of conducting the interview and data analysis began soon after, to preserve data integrity. Recorded data was subsequently erased upon transcription in accordance with confidentiality agreements. The specific steps of the analytical procedures followed are summarised below.

Step 1: Familiarisation with the transcript. Analysis began with the reading and re-reading of transcribed data, and the revision and expansion of handwritten notes.

Transcripts were read several times to enable the researcher to become completely immersed and familiar with the data (Liamputtong & Ezzy, 2005). The researcher paid particular attention to the original words of the participant and attempted to identify and bracket any initial interpretations (Smith et al., 2009). Personal assumptions, biases, and reflections on the interview process were noted in a reflective journal.

Step 2: Initial noting. During this stage, salient words, phrases, comments and sentences were highlighted and circled in each transcript, and anything of interest was noted in the margins. This initial noting consisted of many illustrative comments, including descriptive comments (which focused on the content of participants' statements), linguistic comments (which focused on the participants' use of language, e.g., metaphor, shifts in tense, pronoun use, hesitations, and tone); and conceptual comments (which focused on the researcher's initial interpretative ideas and concepts for further exploration) (Smith et al., 2009). Thus, the process involved a close line-by-line scrutiny of the experiential claims, concerns, and understandings of each participant (Larkin et al., 2006).

Step 3: Developing emergent themes. The next stage involved analysing descriptions and exploratory comments in order to identify emergent themes in the data. In looking for emergent themes, the researcher attempted to convert the transcript and initial notes into specific themes or phrases, which captured the essence of what the participant had said (Smith et al., 2009). The researcher focused on discrete chunks within the transcript, or on specific key words or phrases that appeared frequently throughout the transcript (Larkin et al., 2006). Essentially, the participant's salient words were converted into conceptual themes that characterised meaningful portions of the data. These themes

were then extracted and listed chronologically along with line numbers in the transcript to support the emergent theme.

Consistent with the phenomenological interpretation that is IPA, these resulting themes reflect not only the participant's original words and thoughts, but also the analyst's interpretation (Smith et al., 2009). Similarly, this process represents one manifestation of the hermeneutic circle (Smith, 2007). The original whole of the interview becomes a set of parts, but these then come together in a new whole at the end of analysis.

Step 4: Searching for consistencies across emergent themes. Following the development of emergent themes within each individual transcript, the researcher began to cluster themes according to their interconnections. As suggested by Smith et al. (2009), several data reduction strategies were employed during this process. These included: (1) Abstraction, whereby the researcher identified patterns between emerging themes to develop a "superordinate" (major) theme, (2) Subsumption, whereby emergent themes required a superordinate status to bring together a cluster of related themes; (3) Polarisation, where transcripts were analysed for oppositional relationships between emergent themes to highlight differences; (4) Contextualisation, where the researcher attended to the contextual elements or key life events to organise the emergent themes; (5) Numeration, where the researcher reflected on the frequency with which the emergent themes occurred throughout the transcript, and (6) Function, where emergent themes were examined for their specific function within the transcript (Smith et al., 2009, pp. 96-98). Examples of how these six strategies were employed in the current study are described in Table 3.2.

This process enabled different concepts and meanings to be identified as either new manifestations of existing themes or new themes, and integrated into superordinate themes

that represented the sample as a whole (Willig, 2008). This was repeated for each transcript, with superordinate themes from each transcript compared with those previously elicited. Throughout the analysis of each transcript, the researcher strived to bracket the themes and conceptualisations from previous analyses, allowing new ideas to emerge from each transcript.

#### Table 3.2

Techniques to Assist in Theme Development

#### **Abstraction**

Psychological consequences of pregnancy loss

Shock

Disbelief

Despair

Anger

Guilt

Failure

Shame

## **Subsumption**

Transforming self
Loss of identity/motherhood
Loss of future/expected self
Vulnerability
Resilience
Positive growth

#### **Polarisation**

Negative effects of transformation Loss of motherhood/identity Loss of future/expected self Vulnerability

Positive effects of transformation Resilience Appreciation for life Being a better person

#### Contextualisation

Contextual elements/critical events, for example: Confirmation of the loss Informing others about the loss Deciding to try again Subsequent pregnancy

### Numeration

Shock (n=19) Anxiety in subsequent pregnancy (n=14)

#### Function

Emotional cushioning Coping mechanism to balance hope and fear Instil a sense of control Protect self from further disappointment

Step 5: Looking for patterns across cases. Once each transcript had been analysed and a set of emergent themes identified, the researcher searched for consistencies across cases. As encouraged by Smith et al. (2009), this process involved the formation of new superordinate themes that reflected higher order concepts, as well as the reconfiguration of some themes. This stage of analysis highlighted the researcher's role in the 'double hermeneutic' of IPA, that is, making sense of the participants' collective process of making sense of the phenomenon, while maintaining the integrity of the participants' original accounts (Smith & Osborn, 2003).

As the study was longitudinal, a comparison of themes across individual participant transcripts was conducted to assess whether women's experiences changed over time. In addition, a comparison between transcripts according to gestational epoch was also conducted. This involved searching the emerging themes for similarities and differences

between gestational groups (miscarriage and stillbirth). This process is cyclical, as it requires the researcher to go back over identified themes and confirm or deny their representation across individual gestational cohorts, and over different points in time. Such comparison enabled the researcher to understand the influence of gestation on women's experience of pregnancy loss, and also revealed whether women's experiences of early pregnancy loss (miscarriage) were different from those who experienced late-term pregnancy loss (stillbirth).

Data analysis continued until no new information was uncovered, ('saturation' was reached), at which point the write-up and discussion process commenced (Liamputtong & Ezzy, 2005). The result of this process is a series of superordinate themes and nested subthemes, which are presented in the following chapters. Excerpts illustrating each of the resultant themes are presented for verification.

# Research Rigour

In qualitative research, the need to capture participant's subjective experiences without imposing previously learned information presents an ongoing challenge (de Wet & Erasmus, 2005; Flowers, 2008). It has been argued that it is virtually impossible to find untainted perceptions, as we are already part of the world and inseparable from it (Heidegger, 1962). In this study, the opportunity exists for multiple spheres of meaning making, as the researcher extracts themes and meanings from the participants' individual words. At the very least, there are two: that of the participant and that of the researcher (Smith et al., 2009). This reflects the double hermeneutic, the dual process of interpretation.

To ensure that the researcher consistently engages with the subjective meanings of participants' experiences, they must adopt numerous verification strategies and self-correcting mechanisms at each stage of the research process (Morse, Barrett, Mayan, Olsen,

& Spiers, 2002; Ryan-Nicholls & Will, 2009; Tobin & Begley, 2004). This ensures that the research process is rigorous (Morse et al., 2002). Following much contention within the literature as to how rigour is attained in qualitative research, several researchers have argued that the terms 'reliability' and 'validity' are only applicable to quantitative research and that new criteria must be adopted for ensuring rigour in qualitative inquiry (Leininger, 1994; Lincoln & Guba, 1985; Rubin & Rubin, 1995). As a result, Lincoln and Guba (1985) substituted reliability and validity with the parallel concept of 'trustworthiness', which is demonstrated through credibility, transferability, dependability, and confirmability.

Credibility (comparable with internal validity) addresses the goodness of fit between participants' accounts and the researcher's representation of them (Schwandt, 2001). Hence, it looks for evidence that the description is credible. Credibility of the current study was demonstrated through member checking and supervisory debriefing (Lincoln, 1995). Member checking is a verification technique that involves soliciting the participants' feedback in relation to how well their experience fits the description and interpretations that the researcher has presented (Lincoln & Guba, 1985). Member checking was utilised during each participant interview and again after the analysis was completed. While interviewing each participant, the researcher frequently paraphrased her statements to check for accuracy in interpretation as well as probe for elaboration. Subsequent interviews also provided the opportunity for clarification and reflection, and the themes generated in the first interview were used as a basis for subsequent interviews. This process ensured that participants had the opportunity to explore the same themes in different ways, and that the researcher could seek clarification if required. Upon completion of the data analysis, participants were contacted for final verification, to ensure the analysis and final subthemes represented an accurate portrayal of their experiences.

The emerging themes and meanings were also cross-examined by the research supervisors throughout the research process. This took place via email or in a scheduled meeting during each phase of the data analysis. This form of cooperative inquiry is central to the IPA approach, and allows participants and supervisors to agree with or challenge the researcher's interpretation. Cross-validation also assures the fittingness, credibility, auditability and consistency of independent coding, and helps to reduce any bias (Shaw, 2001).

Transferability (comparable with external validity) refers to the generalisability of the research findings (Tobin & Begley, 2004). To increase transferability, qualitative researchers should focus on two key considerations: (1) how closely the participants are being linked to the context being studied, and (2) the contextual boundaries of the findings (Jensen, 2008). The current study was concerned with women's experiences of pregnancy loss, and accordingly, women who had experienced pregnancy loss were selectively recruited from a major maternity hospital in Western Australia. In terms of the contextual boundaries of the findings, it is likely that the findings can be generalised to other populations within Australia and abroad, however generalisability would almost certainly be limited to developed countries. Thus, generalisability would be constrained to the experiences of other individuals who are in comparable situations (Horsburgh, 2003). This position is supported by the comments of Popay and colleagues (1998) on the subject of generalisability, who emphasise that "the aim is to make logical generalizations to a theoretical understanding of a similar class of phenomena rather than probabilistic generalizations to a population" (Popay et al., 1998, p. 348).

Dependability (comparable with reliability) is achieved through the process of auditing (Tobin & Begley, 2004). Researchers are responsible for ensuring that the research process is logical, traceable, and clearly documented (Schwandt, 2001). In the current study, dependability is demonstrated through the use of an audit trail to ensure

transparency. The researcher frequently recorded reflective memos regarding her observations and the origins of her interpretations. This also facilitated a reflexive purpose, whereby reflection served to promote an awareness of personal values, experiences and presuppositions as the research unfolded. Reflexivity is central to the audit trail and enhances the quality of research through increasing the researcher's awareness of behaviour and biases which may otherwise affect the interpretation of responses (Jootun, McGhee, & Marland, 2009).

Prior to data collection, the researcher reflected on her pre-existing knowledge of pregnancy loss in a research diary. Before, during, and immediately after interviews she added any emerging thoughts and views (Burns & Grove, 2003). This provided her with the opportunity to monitor the extent to which any theoretical frameworks might be imposing on the data (Hamill & Sinclair, 2010). In addition, the researcher performed a preliminary literature review instead of an extensive review prior to data collection as a way of familiarising herself with the topic area (Cresswell, 2003; Hamill & Sinclair, 2010). A comprehensive review was only completed after data analysis as a way to preserve the inductive integrity (Cresswell, 2003).

Confirmability (comparable with objectivity) relates to the neutrality or freedom from bias of research findings (Ryan-Nicholls & Will, 2009). However, in qualitative research the findings are not neutral and value free (Morse et al., 2002). Instead, the researcher's own values and assumptions are acknowledged – a defining characteristic of interpretative phenomenology (Morse et al., 2002). This inconsistency had led some researchers to conclude that confirmability is not a suitable criterion for assessing rigour in phenomenological research (de Witt & Ploeg, 2006). However, other researchers assert that confirmability is more about ensuring that the interpretations of the findings are clearly derived from the data, and therefore is a suitable criterion upon which rigour can be assessed (Tobin & Begley, 2004). Essentially, confirmability is achieved by

fulfilling all of the above criteria (credibility, transferability and dependability).

Engaging in all of the aforementioned processes ensured rigour of the research was attained.

# **Summary**

This chapter has outlined the research methodology applicable to the current study, and provides a rationale as to why interpretative phenomenological analysis was selected as the most appropriate means to address the research question. The IPA procedures outlined by Smith and colleagues (2009) were presented as a guide for sampling, data collection, analysis, and interpretation. Difficulties pertaining to interpretive bias and the processes adopted to ensure research rigour in the study were also discussed.

The emergent themes resulting from the analysis are divided into three chapters according to the context of women's experiences. Chapter Four describes women's bereavement experiences following pregnancy loss, Chapter Five outlines women's experiences of support, and Chapter Six focuses on women's experiences of anxiety in the subsequent pregnancy. Quotes from the participants are used to illustrate participants' experiences in their own words. These quotes are not meant to prove or verify the themes, merely to elucidate the conclusions derived from the intensive analyses of the participants' descriptions of their experiences.

Chapter Four: Experiences of Bereavement 87

# **Chapter 4: Women's Experiences of Bereavement Following Pregnancy Loss**

This chapter describes women's experiences of bereavement following pregnancy loss. The analysis yielded five superordinate themes and seventeen subthemes within this domain. These emergent themes are presented in Table 4.1. The superordinate themes include: A Painful and Unexpected Reality; A Complex and Enduring Grief; An Undesirable and Rejecting Self; Maintaining Connections with the Baby; and A Transformed Self.

The findings indicate that pregnancy loss results in a bereavement experience that is both unique and complex. Women not only grieve for the loss of their deceased child, but also grieve the loss of motherhood and all that the child had come to represent. This grief is severe, traumatic, and persistent, and is accompanied by immense guilt, anger, shame, selfblame, vulnerability and confusion. However, the experience of bereavement is also one of positive growth and enlightenment. Bereaved women report becoming more empathic and appreciative individuals as a result of their bereavement experience. Furthermore, they make concerted efforts to integrate the baby into their lives in a manner that is constructive and meaningful. A discussion of these findings is presented is chapter Seven.

# **Emergent Themes**

Table 4.1 Structure of Emergent Themes

Superordinate Themes and Subthemes	Participants Endorsing Theme (n)
An Unexpected and Painful Reality	
Shock, disbelief and despair	19
The trauma of giving birth to a stillborn baby	14
Seeing and holding my stillborn baby	12
Leaving the baby behind	6
Sharing the bad news	6
A Complex and Enduring Grief	
Floating in grief	9
Loss of motherhood and future self	5
Searching for guidance on grief expression	5
Adjustment, not recovery	8
An Undesirable and Rejecting Self	
Why me? It's not fair!	11
It's my fault	10
I've failed as a mother	5
Maintaining Connections with the Baby	
Thinking about the baby	6
Integrating the baby and memorialisation	9
A Transformed Self	
Acceptance and spiritual growth	8
Empathy and gratitude	5
Vulnerability and loss of control	5

# An Unexpected and Painful Reality

Collectively, the bereaved women tended to describe their experiences of pregnancy loss as painful, traumatic, and unforeseen. The anticipation and excitement of motherhood

was abruptly removed as expectant mothers were confronted with the agonising truth – that their baby had died.

Shock, disbelief, and despair. When faced with the reality of their pregnancy loss, the bereaved women described feelings of shock, fear, emotional numbness, and intense despair as initial characteristics of their bereavement experience. These feelings were compounded by an immense sense of disbelief and confusion, at such an unexpected turn of events. For example, Emily recalled how her excitement at giving birth soon turned in to fear and despair as she began experiencing severe complications:

"He was overdue, so we were doing everything we could to try and get him to come naturally. Sex, acupuncture, stretch and sweep... I wanted to have a home birth rather than have him at hospital. ... Then it got to the day when he was born, it was a Sunday. I woke up in the morning and started having labour pains. I was very excited, he was finally going to come! ... The contractions started to get stronger, so I went to wake up my partner and said it's happening, it's happening! He called the midwife... they set up the birthing pool...but the pain started to get quite bad. After six hours of excruciating pain I was still only 3cm dilated. So I went to the hospital and they gave me some pain relief. I was in the hospital for a further six hours in labour. They were monitoring the baby's heartbeat the whole time, and then suddenly his heart rate just dropped really quickly... I was quite out of it from the medication that I don't remember too much of it, but the one thing I remember clearly is when his heart stopped. I remember hearing the baby's heart rate is 80, baby's heart rate is 60, then, we can't find a heartbeat. I was rushed away for an emergency Caesarean...they tried to resuscitate him...but it wasn't enough. Worst moment in my life, I pretty much died inside at that moment." (Stillbirth, 40 weeks/ Interview 1)

For most women, the disruption of the implicit belief that pregnancy leads to a healthy newborn at the end of nine months resulted in utter shock. Phoebe stated:

"They couldn't find a heartbeat. You could see it written all over her face before she actually told me. I was in such shock." (Stillbirth, 40 weeks/ Interview 10)

Grace's shock and distress was also evident. She described the experience as:

"It was like going to hell. I was bawling, screaming, just clinging to my husband. I went into shock...I was numb." (Stillbirth, 40 weeks/ Interview 1)

Similarly, Audrey and Maria described how they were stunned and unprepared for such an unexpected revelation:

"They were taking so long to find a heartbeat that my husband and I were actually laughing. Not once did we think there wouldn't be a heartbeat...that they were going to tell me that my baby was dead."

(Audrey/ Stillbirth, 25 weeks; Miscarriage 15 weeks/ Interview 1)

"It wasn't until I went to hospital that I understood I had actually lost the baby. They did an internal and they could see that everything was completely gone. And that moment was just awful. You know, when only a week before I had my scan and the baby was there, and now it was empty. And I think about how perfect it was gonna be, there would have been exactly two years between them...but now I'm left wondering what's happening to its poor little soul..."

(Maria/ Miscarriage, 8 weeks/ Interview 1)

Some women had a level of awareness about the potential for early pregnancy loss, but held the common belief that once they were past the first twelve weeks, they were safe. Ruth described her ignorance as follows:

"Before we lost him, we didn't know that something like this could happen. You just assume you fall pregnant and there's a healthy baby at the end of it. It's like they warn you about the first 12 weeks, and they warn you about the possibility of Down syndrome...but you don't hear about anything else." (Stillbirth, 31 weeks/ Interview 1)

Likewise, Grace had never considered the idea of pregnancy complications, particularly during the final stages of her pregnancy:

"I never thought anything could go wrong. I mean, I was on the home stretch, and you never think of your baby dying, especially at this stage" (Stillbirth, 40 weeks/ Interview 1)

Other women, like Audrey, had minimal to no level of awareness about the potential for pregnancy loss.

"Before I lost my first baby, I never knew a baby could die inside of you. I know that sounds really naïve, but I was." (Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 1)

For those women who had considered the possibility of loss, the reality of this occurrence resulted in a heightened sense of anxiety. For example, Paige, who had not previously endured a spontaneous loss but was familiar with the statistics of early pregnancy loss, described the following:

"The Doctor looked concerned and I was worried that there was something physically wrong with the baby. Then he said do you mind if we do an internal [ultrasound], because I'd like to see a different angle. And by then my heart was racing, I was beginning to feel like this wasn't good...So he did the internal scan, and said that he couldn't find a heartbeat. This was my worst nightmare, like all my fears had come true." (Miscarriage, 7 weeks/ Interview 1)

Although Paige understood what was happening, and had even contemplated the possibility of a miscarriage, she still wasn't prepared for the outcome.

"I was cautious, because it was my first scan...and you know these things can happen. But I really wanted to get confirmation that it was all good. ... And then they told me that I'd had a miscarriage, it still felt like I was in this weird movie, that it wasn't happening to me." (Miscarriage, 7 weeks/ Interview 1)

Thus, the experience of pregnancy loss appeared to be a surreal and traumatic event, regardless of gestational period. Not even those women familiar with the statistics or who had an awareness of the potential for loss considered the possibility that it could happen to them.

The trauma of giving birth to a stillborn baby. Among women who experienced a stillbirth, the unexpected and painful reality of the pregnancy loss was further complicated by the act of having to give birth to a dead baby. Several women shared their shock and disbelief at being told that not only had they lost their baby, but they also had to give birth naturally. Amanda explained:

"They told me I had to give birth. I was mortified. I thought, oh no, there is no way I'm doing that! They explained what I was faced with and I thought, are you kidding? This just can't get any worse!" (Stillbirth, 26 weeks/ Interview 1)

The women reported a sense of feeling overwhelmed and unprepared for the process of labour and birth. This sense of feeling unprepared for labour and birth was mediated by the experience of guidance and support received. For example, Amanda reported that she was

able to calm herself down somewhat once the midwives explained to her why a natural birth was necessary for the viability of future pregnancies. She became more accepting of the process as she became more familiar with what was going to happen.

"The midwife explained why, you know, for future pregnancies and all, and I was like okay, I get that. As the day went on we got more information...one Doctor was really good..." (Stillbirth, 26 weeks/ Interview 1)

In Susan's experience, she felt that the staff did not take the time to explain to her what was happening and what she could expect during the birth. As a result, she became very distressed and confused. Susan described:

"They told me I had to give birth naturally, and no one really explained why. They just said that this was the best way to do it because you're so small. And I was so scared because after two C-sections I was told not to have a natural birth. I was given strict instructions not to. Then here I am being told I have to give a natural birth with the real fear that my uterus could probably rupture, that I might never be able to have children again." (Stillbirth, 20 weeks/ Interview 1)

In instances where the baby's death was confirmed prior to spontaneous labour, women were given three options. They could choose to either stay at the hospital and wait to be induced, go home and wait to be induced, or go home and wait for labour to occur naturally. Most women chose to go home and return to the hospital to be induced the following day or a few days later.

"They gave us a choice. They said we could go home and come back the next morning, or we could stay at the hospital overnight. We chose to go home and get our things and then come back" (Ruth/ Stillbirth, 31 weeks/ Interview 1).

"It was meant to be on a Friday but I had my daughter's recital on that day which I wanted to be there for so I said no. I didn't end up going to the hospital until the following Monday." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

In retrospect, the majority of women who decided to go home were grateful for the decision. This gave them the opportunity to reflect on what had just occurred in the privacy of their own homes, away from the clinical setting of the hospital.

"...coming home was good because it gave [my husband] and I a chance to talk, some private time." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

"They were just going to put me straight in for the induction, but I didn't want to. I wanted to go home first...to try and let it all sink in. And I'm glad we did, I needed that space." (Phoebe/ Stillbirth, 40 weeks/ Interview 1)

For Chloe however, this period was very uncomfortable and distressing. She expressed:

"That night was very strange for me. Laying there knowing he wasn't alive inside me. And the next morning I woke up with lots of blood everywhere..." (Stillbirth, 39 weeks/ Interview 1)

Several women had no option but to remain at the hospital, as their labour commenced soon after being told their baby had died or was going to die. This was true for women who experienced either a miscarriage or stillbirth:

"The doctor came to explain to me that I was going to lose my daughter...a few hours later I started going in to labour. They rushed me to the labour ward...and she passed away during labour..." (Jenny/ Stillbirth, 21 weeks/ Interview 1)

"We went to the hospital about 11pm and I got admitted about 3am the next morning. The cervix was open so they took me down to the delivery ward and I had to give birth. Nine hours of labour." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"...the specialist said to me, well, the cervix is open...the water is all gone...the baby is coming. And then I remember I said I needed to go to the toilet, cos I wanted to wee. And the next thing I knew...this strong bleeding...and the baby came out..." (Olivia/ Two Miscarriages, 18 and 12 weeks/ Interview 1)

The process of labour and birth was described as painful and traumatic, regardless of the stage of loss. This was not only attributable to the trauma of giving birth to a deceased baby, but was the moment in time when the reality of loss was confirmed. Essentially, birth signified death, and the experience of miscarriage or stillbirth resulted in a profound realisation that the loss was real.

"The delivery itself was pretty awful. I had to get cut with forceps, I had a third degree tear, and afterwards my temperature skyrocketed. I was dizzy, my blood pressure dropped...it wasn't a pleasant experience...traumatic all round." (Grace/ Stillbirth, 41 weeks/ Interview 1)

"I lost an incredible amount of blood, it was literally pouring out of me...they gave me these vials to collect it. Then the placenta was stuck...it was just horrific." (Audrey/ Miscarriage, 15 weeks/ Interview 1)

"I think I did most of my grieving during the labour...that was very long and hard. And I was so exhausted...physically and emotionally...that was the worst day. I almost cried myself dry while I was giving birth." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"It was extremely hard...it was so hard to focus on the birth. He was our first baby, we had been so excited for him to come...and now I was having to give birth like this. There was going to be no cry, and I was going to have to go home with empty arms." (Ruth/Stillbirth, 31 weeks/Interview 1)

Several women commented on how surreal the whole experience was for them, admitting that they almost dissociated from the actual birth because the reality was so painful.

```
"I don't remember much of it...I was so numb, so drained."
(Phoebe/ Stillbirth, 40 weeks/ Interview 1)
```

"It was like it was happening to someone else, I couldn't believe this was happening to me."(Chloe/Stillbirth, 39 weeks/Interview 1)

"I didn't allow myself to think too much about it... I really just shut down and thought to myself, I've really got to do this..." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

Some women admitted to feelings of hope and denial, revealing that even though they understood their baby had died, they secretly hoped for a miracle.

"In the back of my mind I was secretly hoping that when she actually came out she would cry and she would be alright." (Grace/ Stillbirth, 41 weeks/ Interview 1)

"I refused to believe it, I didn't want to believe it. Some small part of me clung on to the hope that maybe the doctors were wrong...that maybe she was still alive inside of me...I so wanted that to be true," (Jessica/ Stillbirth, 20 weeks/ Interview 1)

For some women, the experience was frightening as well. For example, following a 20-week ultrasound where everything appeared normal, Eveline returned to the hospital

concerned about subsequent fluid loss and spotting. Upon examination, it was revealed that she was already dilated and that her membranes were exposed.

"they could see my membranes and I was dilated, not fully but it was completely open. She was only 21 weeks at that point so it was a matter of seeing if I could last, I was terrified. They put me on bed rest...but then of course because my cervix was open I got the bacteria that causes early labour and my waters broke...she had survived up until that point...but by the time she was born she had passed away." (Stillbirth, 21 weeks/ Interview 1)

Susan also spoke about the trauma she experienced, whereby one minute she was on a camping trip with her family, and the next she was being rushed to hospital with severe complications.

"I had just had my regular scan on the Monday and everything was fine. On the Friday we arrived. Saturday night, I was just sitting there in the caravan relaxing and I got up to go the toilet, and my waters broke. I didn't realise it was my waters, I thought maybe I'd wet myself...but the next day there was all this blood in the toilet. We raced to the hospital, where they reassured me that everything was fine. I was sent back home...only to return back to the hospital with severe pain in my stomach...straight away he [the specialist] put me on antibiotics...and they kept me overnight...The next minute, I get rushed back home to [selected hospital], to see my obstetrician...and more scans. That's when he said I'm sorry...but the baby is coming, and there's nothing we can do. He's too young to save..." (Stillbirth, 20 weeks/ Interview 1)

This was only the beginning of Susan's traumatic ordeal as being in a private Catholic hospital, she was unable to be induced and was instructed to await natural delivery. This reality was especially distressing for Susan as she was not only dealing with the delayed labour of her deceased baby, but her own health was now greatly at risk.

"...to make matters worse, being in a Catholic hospital...they weren't allowed to bring the baby into labour, I had to wait until the baby came. And they couldn't tell me when that would be. In the meantime...my health was at risk...I was rushed to [another hospital] where there were further complications...they had to get special permission to induce because I was under 22 weeks old. All the paperwork had to be signed. And in the interim they were hoping that the baby would come into labour...obviously by now I was very stressed and panicky. By now it had been five days in and out of hospital...and no-one could help me. They finally got clearance...they began to induce me...and it was quite a long labour, about 6 hours. And on top of that, I had to have him naturally. And I'd only had two Caesars before...so I didn't know what to expect, and there was a lot of panic about my

uterus rupturing...that I could possibly lose my womb and not be able to have another child. So there was so much fear and agony mixed in through the whole thing..."

Despite the emotional and physical distress the women described giving birth to a deceased baby, several women reported being grateful to have been given the opportunity to give birth naturally. In particular, they felt that it was important that they could give their baby "something".

"I feel caesareans are so impersonal. By giving birth naturally, I felt more of a connection to her. I felt like I'd given her something." (Alyssa/ Stillbirth, 38 weeks/ Interview 1)

"I felt like that was something I wanted to do for her, I'd gotten that far." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Whilst the women were unable to adequately express what this "something" was, it appeared that the physical and emotional distress they endured was meaningful. They wanted to acknowledge that their baby was important to them, and ensure that this connection was validated. In addition, the process of giving birth was meaningful and important in terms of assisting the women to work through their grief. As Amanda and Stephanie expressed:

"I feel it was very important [the process of giving birth]. It helps to acknowledge the birth of the baby as well as helps you go through the grief process. If I hadn't of had that experience I would have felt quite removed." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

"Giving birth to [baby] was important because I still wanted to go through with what I had planned. Even though it wasn't the birth I wanted it helped me get through it...it was important for the whole grieving process." (Stephanie/ Stillbirth, 39 weeks/ Interview 1)

Seeing and holding my stillborn baby. Following the difficult process of labour and birth, women who experienced a stillbirth were faced with the confronting decision about whether or not they wished to see and hold their stillborn baby. Unlike previous generations, it is now common practice for hospital staff in the setting where this study

occurred to offer parents/mothers the opportunity to spend time with and hold their deceased baby. This created discomfort for most women, who were unsure how to respond. Many women described their hesitancy over seeing their baby for the first time, worried that he or she would look deformed, or that spending time with their stillborn baby would make the experience more difficult. Some were concerned that the decision to hold and bathe their deceased child might be perceived as a bit morbid. However, most women were surprised at how perfect and complete their baby looked, and this provided them with some sense of relief.

```
"He looked perfect in every way."
(Phoebe/ Stillbirth, 40 weeks/ Interview 1)
```

"Apart from the bruising, he looked just like a normal newborn." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

"He looked just like his father...yeah he was cold, but it wasn't scary." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I was excited because I wanted to know what he looked like. And that moment, oh my gosh, he had my nose. And I just cried. He had my nose and my hair, and I was so happy that he looked like me...it was such an emotional time." (Chloe/ Stillbirth, 39 weeks/ Interview 1)

During this time with their baby, the women were also provided with the opportunity to have photographs and hand or foot print casts taken of their child, as ways of remembering their baby. These tangible mementos provided some solace for the bereaved mothers, who reported taking comfort in possessing a 'memory box' full of their baby's personal artefacts. These included baby and maternity clothing, blankets, footprints, fingerprints, plush toys, locks of hair, hospital name bracelet, birth/death certificates, sympathy cards, personal journals, and the baby's ashes. Many of the women chose to share these mementos with the researcher during the interviews, and photographs and/or birth certificates were often on display in the women's homes. Audrey proudly announced:

"Both my children's birth certificates are up there on the wall" [in reference to her live-born son and stillborn daughter's birth certificates on display in her living room]. (Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 1)

Jenny also had visual reminders of her daughter on display:

"We've got pictures of her in our bedroom...and our son often points to them and says proudly 'that's my sister!' And we say, yes!" (Stillbirth, 21 weeks/ Interview 1)

Ruth shared a photo album of her son that she had created online, that she had printed for several members of her family. She also proudly displayed a novelty butterfly in a jar. which she had purchased in memory of her son.

"There he is, our beautiful butterfly." (Stillbirth, 31 weeks/ Interview 1) Even among women who felt unable to look at their mementoes "just yet", having the mementoes to refer to at a later stage was comforting.

"We have a teddy with his ashes inside...it also has his name and date of birth on the front. So I can cuddle him when I want to...and that's really nice to have." (Phoebe/ Stillbirth, 40 weeks/ Interview 1)

"I've got a little treasure box...but I don't like to look at it. It's just too hard. I've put it away for another time." (Susan/ Stillbirth, 20 weeks/ Interview 1)

Leaving the baby behind. Although the physical and psychological trauma of the loss itself was a difficult time for all of the bereaved women, many recounted the painful reality of having to leave their baby behind upon their discharge from hospital. Several women reported the grief and pain at going home with empty arms, describing an intense emotional yearning and sadness.

"The hardest thing about the whole experience for me was walking out of that hospital knowing she was still there. That was really hard. I felt like I was leaving my daughter behind, it was a really strange feeling...when I got home, I just felt so empty. I wanted her back so much." (Mary/ Stillbirth, 24 weeks/ Interview 1)

"It was very difficult having to come home without our daughter. I didn't want to let her go. I didn't want her to be alone... That was really hard. The house felt so empty... I felt so empty." (Jenny/ Stillbirth, 21 weeks/ Interview 1)

"Coming home to an empty house was the worst moment of my life. I was screaming, absolutely screaming. I'd never cried like that in my life. It was so painful." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"You know, you go into hospital to give birth, and you expect to come home with a live baby. Coming home without her...the whole drive home I was bawling my eyes out. I felt like I'd left her, like I'd abandoned her at the hospital." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Grace described how she felt particularly vulnerable and at risk emotionally, and was thankful that she had the strong support of her sister when she was in such a distressed state:

"I think if my sister hadn't of been there, I would have been in a very dangerous place emotionally. I'm wondering whether social workers or psychologists need to do home visits or something like that once you come home. Cos coming home was just awful, it's the most traumatic thing. I mean, her cot was just beside the bed, and all her pretty baby things were around the house, just waiting for her...It wasn't really until I came home that everything really hit me. And it was this overwhelming feeling of complete anguish and sadness." (Stillbirth, 41 weeks/ Interview 1)

Amanda conveyed a similar perspective, sharing how she felt extremely vulnerable upon discharge, when her support system was abruptly removed:

"One thing I would have liked is for maybe the same midwives at the hospital to come have visited me at home. Because they were just wonderful...I really felt protected and supported. And that's what's so scary about leaving the hospital. You have all this support and then you're home on your own. That's when the wheels fall off and it all hits." (Stillbirth, 21 weeks/ Interview 1)

**Sharing the bad news.** The need to inform family and friends about the baby's death served as another difficult and painful reality. This was especially awkward and challenging considering that many people were aware of the baby's due date, and were anticipating the baby's arrival. As Grace described:

"I had actually posted a message on Facebook before the weekend saying that I was scheduled to be induced on the Monday...telling people to 'watch this space!' And when they didn't hear anything they were all phoning and leaving me messages wanting to hear the news. Then I had to tell them all what happened..." (Stillbirth, 41 weeks/ Interview 1)

Emily also discussed her decision to share the bad news on social media:

"I put a message up on Facebook the next day telling people what had happened and not to call me at the moment because I was very emotional. And that was good. I received a lot of private messages of support... I felt it was important to guide people into what was appropriate. But of course there were some people who when they saw me for the first time [after the loss] didn't know what to say. That was a bit awkward." (Emily/ Stillbirth, 31 weeks/ Interview 1)

Sharing the news of the loss was difficult, regardless of the type of loss. For example, several of Paige's friends and family knew about her pregnancy and that she was going for her first scan.

"I had to call Mum, and that was very emotional...and then of course I'm getting so many messages from friends asking how the scan went. At that point I thought, this is too much, I just need to send a message to everyone letting them know what happened. That text message alone took me about an hour and a half to write because every time I would read it I would cry. That whole saying out aloud just made it so hard." (Paige/ Miscarriage, 7 weeks/ Interview 1)

Leanne also conveyed how she dreaded informing her family and friends, as she knew they would share in her disappointment:

"You know, we'd held off telling everyone until the three-month mark...so we were safe. Or at least we thought. Everyone was happy for us...and now we had to go tell them the bad news...my sister, she couldn't wait to be an auntie..." (Miscarriage, 18 weeks/ Interview 1)

## A Complex and Enduring Grief

The unanticipated and sudden loss of pregnancy resulted in a complex and enduring bereavement experience for the majority of women, regardless of gestation. In particular, the experience of grief was traumatic and debilitating, and resulted in marked psychological distress. In addition, it was complicated by supplementary losses, including the loss of motherhood and the mother's sense of self. The women struggled to cope with their grief in a society where mourning expectations were noticeably absent, and they subsequently sought guidance as to how to cope.

Floating in grief. In the days and weeks immediately following the loss, women's experiences of grief were physical as well as psychological. Women described feeling "completely numb" (Emily/ Stillbirth, 40 weeks/ Interview 1), like a "total wreck" (Phoebe/ Stillbirth, 40 weeks/ Interview 1), and being in an "emotional fog" (Grace/ Stillbirth, 41 weeks/ Interview 1).

"I went to sleep that night, but the next morning I woke up and it just hit me like a tonne of bricks. My chest was tight, I couldn't breathe. All those things you feel when you've got a broken heart, that's what it felt like. Like someone had literally torn a part of me out, and I was left with this piece missing...I couldn't stop crying. I felt like I was going to be sick. I wanted it back so badly. I couldn't believe that it was gone forever." (Paige/ Miscarriage, 7 weeks/ Interview 1)

Emily stated that for the first few weeks after losing her son she was "floating in grief, surrounded by grief." For her, each day was a struggle as she was consumed by grief. She hardly left the couch, and she reported losing touch with reality and what was happening in the world around her. These feelings of detachment persisted for many months.

"The only thing you can do is endure it, really feel it. And that's what I did. Every day is hard. I cry every single day. It gets very intense. You think you know what sadness is like and then you go through something like this. I didn't know what sadness was until now." (Emily/ Stillbirth, 40 weeks/ Interview 1)

The women also experienced significant disruptions in their sleeping and eating patterns in the weeks and months following the bereavement. Some women reported a marked decrease in their appetite, as Leanne and Maria stated:

"I couldn't eat. I completely lost my appetite. And the ironic thing was that I had been avoiding all those foods...and now that I was allowed to eat them, I didn't want to." (Leanne/ Miscarriage, 18 weeks/ Interview 1)

"I went to go eat a piece of salami the other day and went to stop myself, thinking I couldn't have it. But then I thought we yes I can, because I'm not pregnant...and then I just stared at it and was so angry I just shut the fridge and walked off. I didn't want it anymore. And I love salami!" (Maria/ Miscarriage, 8 weeks/ Interview 1)

Others reported sleep disturbances following their loss, either in the form of nightmares, flashbacks or insomnia.

"I couldn't sleep or think about anything else... I had to get sleeping tablets just to get some rest." (Phoebe/ Stillbirth, 40 weeks/ Interview 1)

"I keep reliving the memory of him over and over again, every day...being told there was no heartbeat. Seeing him there like that. I feel like it's going to be that day, [date of loss], for the rest of my life. I'm stuck on that day." (Emily/ Stillbirth, 40 weeks/ Interview 1)

Several women described how they would often awake in a state of confusion as they still felt pregnant and would even experience pregnancy symptoms such as phantom kicks.

"I wake up in the middle of the night feeling as though it must have all been a bad dream, a nightmare. It was the same the morning after I lost him...I woke up in hospital hoping it had all been a bad dream and that any minute the nurse would be coming in with my baby telling me to breastfeed...but I know what happened. And I have to try and stop myself from thinking like that." (Chloe/ Stillbirth, 39 weeks/ Interview 1)

"Some nights I go to sleep and I wake up thinking I felt the baby kick. And I know it's not possible...but I feel these phantom kicks..." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

Loss of motherhood and future self. When talking about their yearning and sadness, several women spoke about how it wasn't just the loss of their baby that made them sad, but that it was also the loss of hopes and dreams they held for that baby's future, and what should have been.

"Of course losing him has made me incredibly sad, but it's more about the fact that I think about what could have been. He would have had so many friends at school...I had a dream about him graduating high school the other night. He was this tall, good looking boy...and then I woke up really upset because I thought well, he never got that chance to grow up." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"It's the loneliness, the constant emptiness. Sometimes I just sit here and think...what if it hadn't turned out this way? There would be toys everywhere, I would be on the floor playing with him instead of sitting here on the couch crying..." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

The experience of loss resulted in a complex bereavement experience whereby the women grieved for multiple losses, including the loss of their baby and the loss of their future self (i.e.,

motherhood). Women's attachments to their baby's and their plans for their baby's future, were evident from early on in pregnancy, as the following excerpts illustrate:

> "It was real to me from the moment it was conceived. I already felt connected to it. Because we really wanted another baby...we had already started talking about baby names. And I had already started talking to it and planning our whole next year around the baby...and having had a baby already, you're already aware of the potential for this tiny foetus to become this awesome human...I really felt connected to it." (Maria/ Miscarriage, 7 weeks/ Interview 1)

"I've had problems my whole life attaching myself to anyone, this was the first person I was actually attached to, so it was really difficult." (Phoebe/ Stillbirth, 40 weeks/ Interview 1)

"It wasn't just the loss of Charlotte, it was the loss of all my hopes and dreams." Wanting to be a mother for so long, having her in me for so long, knowing all her little guirks when she moved...and then suddenly her not being there. She was my first child." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Searching for guidance on grief expression. Deliberating on the 'right way' to grieve was also conveyed by many of the bereaved women. It was clear that they held certain expectations as to how they felt they should be coping, and they sought guidance and reassurance to ensure their grief was normal. Often, the women took it upon themselves to seek information as to 'how' to grieve.

"I read a lot of books on grief and they all said the same thing. To let yourself grieve and focus on the pain and deal with it. And that's what I did. And it's hard because normally in life you do everything you can to avoid pain, and this book was telling me to face it. So I immersed myself in it... I really let myself feel it. And the only thing you can really do is endure it...and then it does start to get less and less." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I did some research on the internet to try and find out how other people cope with it, and that helped me a bit... I also read a good book I got from my Mum. It's called good hope, sudden death, or something like that. It's about miscarriage, and grief, and parenting...that sort of thing. It has lots of different questions you can ask yourself. And the one I'm having trouble with at the moment asks, 'when do you know that your grieving is over?' And I'm stuck on this one...because it will probably never be over." (Stephanie/ Stillbirth, 39 weeks/ Interview 1)

"I've been reading through all my books and stuff about loss, and how to cope, and all the different stages and emotions you go through. So I've been going through my own process." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Many women also shared their ways of working through their grief, and how important it was for them to enable grief expression. Some mothers took comfort in keeping a journal or writing letters to their baby as a way of expressing their heartfelt feelings and working through their grief.

"I write a lot in my journal. It's a good way of getting the thoughts out of my head. Stops them going around constantly. And I'm keeping a blog. Every month on his anniversary I write a blog, and share it on Facebook. I've had a lot of wonderful emails in response to that...I'm finding its helping others who read it and it's also quite therapeutic for myself to write it." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I've tried to keep a diary of all the thoughts I have. It helps me to get them down. Work through my grief. Not reasons for him dying, but trying to make sense of what happened. And trying to find how this whole experience can benefit me...I want to find a way where I can integrate him into my life in a way that I can be happy when I think about him, that he was alive. That he's a gift. That's the place I want to get to." (Stephanie/ Stillbirth, 39 weeks/ Interview 1)

In addition to journal entries, several women chose to release their emotion through paintings, drawings, and other forms of visual art.

"I also started a visual art journal, which was like an outpouring of emotion into art. And that I found very helpful." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I wrote her a letter...and I've been making a little mosaic for her in the garden..." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Adjustment, not recovery. Over time, the women reported that their experience of grief slowly became less intense. The women progressed from being consumed by grief, and crying every day, to learning to live with their loss and adapt to life without their child. Many women spoke candidly about their 'grief journey', depicting grief as a continual process of adjustment and transformation. Emily described her grief experience as follows:

"Initially, I felt so bad that I thought I was going to feel that way forever. I felt like my whole life was ruined. I thought I'd never be able to think about or talk about anything else. But I reached a point at about 8 weeks where I suddenly realised that I was going to survive it, that I would be ok. I still cry every day, and I still think about Noah constantly...but my partner and I can laugh now, we can go out and have fun. It's just not sad all the time." (Stillbirth, 40 weeks/ Interview 2).

Emily's grief and pain continued to heal with the passage of time, reducing in intensity.

"As time passes it does get easier. The pain is still very much intense and deep...but compared to those first few months, where everything around me seemed painful, even the air that surrounded me...it was such intense pain. But now I'm getting back into normal life again." (Stillbirth, 40 weeks/ Interview 2)

Although reducing in intensity, the women were quick to point out that by no means did they feel they were "over" their grief, or that their grief was "resolved".

"I feel like I've compartmentalised my grief...but it's in no way resolved. I still miss her dearly." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"It has gotten easier, but I don't think it will ever be over. The bad days are still just as bad. Just not as long, and not as frequent. Like maybe I cry for an hour instead of the whole day..." (Stephanie/ Stillbirth, 39 weeks/ Interview 2)

"It's been a very prolonged thing really. I think I'm now at the stage where the shock is starting to wear off, but now I'm dealing with all the rest" (Amanda/ Stillbirth, 26 weeks/ Interview 2)

Women likened their grief experiences to "waves of emotion" (Stephanie/Stillbirth, 39 weeks/ Interview 2), "going up and down" (Phoebe/ Stillbirth, 40 weeks/ Interview 2), or being "on an emotional roller coaster" (Eveline/ Stillbirth, 21 weeks/ Interview 2).

"I have my good days and bad days still...more good days now...but it still creeps up on me." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"Some days I can smile, laugh about it even, other days I just collapse in a heap." (Emily/ Stillbirth, 40 weeks/ Interview 2)

"It does get easier, but it will never go away. I will never forget him. I'll move on with my life yes...but I'll never get over it. He's part of me now...he was my son." (Stephanie/ Stillbirth, 39 weeks/ Interview 2)

The continuity of grief was particularly evident during women's accounts of significant dates or anniversaries in association with their baby's death. It was clear that certain days of the year (e.g., the anniversary of the birth/death, the baby's due date, Mother's Day, Christmas, etc.) were especially difficult for the women. For example, Grace described how the anniversary of her daughter's death was a very emotional and surreal experience:

"We went to Charlotte's memorial at the cemetery and I was just standing there seven months pregnant...it was very surreal. Charlotte seemed like the be all and end all of my life...and here I was expecting to deliver again so soon...there were a lot of mixed emotions." (Stillbirth, 41 weeks/ Interview 3)

Similarly, on her baby's due date Jessica recalled:

"I just didn't want to get out of bed, I was so sad. My husband wasn't home so luckily I had my friend over to keep me company and drag me out." (Stillbirth, 20 weeks/ Interview 3)

For others, certain dates or days of the week were particularly challenging, especially in the first few months following loss. Ruth described how Monday's, Tuesday's and Wednesdays each week were the hardest:

"Because Monday morning was the last time I felt him move, Tuesday night around 11pm was when we found out that there was no heartbeat, and Wednesday morning he was born." (Stillbirth, 31 weeks/ Interview 1)

Although these immediate anniversary reactions appeared to dissipate over time, anniversary reactions on special dates such as Mother's day and the anniversary of the baby's death were still present for most women at follow-up (twelve to eighteen months).

## An Undesirable and Rejecting Self

The experience of pregnancy loss resulted in a myriad of unwanted emotions that the women perceived as negative. These included anger, guilt, failure, shame, self-blame, and jealousy, and the women outwardly expressed their underlying resentment for feeling the way they did.

Why me? It's not fair! Following an initial state of shock, sadness and yearning, all of the women expressed a profound sense of anger in response to their pregnancy loss. This anger was often directed at themselves, their friends, service providers, God, and other pregnant women. Indeed, the source of the anger depended on each woman's personal

experience of loss as well as their interpretation of that experience. For example, in instances where women believed the pregnancy loss could have been prevented, there was a lot of anger at service providers in regards to unsatisfactory medical care and follow up. Olivia remarked:

"They shouldn't have sent me home...they told me what I was experiencing was normal, without really even checking me out." (Olivia/ Two Miscarriages, 12 and 8 weeks/ Interview 1)

Audrey also vented her anger and frustration:

"I have so much anger at the Doctor that ignored me..." (Miscarriage, 15 weeks/ Interview 1)

For others, anger was an overt reflection of an underlying sense of hurt and injustice. Comments such as "Why me?" (Emily, Ruth), "It's not fair" (Jessica) and "I feel so ripped off" (Eveline) were prevalent, as were remarks directed at other pregnant women perceived to be doing the wrong thing. For example Eveline described her intense anger at seeing heavily pregnant women smoking:

"It's despicable. I just want to hit them with something! ...they're abusing that right and privilege that they have. It's insulting is what it is." (Stillbirth, 21 weeks/ Interview 1)

Jessica described similar frustrations:

"I did all the right things and really wanted this baby. I mean, I didn't drink, I don't smoke, I don't do drugs...and they fall pregnant just to get the Baby Bonus." (Stillbirth, 21 weeks/ Interview 1)

Grace's anger and sense of injustice was particularly evident:

"You know there's especially resentment when you are out and see young mothers, who are obviously of low socioeconomic status, they're either yelling at their kids, or they're smoking whilst they're pregnant. I get quite angry when I see that. Cos I think well I've done everything conceivable to look after this baby – I've eaten all the right foods, didn't drink, don't smoke, taken vitamin supplements, built up the family home...everything possible to give her a safe and loving environment. And then you see people like this...who really don't deserve the privilege...and they can just get pregnant and have babies so easily." (Stillbirth, 41 weeks/ Interview 1)

For others, anger was accompanied by an underlying sense of resentment. Most women found it difficult being confronted by other pregnant women or women with babies, as these women were a constant reminder of what they had lost.

"And they seem to be everywhere, everywhere you look. I see women walking their babies in prams and I hate them. And TV shows to do with babies and losses...it's like you're constantly reminded." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

Grace described how it was difficult for her to watch baby commercials without becoming teary:

"One minute I'm laughing at a TV show, the next minute a Huggies commercial comes on and I'm bawling my eyes out." (Stillbirth, 41 weeks/ Interview 1)

Many women spoke of their discomfort and sadness at being around other women and children, feeling as though they had to put on a brave face to the world even though they were hurting so deeply inside.

"My friend had her baby boy a few days after I lost, and that was really hard. I kept a brave face when I saw him, but as soon as I left and walked back to the car I started crying. Even though I was happy for her, I was sad for myself." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

"It's been hard for me because my sister just had her baby 3 weeks ago, and my friend also just had her baby, both boys, and we were all close together...so it makes me sad when I think that Max could have been best friends with his little cousin and my friends son...it's really hard because of course I'm happy for them but part of me is also thinking well when is it going to go right for me?" (Rachael/ Stillbirth, 21 weeks/ Interview 2)

Consequently, many women resented other women's happiness and ability to fulfil the dream they themselves so desperately wanted.

"I hate it when you see these pregnant women and others are touching her belly excited all around her asking how long and carrying on and such. I want to say...you can lose that baby you know! Stop being so happy! And it's the same with my neighbour...the girl upstairs has a baby about two months older than my son, when I hear it I feel like f\*\$k everyone with their f\*\$ken healthy babies! They all get to take their babies home, and I got to take away nothing!"

(Emily/ Stillbirth, 40 weeks/ Interview 2)

"You know how Facebook is really good for sharing and stuff, well the difficult thing about it is constantly seeing photos of everyone else's kids, laughing and giggling and all that. That's hard. It's just in your face all the time. I want to be happy for them but I honestly don't want to see it." (Phoebe/ Stillbirth, 40 weeks/ Interview 1)

Being confronted by women who complained about the challenges of motherhood appeared to foster feelings of anger and resentment, as Amanda conveyed:

"I hear her complaining, oh I'm up all night with the baby...she keeps me awake all night, I'm so tired...I don't want to hear it. The complaining really gets to me. I keep thinking, you should be so grateful that you've got one. I wish I could be up all night with my baby, I'm not sleeping anyway." (Stillbirth, 26 weeks/ Interview 1)

Rachael described a similar experience:

"There's this one lady at work who said "I just want this out of me!" And I just felt like saying well no you don't, cos it would be dead! I get the urge to say things like that but I hold back. But seriously, I wish they'd stop complaining and just appreciate it. I want to say well you're going to have a healthy baby at the end of it and I didn't, so shut the hell up!" (Stillbirth, 21 weeks/ Interview 2)

It's my fault. Internal projections of anger appeared to reflect underlying feelings of guilt and self-blame. Overall, the women described an overwhelming sense of responsibility for their loss, and comments such as "I must have done something wrong" were prevalent. The women believed that they inadvertently played a role in their baby's death and blamed themselves. Some women attributed their loss to something they did or ate:

```
"It could have been that piece of cheese I ate."
(Maria/ Miscarriage, 8 weeks/ Interview 1)
```

"I should have stayed on the couch and not rushed around so much." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

```
"I was too stressed at work."
(Olivia/ Two Miscarriages, 18 and 12 weeks/ Interview 1)
```

"I shouldn't have bent my knees that way... I got out of bed wrong and must have squeezed on the waters." (Susan/Stillbirth, 20 weeks/Interview 1)

Although they questioned such conclusions, the women were not satisfied with the explanation that they were just unlucky. They strongly believed that they played a role in their baby's death. This rationalisation persisted even among women who had been given a probable cause, such as medical reports indicating that there was a problem with the placenta or the umbilical cord.

"Well the tests said that the cord was hyper coiled. There was a blood clot, so he couldn't get enough oxygen. And I realised afterwards that shortly before I lost I had gone to bed a different way, I had slept on the other side because it wasn't comfortable...and in the end there was something wrong with the cord. All this turning may have caused it to hyper coil." (Stephanie/Stillbirth, 39 weeks/Interview 1)

Such feelings of guilt and self-blame were particularly heightened among women who felt that they should have known better, or could have prevented the loss if they had acted differently.

"It's my fault I lost this one... I lost before and should have noticed the warning signs...if I had gone to the hospital earlier to check then maybe they would have been able to stop me from losing the baby, but I didn't." (Olivia/ Two Miscarriages, 18 and 12 weeks/ Interview 1)

"Maybe if I hadn't of walked around so much, and just remained on bed rest, she could have possibly survived." (Eveline/ Stillbirth, 21 weeks/ Interview 1)

"I feel like it's my fault. I don't know how to explain it, it's hard. But I feel like I was his Mum, he was inside of me, I could have done something to prevent this. I mean I know better, but a part of me will always blame myself for this on some level." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

Stephanie reported how she had been conscious of various "negative thoughts" during her pregnancy that something would go wrong with her baby, particularly fears that he would be born handicapped. She felt that she might have caused her son's death because deep inside she had entertained the thought that she didn't want to raise a handicapped child.

"I wasn't quite sure whether or not I might have caused it by thinking all of those things I had been...like a self-fulfilling prophecy sort of thing...It's like I tried so

hard to prevent him from being handicapped, because I didn't want that, and maybe he needed to be handicapped to fulfil his life's purpose. And maybe he was handicapped and I prevented him from living" (Stillbirth, 39 weeks/ Interview 1)

Adding to this heightened sense of guilt and personal responsibility was awareness post-loss that one of the warning signs to look out for is a lack of foetal movement. Consequently, these women felt an enormous sense of guilt over not being mindful about this.

"One of the first things they asked me in hospital was when was the last time you felt him move? I couldn't remember exactly, and I felt so guilty." (Alyssa/ Stillbirth, 38 weeks/ Interview 1)

"I felt a bit of guilt like I'd failed as a mother. That I should have known something was wrong. Cos I hadn't noticed that she hadn't moved in a while..." (Grace/ Stillbirth, 41 weeks/ Interview 1)

For Phoebe, this sense of guilt led to anger that she wasn't informed or warned about such risks. Phoebe stated:

"I think there needs to be more awareness of the things that could go wrong. Even just one pamphlet that details what your foetal movements should be like. And maybe a foetal movement chart or something that you could stick on your fridge. I mean, they give you all these pamphlets on birthing classes, how to breastfeed, cot death, etcetera ...but not one that says you should monitor your foetal movements!" (Stillbirth, 40 weeks/ Interview 1)

I've failed as a mother. Several women reported feeling as though they had failed as a mother, and described feeling great shame as a result of their loss. What should have been so easy to achieve – and indeed appears so easy for other pregnant women, was not. In particular, the women felt that they had failed as a mother and/or that their body had failed them.

"All I've ever wanted is to be a mother...and I can't even do that right!" (Leanne/ Miscarriage, 18 weeks/ Interview 1)

"Sometimes I have my little down moment and think why don't you [husband] go off and find a woman who can have a baby? Go find someone whose insides work!" (Rachael/ Stillbirth, 21 weeks/ Interview 2)

The perceived disappointment of the women's partner's and relatives appeared to exacerbate the women's feelings of failure and shame. Ruth conveyed her sadness for her husband and their extended family, as their future aspirations as parent and grandparents were taken away.

"My husband is a real family man, and this child, being a boy, would have been the sixth to carry the name...and his parents were going to be grandparents for the first time...so that was really hard...And then when my husbands brother found out that they were pregnant and phoned his parents from here to say that they were going to be grandparents...that was very hard for me to hear. Because they are already grandparents but because he is not here, they can't see him, they don't see it that way. I feel guilty for that." (Stillbirth, 31 weeks/ Interview 2)

The effect that pregnancy loss has on the mother's perception as a 'failed mother' is further evident in women's accounts of exchanges with strangers. When faced with the question, "Do you have any children?", many women struggled to answer it. To answer "yes" requires the mother to elaborate in detail on her loss, a revelation she is not entirely comfortable with disclosing to strangers. To do so also tends to result in an awkward encounter, whereby the stranger is unsure how to respond. However, to reply "no" results in the mother feeling a strong sense of guilt at denying their deceased child. As Ruth explained:

"What I find especially difficult is when people see me pregnant now and ask me if this is my first baby. I don't want to say yes, because I don't want to explain myself. Especially to strangers. But when I say no, I feel so guilty, like he doesn't exist. Because I did have a son, and we lost him. But you just can't tell people that. People don't see you as a mother." (Stillbirth, 31 weeks/ Interview 3)

Audrey described a similar discomfort upon completion of a census form (Australian collation of population statistics), whereby she was asked to provide details of her number of children.

"I had to fill out the census form and it asked me how many children I had. I didn't know how to answer it. There needs to be a rewording of the question or something asking about living and deceased children. I mean, its not recognising I'm a mother." (Audrey/ Miscarriage, 15 weeks/ Interview 2)

### Maintaining Connections with the Baby

The expression of continuing bonds with the deceased baby was a common occurrence among the bereaved women. This occurred on both a conscious and subconscious level, and took a variety of forms. Maintaining connections with their baby appeared to serve a positive function, in that it seemed to facilitate women's adjustment and acceptance of the loss.

Thinking about the baby. Many women described how they frequently thought about their baby, and contemplated about what their life would be like if their baby were here. They fantasied about what personality their baby might have, and what behavioural milestones their baby would have achieved at this particular point of their lives. For several women, this reflection would occur on an almost daily basis, even up to a year post-loss and beyond.

"There still isn't a day that has gone by where I don't think about him. He still pops into my head, he's always there. And often I think about how different things would have been had my son still been here. He'd be walking now." (Susan, Stillbirth, 20 weeks. Interview 3)

"I still wake up every morning and think about her. What she would be like if she were here with us now, probably crawling. I still wake up every morning and look at the picture of her in our bedroom...I say good morning to her in my head and smile." (Jenny/ Stillbirth, 21 weeks/ Interview 2)

"losing my daughter [stillbirth]...I still carry that loss around with me, even though it's been nearly five years since she died. I still think about her every day." (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 2)

Stephanie spoke about the importance of setting aside some time each day to pause and reflect on her son. She found peace in ensuring a continued connection with her son.

"I like to sit outside in the garden and watch the butterflies and think of him...and in the evening I light a special candle for him. Even though he's dead...it's still me that keeps him alive. When I see something beautiful...a flower, the warm sunshine...I think of him. Anywhere that is beautiful, I'm reminded of him. And having that connection just gives me lots of peace." (Stephanie/ Stillbirth, 39 weeks/ Interview 2)

**Integrating the baby and memorialisation.** In addition to spending time thinking about their baby, the women spoke of their conscious efforts to integrate the baby into their life in meaningful ways. Several women purchased personalised jewellery - (e.g., a necklace or bracelet with the child's initials), or other memorabilia - (e.g., a butterfly fridge magnet, a novelty fluttering butterfly in a jar, a heart, wristbands, an angel for the Christmas tree) as a way of keeping their child's memory alive and ensuring their presence as part of the family was acknowledged.

"We got given a heart each at the service that we like to carry around... I actually lost mine at one stage and my husband said to me, here, hold mine, I'll go and find yours...and we also bought a special urn with Max's ashes in it. We laugh actually because sometimes we bring Max's ashes with us and make a joke that we're taking him for a walk!" (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"He was cremated in the butterfly garden at King Edward, and there's our butterfly [points to novelty butterfly in a jar on the mantelpiece that flutters]...and I'm wearing a special gold butterfly necklace with his initials on it that my husband bought for me...and there's our little photo book on the coffee table that I made for him on the internet...we like to look through that and remember him when we want to." (Ruth/Stillbirth, 31 weeks/Interview 1)

"I made this special wristband for everyone, to remind us of William. My husband has one too, and so does my daughter. William also had one but he was cremated with it." (Stephanie/Stillbirth, 39 weeks/Interview 2)

Often, mementoes were shared with family members, especially children, who were shown photographs and encouraged to talk about their deceased sibling.

"We've let them see all the pictures of Hunter and tried to explain that he's in heaven and whatever star you see in the sky, that's him." (Susan/ Stillbirth, 20 weeks/ Interview 2)

At times this was difficult for the women, but they felt it was necessary to explain to their children who were distraught and confused.

"My youngest used to come up to my stomach and say "bubba", I had to teach her to say "no bubba, bubba gone", and that was hard. Of course they are too young to understand but it was just heartbreaking for me when my three-year-old came up with a picture she drew and said "this is baby dead". I just burst in to tears." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

Chapter Four: Experiences of Bereavement 115

In addition to keeping and sharing mementoes of the deceased baby, the bereaved women reported holding memorials and vigils to honour their baby in the long term. For example, on significant dates such as anniversaries of their death, the bereaved women described lighting candles, buying flowers, releasing balloons, and engaging in other special activities to honour their baby's memory. This primarily occurred among women who lost their child in the later stages of pregnancy (i.e. stillbirth). For example, Jenny reported buying roses in memory of her daughter 'Rose' on her anniversary, while Ruth released balloons with her husband at a private memorial ceremony by the beach. Eveline planted a cherry blossom that flowered only during the month of her daughter's anniversary, and scattered her ashes underneath it. Instead of buying a gift on her baby's birthday, Grace chose to donate to a community organisation every year on the anniversary as a way of honouring her child. Emily entered a fundraising 'fun run' and was able to raise three thousand dollars for the organisation in her son's honour. At Christmas time, Susan helped her children put up a special tree ornament dedicated to her baby. Many of the women also reported visiting the cemetery often, especially on anniversaries or special occasions such as Mother's Day.

These conscious efforts to honour and remember their baby were avenues in which the women were able to maintain ongoing connections with their baby. The women wished to facilitate ongoing connections with their baby, and were adamant that these bonds would never be broken. As Ruth stated:

"He will always be here. Maybe not in our arms, but in our hearts." (Stillbirth, 31 weeks/Interview 2)

#### A Transformed Self

Several women described their experience of pregnancy loss as a catalyst, and spoke of an altered sense of self. These conceptualisations of change were interpreted both positively and negatively, in terms of perceived gains (i.e., acceptance and personal growth) and losses (i.e., loss of naivety and loss of control).

Acceptance and spiritual growth. Many women spoke about their struggle in coming to terms with and accepting their loss. For some, understanding or presuming the cause of death facilitated acceptance of the loss, especially when the death was attributed to medical or natural causes.

"I was lucky actually, because I got the answers as to why we lost her, whereas a lot of people never get answers...but for me they're pretty certain it was my fibroids...and I'm going to have an operation to get rid of them." (Eveline/ Stillbirth, 21 weeks/ Interview 1)

"I'm able to think about it from a scientific point of view, I mean, I'm a biologist and I've studied mutations and stuff like that...so I do appreciate nature's hand in taking care of it for me...as that's most likely what it was. She may have been born with anomalies otherwise, and I don't know how I would have coped had my baby been abnormal." (Maria/ Miscarriage, 7 weeks/ Interview 1)

"I've done a lot of reading on the research about bacterial infections...there's a whole lot about bacteria being responsible for a large amount of unexplained stillbirths...so that's helped to give me some level of understanding, although they still don't know why it occurs." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Acceptance often ensued after many months of contemplation, when several women professed that their loss must have "happened for a reason", medical or otherwise. This rationalisation was often influenced by spiritual or religious beliefs, and it was these beliefs that assisted them in coping with their loss.

"I tell myself it just wasn't meant to be. I think that maybe it happened for a reason, that maybe I wasn't meant to be a single mother and God didn't want me to suffer because it would have been so hard raising him on my own. And I also think that maybe something was wrong with him and God didn't want him to suffer." (Chloe/ Stillbirth, 39 weeks/ Interview 2)

Spiritual beliefs not only assisted women to accept what had happened (e.g., the idea that the death was part of a bigger 'plan'), but it also brought them solace.

"A strange thing happened actually. A friend of mine is actually seven weeks pregnant now, and that's exactly how long ago he was taken away. So the same time he was taken away a new baby was made. So we say it happened for a reason." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

Thus, rather than believing the loss was just a random event, women believed that the loss had a purpose, or "happened for a reason", and this belief brought them comfort.

Furthermore, this line of reasoning was considered the better alternative to dying at a later stage from further illness, and the women were able to readily identify factors that would have made the experience all that much worse.

"I keep telling myself that it's better that it happened now, than if he was with us for two years and then he died, or that he was sick. Or if he was born and had to have many operations all his life, or died shortly after birth. This way he didn't suffer, so I'm grateful in a way that it happened now and not later." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

Other women made no attempt to ascribe meaning to their loss, nor were they able to source any comfort from attributing the death to a spiritual being. On the contrary, the prospect of accepting that the death "must have happened for a reason" seemed like a ridiculous insinuation. For example, Emily described:

"I hate it when people tell me it happened for a reason. I mean, what reason could there possibly be for taking away my beautiful baby boy?! Cos how can a child be better off dead than in their loving mothers arms? And who am I to say that the meaning of life is related to the length of it?" (Stillbirth, 40 weeks/ Interview 1)

Similarly, Grace and Eveline commented:

"Sometimes things just happen for no reason, and you just need to accept it." (Grace/ Stillbirth, 41 weeks/ Interview 1)

"There is no reason. What reason could there possibly be for losing her? We lost her because of medical problems, and that's that. For me there is no greater reason." (Eveline/ Stillbirth, 21 weeks/ Interview 1)

In the quest to find meaning and make sense of their loss, many women reported asking themselves the question "Why me?" in response to their loss. This question appeared to create much turmoil. Ruth stated:

"I kept asking why us? Because I'm only 24, I'm still so young. All our scans were good, there were no problems." (Stillbirth, 31 weeks/ Interview 1)

Paige described how she was able to attain a greater sense of acceptance once she changed the way this question was interpreted.

"I was driving myself crazy asking 'why me?'. Then a friend told me this story...and I came to the realisation, well why not me? What makes me so special? Yeah the statistics are there...1 in 4 or whatever, and I'm the unlucky one. But someone had to be." (Paige/ Miscarriage, 7 weeks/ Interview 1)

Emily reported a similar shift in the way she interpreted and made sense of her loss in order to reach a state of acceptance.

"When Noah died I really went through a lot of this spiritual stuff, in a way that I had never experienced before. When faced with death, you think a lot about the meaning of life, and the meaning of death...it just comes naturally. To me, the way to get through death was to focus on love, love towards other people. It's been my way of making sense of what happened. That whilst we are alive we should be focused on caring for other people and showing them love. Life is short." (Stillbirth, 40 weeks/ Interview 2)

Empathy and gratitude. Although most women struggled to find anything positive from their loss, some women spoke about the feelings of empathy and appreciation they had experienced as a result of their pregnancy loss. For Emily and Stephanie, the experience was one of positive growth and self-awareness. The experience made them more empathic, and increased their appreciation for the smaller things in life.

"It's been such a transformational experience, losing a child. I feel like I've become a lot less self-absorbed and I try to be more compassionate to others now who go through hardship. I feel like I have more empathy for them. And you can't really feel that empathy until you've been through something like this. Before I lost, I had this mindset that the most important thing in life was to be happy. But it's not about that. The sad times are just as important too and it's important to go through them, to go through the darkness. It helps you become a more real person." (Emily/ Stillbirth, 40 weeks/ Interview 2)

"I appreciate the small things now that Jack died. I think what happened was a way of telling me to slow down and pay attention to the smaller things. It made me realise what I do have. What happened to Jack, I would have never wanted it that way. But what it has done for me has been really positive. I think I never had much empathy before, I think I could never really understand what people were going through. But losing Jack, it's made me have more empathy...and it's been a big learning curve for me." (Stephanie/ Stillbirth, 39 weeks/ Interview 2)

Eveline also spoke about reprioritising her life, and that now she wasn't so worried about the small trivial things that didn't matter.

"It's made me realise how lots of things we worry about are right down here..." [gestures to suggest the bottom end of the scale]. (Stillbirth, 21 weeks/ Interview 2)

Similarly, Jenny conveyed:

"I've learnt not to take having a baby for granted. I appreciate every moment now. Before I lost my daughter I was studying and stressed, putting a lot of pressure on myself. But now I've postponed that so I can spend more time at home with my son so I don't miss a moment. When he's a bit older I can always take up studying again. It's made me realise what's important." (Stillbirth, 21 weeks/ Interview 2)

Vulnerability and loss of control. For many women, the experience of pregnancy loss brought awareness that not everything in life can be controlled.

"I've learnt that you can't be in control all the time. And that's an important lesson. I like being in control. My whole life I've taken control of what I've wanted to do and how I've wanted to do it. Then I lose Charlotte. It kind of helped put things into perspective a bit. That things don't always run smoothly and you can't have control over everything in your life." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"I used to think you fall pregnant...you get a baby at the end of it. That's just what happens." (Audrey/ Miscarriage, 15 weeks/ Interview 1)

"I had everything planned...get married, go travelling, steady job, build the house, and then have a baby." (Grace/ Stillbirth, 41 weeks/ Interview 1)

This insight was particularly apparent among women who were conscious of their age. As Olivia stated:

"The difficulty is I'm not getting any younger. I'm going to be 36 this year, and as I get older...my chances of having a baby are less and less. And I really want another sister or brother for Sienna...but I'm really worried that it's not going to happen." (Miscarriage, 12 weeks/ Interview 2)

The sense of helplessness and vulnerability following the loss of their daughters transpired into fear for their other children as well for Jenny and Susan. The women became very protective and fearful over their loved ones because they now "know" how easy it is to lose someone close to them.

"I realise in myself that I've become very protective now as a mother. I'm very protective now over my son. I want to make sure that he's ok, and always worry when he's not with me that something could go wrong. I'll probably always feel like that now because of what happened. You realise that life can be taken away so easily." (Jenny/ Stillbirth, 21 weeks/ Interview 3)

"I've become extra clingy with her, I'm constantly checking up on her...it wasn't like that with the others. But now that you know life can be taken away so easily, you don't take anything for granted. And I think that's why I've become extra panicky about everything." (Susan/ Stillbirth, 20 weeks/ Interview 3)

This acquired sense of vulnerability made women increasingly anxious, especially during the subsequent pregnancy. This anxiety in the subsequent pregnancy is discussed in Chapter Six.

### Summary

The findings in this chapter reveal how pregnancy loss results in a unique and complex bereavement experience. The loss is a painful and unexpected reality, whereby women experience marked shock, disbelief and despair as their future hopes and dreams are suddenly shattered. The loss is accompanied by intense and persistent grief, with anger, guilt, failure, shame, self-blame, and anxiety as significant components of the bereavement experience. In addition, the bereaved women questioned their identity as a childbearing woman and mother and experienced marked vulnerability.

The bereavement experience was described as cyclical rather than linear (i.e., "an emotional rollercoaster"), and enduring rather than finite (i.e., "it never goes away"). The women spoke of the process of integrating and adapting to their loss, rather than a resolution or recovery from it. Furthermore, they described in detail their continued

Chapter Four: Experiences of Bereavement 121

attachment to their deceased baby, and spoke of the ways in which they ensured these connections were maintained. The experience led to an eventual acceptance of their baby's death, and perceived positive growth.

In the next chapter, women's experiences of professional and interpersonal support are examined, in order to determine what women perceive as helpful and unhelpful following their loss.

Chapter Four: Experiences of Bereavement 122

Chapter Five: Experiences of Support 123

# Chapter 5: Understanding the Nature of Positive and Negative Support Following **Pregnancy Loss**

Chapter five explores women's experiences of support following pregnancy loss. The analysis yielded five superordinate themes and twenty-two subthemes within this domain. These emergent themes are presented in table 5.1. The superordinate themes include: From Diagnosis to Birth: The Need for Sensitive and Empathic Care: During and After Labour and Birth: The Significance of Midwives; After-Care: The Need for Improved and Continued Support; The Significance of Familial Support; Advice for Peers: How To Support My Grief; and Seeking A Shared Grieving Experience.

The findings indicate that women's perceptions of interpersonal and professional support impacted their grieving experience in both negative and positive ways. Women felt respected and supported when others acknowledged their grief and conveyed empathy and sensitivity towards them. In addition, relationships with significant others were strengthened when women felt able to openly express their grief with others who shared a common understanding. In contrast, support was perceived as inadequate when women's grief was minimised or ignored, or when others responded insensitively to their loss. This often led to feelings of anger and hurt, and experiences of isolation and abandonment.

## **Emergent Themes**

Table 5.1 Structure of Emergent Themes

Superordinate Themes and Subthemes Pa	articipants Endorsing Theme (n)
From Diagnosis to Birth: The Need for Sensitive and Empath:	ic Care
Don't ignore my concerns	6
Don't prolong my distress	5
Help me to prepare for labour and birth	6
Convey sensitivity and personal care	12
Gently encourage me to see and hold my baby	7
Providing mementoes	6
After-Care: The Need for Improved and Continued Support	
Provide me with adequate aftercare	9
Don't blame me for my baby's death	4
It's not a medical problem It's a baby!	5
Provide me with personalised care	6
Offer me professional support	6
The Significance of Familial Support	
Maternal support: I needed my Mum and my sister	8
The significant other: Losing our baby strengthened o	ur bond 10
Advice for Others: How To Support My Grief	
Acknowledge my loss and don't avoid me	6
Don't minimise my grief	6
Don't mask my grief with unhelpful comments	10
Just listen and let me talk	5
Don't offer advice unless you've been there	4
Show you care, but don't treat me differently	5
Seeking A Shared Grieving Experience	
Grieving together as a couple	9
Accessing other women who have lost a baby	5

# From Diagnosis to Birth: The Need for Sensitive and Empathic Care

Women's satisfaction with service provision from diagnosis to birth was strongly linked to their experiences of communicating and interacting with health professionals providing this service. This included their perceptions of the attitudes, behaviours, and overall helpfulness of the staff involved with their diagnosis and treatment prior to birth.

Don't ignore my concerns. One predictor of whether women's perceptions of support was how the healthcare system responded to women's initial fears and concerns that something was amiss with their pregnancy. This included general practitioners, as well as emergency department personnel attending to the women. For several women, anger and resentment was clearly prevalent towards their respective general practitioner's, whom they felt ignored the warning signs prior to their loss. For example, Chloe stated that she felt that her doctor disregarded her concerns by sending her home without conducting a proper check-up. She felt that if perhaps her doctor had responded differently, her baby might have been saved.

"I would not go back to the same Doctor. I feel neglected. I still feel he shouldn't have sent me home. It made me very angry...I think about how things could have maybe been different if the doctor hadn't of sent me home...And when I spoke to my other Doctor at the hospital he said to me that if I was his patient, he would have treated me differently...but there is no point getting angry, what's done is done." (Stillbirth, 39 weeks/ Interview 1)

Susan also described her experience of feeling mistreated, she felt ignored by several doctors who inferred that the pain and sickness she was experiencing was just morning sickness. Having been through two previous pregnancies, Susan was certain that the symptoms she was presenting with weren't 'normal', and she conveyed this to several practitioners who all appeared to dismiss her concerns.

"None of the GPs would treat me because I was pregnant, they kept sending me home and saying 'you're just pregnant, you're just sick from the pregnancy'...basically telling me to suck it up. It wasn't until the fifth Doctor I saw

who listened to me and checked me thoroughly, that's when she said 'Oh my goodness you have Pneumonia, we better get you on medication!' Before that no one took me seriously, they all kept saying it was just morning sickness. And although they tell me otherwise, I'm convinced that getting sick had something to do with losing the baby. You know, you hear all these things on the news about infections and stuff and I was feeling completely rotten and went to numerous Doctors to be treated because I was concerned. I knew it was more than a cold. I know my body, I'd had two pregnancies before and I knew it wasn't just nausea. But you know, I can't prove that's what caused it and I'm not looking to blame anyone, but I just wish people would take some responsibility and say yes, it is likely that because you were sick, your immune system was very low, and your membranes were attacked. But no one wants be honest with me. They're all too busy trying to cover their own backsides." (Stillbirth, 20 weeks/ Interview 1)

This sense of feeling neglected was also reported within the hospital setting. Concerned for their babies' wellbeing, several women presented at the emergency department complaining of acute physical symptoms, only to be sent home and told there was nothing wrong. This angered a number of women, who felt they were dismissed without a thorough examination. As Jenny stated:

"I'm very angry because I don't feel that they did enough...they weren't very thorough. They should have looked further into what was actually going on." (Stillbirth, 21 weeks/ Interview 1)

"People who work in emergency should be a bit more understanding about what's going on. I mean, I had a huge fever, I couldn't stand, and I was four and a half months pregnant and she sends me home saying I've probably got a virus. They didn't even bother to check me properly...and I know there's probably not enough space or beds or whatever, but had my husband not been home when I lost and passed out, who knows what might have happened to me." (Olivia/ Miscarriage, 18 and 12 weeks/ Interview 1)

Audrey's anger and frustration at service provision was apparent when she was ignored not once, but twice, by service providers who believed her concerns were unjustified.

"I phoned up the hospital and told the lady I was having Braxton Hicks. And her tone of voice...she said 'Do you know that this is an emergency line? It's far too early for you to be having Braxton Hicks'. So she was pretty much implying that I was making a big deal over nothing, that I was wasting her time. She didn't want to talk to me at all. And then a few days later he was dead." (Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 1)

Audrey recalled how her anger increased following a telephone conversation with her obstetrician to reaffirm her concerns, only to be told again that she was over-reacting.

"After all that happened I called the doctor to tell him how anxious I was feeling and he also said to me, 'Well look, it's not fair to every other pregnant woman out there if I give you an ultrasound now. Just wait until your appointment next week'. I was gobsmacked. How could he say that to me? And I was right, a few days later I came to the hospital and he was dead..."

Audrey expressed how the manner in which she was treated negatively impacted upon her bereavement experience, by escalating her anger. She felt that there was no excuse for such treatment, and that the medical system had completely failed her.

"How you are treated in hospital definitely has an effect on how you cope with your loss. I have so much anger at the Doctor that ignored me. Everyone I've told has pushed me to make a complaint, I have the forms and everything but I don't like to make a fuss. I didn't want to drag him though the mud. Instead, I had a meeting with him personally, and he was very ashamed. He couldn't even talk, or give me answers as to why he ignored my requests for an ultrasound. And I understand the whole financial pressure, you know the Medicare system and all, but with my history [previous loss] he [the doctor] should have listened to me. There is no excuse."

**Don't prolong my distress**. Perceived insensitivity by medical staff involved in diagnosis and treatment of the pregnancy loss also exacerbated women's distress. For example, following an anxious wait of several hours, Audrey was greatly upset when she saw her obstetrician walk past her to take a lunch break.

"I saw the obstetrician come out and walk past me to eat her lunch...that's just not acceptable."

(Miscarriage, 15 weeks/ Interview 1)

Audrey did not have a problem with her doctor taking a lunch break, but was upset by the fact was that she had been told several times that the doctor would be seeing her shortly for her ultrasound, only to be left waiting for hours.

Amanda experienced similar dissatisfaction and distress during her ultrasound scan, when her doctor conveyed that he was having difficulties with the monitoring equipment.

"He was kind of mucking about as doctors do, I wasn't quite sure actually what he was doing, I thought maybe he's out of practice? Then he said, 'I can't actually find a heartbeat, I'm just having a bit of trouble using the equipment', and then I thought well, he's in the wrong spot anyway...and then he brought in this really old scanning machine, and I thought what is that? He stuffed around a bit more and then pulled the curtain around and left the room saving he was going to find someone who could operate the machine properly." (Stillbirth, 26 weeks/ Interview 1)

The manner in which the bad news was expressed, was also perceived negatively by some women. Both Jessica and Audrey conveyed their dissatisfaction at the lack of sensitivity portrayed by their healthcare providers.

"They were looking at my scan asking us whether or not we wanted to know the sex - and all of a sudden the lady just goes 'There's no heartbeat'. No sorry for your loss or anything." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

"We need doctors that are trained in bereavement, because they were shocking. I mean, for somebody in my position who had just found out they'd lost a baby you'd expect them to be sympathetic towards you, they weren't." (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 1)

Conversely, sensitive and appropriately responsive communication was reported positively. These women experienced genuine and empathic care, whereby their healthcare providers responded to their pregnancy loss in an honest and open, sympathetic, and respectful manner.

"I know they [midwives] must deal with these sorts of losses all the time, but they were still sympathetic. They took that time with me, to talk to me. One of the midwives even told me her own story of loss, so that helped too...knowing that she had been through it and understood what it felt like." (Leanne/ Miscarriage, 18 weeks/ Interview 1)

"He [doctor] said look, I'll give you a minute...and asked me if I needed a second opinion. I didn't need one. He explained to me what happened, that I'd had a miscarriage. He sat down with me, and explained what a miscarriage was, and that it was most likely due to chromosomal abnormality or something. He told me that there was a 25% chance of this happening...he was really sympathetic and very nice. He explained everything." (Paige/ Miscarriage, 7 weeks/ Interview 1)

"She [midwife] came and stayed with me, and held my hand. There were only a few birthing suites around and she made sure I didn't see anything, she was very considerate. She stayed there with me in the room until the Doctor came and saw me, talked to me, and then he told me. He said, the news isn't good..."

(Amanda/ Stillbirth, 26 weeks/ Interview 1)

Help me to prepare for labour and birth. Once a foetal death had been confirmed, most women described sympathetic advice and assistance from attending staff as they prepared for the birth of their baby. Most reports were emphatically positive about what was to be expected during labour and recovery, with many women referring to attending midwives as "helpful" and "supportive".

"She [community midwife] arranged everything for me. It was so good to have her. She made sure I got to the hospital and that another woman [midwife] looked after me, because she had to go. She then came back later to help me deliver and in the days following she visited me a lot. I really trusted her. Without her support, I don't know how I could have done it without her."

(Stephanie/ Stillbirth, 39 weeks/ Interview 1)

"I was really blown away with the nurses [midwives]. Such personal, caring service. They really gave me all the time I needed. They actually cared. They even went out of their way to get a certain Doctor because I was so anxious." (Maria/ Miscarriage, 8 weeks/ Interview 1)

"The midwives were really fantastic. The time they spent with me before and during the delivery was really amazing. Their level of care was just amazing, I'm blown away by how wonderful they are." (Grace/ Stillbirth, 41 weeks/ Interview 1)

In some cases however, women expressed that they felt unprepared for the experience of labour and birth, and would have appreciated more information. For example, Susan reported how attending staff mistakenly assumed that she knew what to expect, as she had previously given birth to two babies. For Susan, this experience was different to her previous births, and she felt quite unprepared for the events that unfolded.

"Giving birth under those circumstances was horrible. Especially not knowing what to expect. Everyone just seemed to think I knew what was going to happen because I had two children, but I had no idea. All they said was that it was going to be painful, I was going to have to give birth, and we can offer you these drugs...and that was it." (Stillbirth, 20 weeks/ Interview 1)

Similar views were also expressed by Audrey, who felt that attending staff should have better prepared her for what to expect during her miscarriage.

"I lost an incredible amount of blood, it was just pouring out of me. They'd given me these vials to collect the blood, but didn't explain to me how much blood I was meant to be losing. So I just kept filling them up and emptying them in the toilet. Then the nurse had a go at me saying I should have told her I was losing so much blood and that I shouldn't have tipped them out! Yelling at me in front of the doctors like it was my fault! How did I know?" (Audrey/ Miscarriage, 15 weeks/ Interview 1)

Other women like Amanda felt that doctors needed to be more sensitive to the emotional experience surrounding pregnancy loss and choose their words more carefully. Amanda felt that she was quite traumatised and expected the worst, as the manner in which the information was communicated to her made her incredibly fearful.

"He [the doctor] warned me he was going to be really bruised, and I was already in that supersensitive space I just took it so literally. I remember him saying 'oh...this baby's been dead a long time, he's not in very good shape'. I was mortified. The way he said it just made me really scared about seeing him...and then he didn't actually look that bad. And I wish I had just seen him closer, but I was so worried about how bad he would look that I didn't. And that still plays on my mind to this day. You know, I think they just lose their manner." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

Convey sensitivity and personal care. Despite the traumatic nature of having to give birth to a deceased baby, women's accounts of their treatment and care in hospital during labour and birth were remarkably positive. This satisfaction with care provision was directly linked to their experiences of midwifery care. Midwives appeared to play a prominent role in assisting and supporting the mother during labour and birth, and encouraging her to spend time with her baby. The majority of women praised their midwives for the compassion and support they experienced during their time in hospital. Qualities exhibited by midwives that the women found helpful included: being emotionally responsive and supportive, handling the loss with the appropriate amount of sensitivity, recognising the impact of the loss, and providing guidance and reassurance.

"From the minute I got there, I never felt under-cared for. There's nothing they could have done better, I think they did everything possible." (Eveline/ Stillbirth, 21 weeks/ Interview 1)

"The midwives were great, we couldn't have asked for anything more. The support was there, that's one thing I can honestly say... they were brilliant. As bad as the situation was, I really felt protected and supported. They would spend half an hour talking to me if they could see I needed it, and that made it bearable. That's important, someone who understands and knows what to say."

(Amanda/ Stillbirth, 26 weeks/ Interview 1)

"I can't fault them. They were perfect. On the ward, in the birthing suite, they were amazing. They were always there for me. If I rang the bell for pain or whatever, no problems." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

Many of the women formed a special bond with their midwives, and were extremely grateful for their unwavering support. Several women remarked that they don't know how they would have coped without them.

"It was so good to have the midwife from the community midwifery. She made sure that when I got to the hospital that another midwife looked after me. And later she came back to help me deliver. And in the days that followed she came and visited me a lot. I really trusted her, without her support I don't know how I would have done this. I felt so comfortable with her, I could ask her anything." (Stephanie/ Stillbirth, 39 weeks/ Interview 1).

"She [midwife] was so encouraging...I was in so much pain and didn't have the energy to push but she said, 'Honey, I know you can do this, you're going to have to push, I'm here'. It was such a relief. I don't know if I could have done it without her." (Chloe/ Stillbirth, 39 weeks/ Interview 1)

Seemingly small actions made a significant difference to women's experiences, such as ensuring the women were kept away from crying babies on the maternity ward. Several women conveyed their appreciation that attending staff were considerate and sensitive.

"They [the midwives] were absolutely amazing, I can't fault them. They made sure they kept us away from other rooms with newborn babies." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"The nurses took her away for a little while so that I could have a shower, and then they moved me to another room away from the labour ward so I wasn't surrounded by crying babies. They were absolutely brilliant."

(Mary/ Stillbirth, 24 weeks/ Interview 1)

"They were really good. They actually put me on the cancer ward because I didn't want to be on the delivery ward." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

"She [a midwife] came and stayed with me, and held my hand. There were only a few birthing suites around and she made sure I didn't see anything, she was very considerate. And she stayed there with me in the room until the consults came and saw me, talked to me...she was wonderful." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

Having the midwives share their own personal experiences of loss and knowing what to say at the right time was also reported as helpful by the women.

"She [midwife] held my hand afterwards and told me about her own experience of miscarriage...that was really helpful. I felt like she understood what I was going through...it was really good to have her there." (Leanne/ Miscarriage, 18 weeks/ Interview 1)

"At one stage there were too many people in the room and one midwife walked in and said right! Now everyone is going to leave the room! Cos she knew we needed space. And then another midwife would be the caring one, not that they weren't all caring, they all were...it was just having the right person at the right time. It was a nice touch." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

The inclusion of partners was emphasised as well, especially the opportunity for the women's husband's/partners to stay overnight at the hospital which was greatly appreciated.

"The midwives were really good. They just had that perfect touch. Each of them just knew what to stay to make us feel better. They would always ask us if we needed anything and even when it came to staying overnight they let my husband stay. Which usually doesn't happen in hospitals." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

"They gave us a big room to ourselves, with our own bathroom. And they let my partner stay as well which was fantastic." (Emily/ Stillbirth, 40 weeks/ Interview 1)

Unfortunately, this provision wasn't the case for all hospitals. Jenny's experience reiterates the need for hospitals to provide the opportunity to allow husbands to stay, as having them present appears to be an enormous source of emotional comfort and support for the women following loss.

"The best thing about [first hospital] was that they let my husband stay the night which was great. When I got transferred to [subsequent hospital] the next day they wouldn't let him stay which was really hard. I was there all by myself, it was awful." (Stillbirth, 21 weeks/ Interview 1)

Non-supportive behaviours cited were the perceived insensitivity displayed by some nursing staff, which upset some women and contributed to their distress.

"The midwives that were the most caring were the experienced ones, especially those who had also experienced a loss. I felt with some of the younger midwives that they really didn't want to be there. It was like they were more worried that they might have to work a longer shift now rather than paying attention to what was actually going on. I know it's a job at the end of the day but I think they need to be careful how they come across. It's not very genuine. Maybe there needs to be more education or something..." (Stephanie/ Stillbirth, 39 weeks/ Interview 1)

"One of the midwives handed me over to this other midwife because her shift was finished, and she's just happily chatting away and laughing with this other midwife. There was no take care, I hope you're ok, nothing. No compassion or sensitivity." (Audrey/ Miscarriage, 12 weeks/ Interview 2).

Gently encourage me to see and hold my baby. With the exception of one woman who chose not to see or spend time with her baby, all of the women who experienced a stillbirth described a supportive environment in which they were able to spend time with their stillborn baby. All had the opportunity to see, hold, touch, bathe, dress and take photographs and handprints of their baby, and this time was considered valuable.

"Those times I got to spend with Noah were the best times in my life. It was incredible just to hold him, and look at him..." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I held her for a long time. They [midwives] took her away and washed her and came back. She was wearing this little going home outfit that we had bought for her, and she was wrapped in a rug that my mother in law had knitted for her. ... This time with her was very special, but of course, it's never enough." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Ruth and Chloe also reflected positively on the time they got to spend with their sons, and inferred that they would have regretted their decision had they chosen otherwise.

"We're so glad we saw him and spent that time with him. Because if we didn't we would have always wondered..." (Ruth/ Stillbirth, 31 weeks/ Interview 1).

"I'm so grateful that I had that time with him. And it was the only time we had together. I really would have regretted it otherwise." (Chloe/ Stillbirth, 39 weeks/ Interview 1)

Many women were especially grateful that health care providers recognised their initial hesitancy, and gently encouraged them to see and/or spend time with their baby following birth.

"What I found especially helpful was that they kept asking me if I wanted to see the baby, bathe the baby...and at first I had a bit of a difficult time with it because I didn't know what was acceptable. I mean, how do you parent a dead baby? I was really scared to see him the first day they asked...but the next day I felt brave enough to face it...and it was really nice." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"Afterwards the nurses came to me and asked if I wanted to see him, but I wasn't ready yet. They asked me again later and I was ready this time. What was really good was that they asked me if I wanted them to bring him to me, or if they should just place the basinet in the room so I could walk over. And that's what I chose to do. It took me a while because I was a bit hesitant, I didn't know what to expect when I was walking towards him." (Chloe/ Stillbirth, 39 weeks/ Interview 1)

It was clear from these women's accounts that they were grateful for the opportunity to spend time with their baby. Upon reflection, several women wished they had spent more time with their child.

"One of my biggest regrets at the hospital was not inviting my friends to see him...and spending more time with him. I was so worried what everyone would think...that it would freak people out...but he was my son and I was so proud of him." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I wish I had of spent more time with him...because at the time I wasn't sure about it, it felt strange...but I really wish I had." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

**Providing mementoes.** As part of best practice guidelines, all women who experienced a stillbirth were offered mementoes of their baby, including photographs, footprints, handprints, 'memory boxes', a teddy bear, and support pamphlets. Many felt that this helped to acknowledge the significance of the loss. In addition, memorial services were also viewed as helpful, and were often described as an important means of gaining closure.

"We decided to get her cremated and spread her ashes in the rose garden [at the hospital]. We thought it was nicer having her with other babies, than in a big cemetery. And the service was really nice. It brought a lot of closure..."

(Mary/ Stillbirth, 24 weeks/ Interview 1)

"He was cremated in the butterfly garden at [hospital]. And there's our butterfly [gestures at a butterfly box on the mantelpiece]. We read the bible, and prayed, and then they took him away. The following morning the funeral guy brought him over to our place in a little box. It was a really difficult time for us, but a nice way to remember him." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

"We did the memorial service at [hospital] which was very nice, very useful for us. Very hard, but all our family was there, our parents and the in-laws, the kids, we turned it into a big event because we wanted to. My boss also came from work...I think it was good to help everyone understand what was going on...to say goodbye." (Susan/ Stillbirth, 20 weeks/ Interview 1)

Additional hospital support services such as the presence of a chaplain were also commented on positively.

"The priest was really good. He said a little prayer for our daughter and gave me a candle. I found he was really helpful." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

## After-Care: The Need for Improved and Continued Support

The majority of women spoke positively about their experiences of support in hospital, however, they reported experiences of support following discharge differently. In particular, they reported that their expectations for follow-up care were not realised.

Provide me with adequate aftercare. Most women formed close and intimate bonds with the midwives caring for them in hospital, which was greatly cherished.

However, upon leaving the hospital, the women felt this sense of security and support was abruptly removed.

"The midwives are fabulous in hospital, but I think there needs to be a little more care once you come home... Cos that first week is just so traumatic, you're not really functioning at all, even just getting out of bed in the morning is a big achievement. So yeah, just having someone to discuss with you how you're feeling would be good." (Grace/ Stillbirth, 41 weeks/ Interview 1).

"The midwife support in the hospital is great...but that's what's so scary about leaving the hospital. You have all this support and then you're home on your own. That's when the wheels fell off...I didn't know what to do."

(Amanda/ Stillbirth, 26 weeks/ Interview 1)

One woman, Stephanie, described excellent continuity of care by her attending midwife, who visited her regularly and was available to answer questions. This midwife also ensured that referral sources were available when necessary, and this was also perceived as helpful.

"I speak about Jack with my midwife who is really good, she's become a close friend. She [midwife] has done so much for us. Every question I've asked, she's been there, and when she couldn't help me she organised with another lady from the education department to meet with me...that really put my mind to rest. And the information was very useful. She knows the system, and what I've been through, so that's very comforting" (Stephanie/Stillbirth, 39 weeks/Interview 1).

This reality would have been beneficial for other women, as several women suggested that regular home visits by their attending midwives would have made the transition much easier.

"I think routine home visits or something like that immediately after the discharge would be the best thing. Just to check we're coping okay. Maybe they could schedule it before you leave the hospital, something like 'We're going to come visit you in a few days to make sure everything is ok" (Grace/ Stillbirth, 41 weeks/ Interview 2)

"One thing I would have liked is for the same midwives in hospital to come have visited me at home. I know that's probably not possible but it's different when someone just reads your file and looks at it, the other midwives have been there for you, they've been through it with you. You don't have to tell your story again." (Amanda/ Stillbirth, 26 weeks/ Interview 2)

"A midwife did come to my house once which was great. But I definitely think it would have been good if they could come for weekly visits to talk to me about how I'm going, what I'm feeling, what's normal, that type of thing. Someone to talk to, and check up on us physically as well." (Emily/ Stillbirth, 40 weeks/ Interview 2)

Some of the women in the study described little or no follow-up from healthcare providers, and were dissatisfied with the level of follow-up care they received.

"You know what I would have liked? Just a simple letter in the mail saying 'Hi, I'm sorry for your loss. If there's anything we can do, please contact us'. Just a simple phone call even, asking if I was okay and if I'd like to speak with someone. But instead it was like 'Well, your baby's dead, see you later'. You get discharged and that's the end of it." (Audrey/ Miscarriage, 15 weeks/ Interview 2)

"I had a caesarean and there was no follow-up to check on my scar and that type of thing. Don't they have a community nurse or someone that comes to check up on you when you've had a healthy baby? Why not the same for us?" (Emily/ Stillbirth, 40 weeks/ Interview 1)

Similarly, hospital policy at the referral hospital specifies that women are contacted for a follow-up appointment approximately six to eight weeks post-loss at the specialist outpatient clinic, and this also received criticism. For example, Amanda complained that the process was so long and drawn out, she heard nothing for weeks, so decided to contact the hospital herself.

"I rang them [the hospital] to make an appointment and they didn't return my call. So I put it off for another few weeks cos I needed the courage to ring again, so that was quite difficult."(Stillbirth, 26 weeks/ Interview 2)

Jessica reported a similar story. She was particularly dissatisfied with the hospital service itself, as she had expected it to be more comprehensive.

"The hospital was meant to send me out some information before my six week check-up. Then ten weeks came and I'd still heard nothing. I called them, and they kept transferring me to different departments. When I finally got to the right department, they couldn't find my details, so there was no record of me actually being in hospital... I really think the service needs to be more thorough. I mean, I also went in and they did a little survey asking about whether or not I was depressed and that was about it! I asked the nurse whether or not she wanted to check my stomach and she basically just prodded it a few times and said 'Yep, you're fine!' It's just not good enough." (Stillbirth, 20 weeks/ Interview 1)

Rachael conveyed her frustration at having to return to hospital to have placental tissue removed that was mistakenly overlooked by surgical staff:

"I was back in the hospital shortly after it happened cos the placenta was still half stuck in my uterus. They made a mistake and didn't get it fully out. So that made me angry, cos supposedly you would think they could tell that the placenta was still intact and they should have picked up on it earlier. They should have done the D & C straight away rather than two weeks later." (Rachael/ Stillbirth, 21 weeks/ Interview 1).

Lack of communication amongst healthcare personnel, and failure to follow through on certain administrative aspects, also contributed to women's negative perceptions of aftercare.

"I had at least three different situations where I had to chase people up and follow them up...there was a point where I got very angry. I mean, in one instance the gynaecologist was away on holiday but nobody knew that or decided to tell us." (Eveline/ Stillbirth, 21 weeks/ Interview 2)

"I had a bit of a phone call from the breastfeeding clinic. The social worker was supposed to cancel the breastfeeding and parenting classes, but obviously she didn't. So the poor lady who rang me copped it because I was so upset by it! I later apologised to her but I was so annoyed that the system hadn't updated my records cos people like me don't need phone calls to say hey, come learn how to breastfeed when you don't have a baby anymore!" (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"We had some stuff ups with her cremation. We were told her ashes would be ready on the Friday and that they would call us. Friday came around and no-one called us, then it was the weekend, then Monday my husband phoned. They told us she hadn't actually been cremated yet, so I just panicked at the thought of her lying there all cold and alone. They told us she would be ready by the next day so we went down to the crematorium and they said she still wasn't ready. The next day we went back again and finally brought her home. I went from being so angry and frustrated to complete sadness." (Jenny/ Stillbirth, 21 weeks/ Interview 1)

Don't blame me for my baby's death. Although the majority of women were given some explanation as to why their loss occurred, most were dissatisfied with this explanation. This was not just a reflection of the content provided, but more the manner in which this information was delivered. For example, the women reported that it was common practice for doctors to go through a detailed 'checklist' of possible factors that may have contributed to the cause of death. Consequently, age and lifestyle factors were frequently mentioned which often led to feelings of guilt and blame. Some women felt as though they were being indirectly blamed for their loss, when their healthcare providers insinuated that their weight (e.g., obesity) was a possible contributing factor.

"I felt like although they weren't directly blaming me...they kind of suggested that my weight, diabetes, etcetera may have caused it [the loss]. He was like well you've got to have gastric banding and all this stuff, right at me when I'm lying on the table

in all this pain. Which annoyed me...it felt like he was blaming me. If I ever go back there I will make sure that I never have him again." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"Six weeks after losing him, after the autopsy, I was so angry because the Doctor took me aside and basically said that I should start contraception and wait two years to start trying again because I was too fat." (Phoebe/ Stillbirth, 40 weeks/ Interview 2)

Other women reported being told that their advanced maternal age was an extenuating factor was not helpful, as this was something they couldn't do anything about. They would have preferred to know the underlying scientific cause of death, as Olivia described:

"I know I'm not getting any younger and my chances of miscarriage increase as I get older...but that's not the reason. I had my tests done and my protein and my haemoglobin was all normal, I had no problem. So why does this keep happening if everything is normal? But they don't know. So really, you're left with nothing. No answers." (Miscarriage, 18 and 12 weeks/ Interview 2)

It's not a medical problem... It's a baby! Other negative perceptions of women's dissatisfaction with aftercare were concerned the insensitive attitudes and mannerisms displayed by some staff. In particular, the women described that their specialists tended to treat their loss as a medical event, rather than a bereavement experience. Stephanie felt that her desire for a more holistic treatment was overlooked, in favour of standard care routine.

"After I lost [the baby] the doctor pretty much insinuated that I should not go to the community centre to give birth where there are only midwives next time, but that I should go to the hospital where the 'real' professionals can look after me. He didn't say it in those words but it was clear what he meant. And when I got back home I was quite upset cos I thought well you can try to do everything right on the medical side, but the emotional side is missing. And that's important to me. They want to make sure that the baby is born safely yes, but they don't allow parents to be parents...my doctor didn't really read my birth plan or anything like that, and he tried to push me to have an early induction this time around. I don't like it when people just focus on the situation from a medical perspective rather than psychological. They didn't listen to what I wanted or why I wanted it." (Stephanie/ Stillbirth, 39 weeks/ Interview 3)

Alyssa and Amanda reported similar grievances, whereby they felt that their doctors seemed to trivialise their loss as a medical event, and minimise the emotional component of their loss. Specifically, they criticised their doctors for their matter-of-fact attitude, and their rushed and business-like nature.

"I felt the consultant was very impersonal and insensitive. He was very casual and just stated the facts. Didn't really care too much about our questions that still remain unanswered, he was very disinterested really. The whole thing felt very rushed, just like we were just another patient. He hadn't really prepared, he just walked in and looked at the chart and that was about it. He didn't explain anything in detail." (Alyssa/ Stillbirth, 38 weeks/ Interview 1)

"The doctors...we saw a resident, you know, they're just very removed. So impersonal, they're not like midwives." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

Other women like Audrey, described being offended by the use of particular terminology that they considered to be disrespectful.

"I had a follow-up with my obstetrician and do you know what he said? 'When the baby expired.' When my baby expired? That is just the most inappropriate thing you can say to someone who has just lost their baby! It made my skin crawl." (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 2)

Audrey felt hospital staff did not convey the sensitivity that she expected following her loss. She suggested that staff should be better trained in this respect and that certain individuals shouldn't be working in healthcare if they continue to behave in this manner.

"I really strongly believe that doctors and nurses should undergo bereavement training. They need to know how to respond appropriately to women who experience a loss like this. They just can't treat this like a job. Maybe there should even be some sort of recruitment process to select doctors and nurses who are more suited to this field."

(Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 2)

**Provide me with personalised care.** Women who were satisfied with the quality of care they received during follow-up consultations described a caring and sensitive practitioner, who devoted the time and attention needed to discuss their concerns. Several women spoke positively about their obstetricians, who helped to alleviate their fears and instilled hope for the future.

"My obstetrician was great. Any questions I had were answered and any anxiety I had he dealt with really well. He helped to calm me down, even when I was being really irrational." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"One of the best things anyone said to me was my obstetrician who said, 'You might have had advice that you should wait a year after a caesarean, but as long as you're emotionally ready, go for it'. And that was such a great thing to hear. It just filled me with joy. We could begin to move forward, but first we had to heal ourselves emotionally" (Emily/ Stillbirth, 40 weeks/ Interview 2)

Other women consulted specialists, who were also held in high regard for the comprehensive examinations they carried out in order to get some answers.

"I went to see a specialist, and the attention he gave me, I've never seen anything like that. He listened to everything I said and when I came back he knows exactly where we had left off. He did a whole series of tests with me." (Susan/ Stillbirth, 20 weeks/ Interview2).

"This one specialist was wonderful. He explained everything to me...finalised everything...consulted with my GP..."
(Olivia/ Miscarriage, 12 weeks/ Interview 2)

Positive comments were also made in reference to the hospital's provision of information pamphlets directed specifically at women who had experienced pregnancy loss. These were viewed as enhanced personal care and were sensitive to the women's needs.

"One of the best things about the care in hospital was how personal it was. Even down to the pamphlets. I remember there was one saying 'Physiotherapy: After the loss of your baby'. And I'm sure originally it was just for people who had babies, but they went to the effort of acknowledging the loss and changing the title." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I really liked that pamphlet that was directed at miscarriage...that had some really useful information. Because a lot of the material you find is about later term losses...the fact they broke it up like that, explaining what was happening...that was a nice touch." (Leanne/ Miscarriage, 18 weeks/ Interview 1)

Likewise, the women also interpreted the hospital's policy of marking patient files with a teardrop to signify a previous loss positively. The women felt this conveyed sensitivity and acknowledged their loss.

"One thing I really appreciated was when I saw my file at the hospital. It had a tear drop on the front with my daughter's name and date of birth on it, signifying that I'd

lost a baby. That was nice. It was kind of a marker for other people in the hospital who saw my file to be a bit sensitive, so that was good." (Audrey/ Stillbirth, 25 weeks/ Interview 2)

Offer me professional support. In light of the perceived shortcomings women described concerning aftercare, several women suggested that some form of bereavement counselling during this time might have been beneficial.

"I think after you have a miscarriage they should supply maybe about six counselling sessions. And make them reasonably priced and accessible. Maybe a few north of the river and a few south." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

"Mentally, I think there needs to be a bit more care once you come home. Maybe a psychologist or counsellor who routinely follows up... just that extra bit of support. Because it's hard to acknowledge or recognise that you need to discuss certain things that you can't deal with..." (Grace/ Stillbirth, 41 weeks/ Interview 1).

Whilst all women were provided with information pamphlets outlining different support groups and counselling services that were available, these were often deemed as inaccessible or not specific to their particular needs.

"I mean, there's places you can go and hotlines you can call, but it's hard when you're in that emotional space to make the call. It's hard enough just to have the energy to get up in the morning, so you're very vulnerable...it would have been good to have that extra support there." (Grace/ Stillbirth, 41 weeks/ Interview 1)

"I feel like there's nothing out there for us. I mean, I know we can access SIDS and KIDS [community support service] but that's not specific to losing a baby." (Jenny/ Stillbirth, 21 weeks/ Interview 1)

"We had actually planned to see a counsellor together around the corner from us that the hospital referred us to. But when we called them to try and make an appointment, we found out that they only dealt with Aboriginal customers! So we were told to go to one in the city instead. However, the latest appointment was 6pm and my husband doesn't get home from work until then so it wasn't possible. When we told the hospital they didn't know and they were very annoyed because when they tried to call them they said they didn't turn anybody away. But they did! I think they filed a complaint on our behalf." (Mary/ Stillbirth, 24 weeks/ Interview 1)

Women who utilised support services described them as useful. For example, Phoebe was able to attend counselling services at a nearby hospital on a fortnightly basis and found they assisted her.

"I've been attending counselling every two weeks now. She's been helping me deal a lot with my anxiety issues in addition to my grief." (Stillbirth/ 40 weeks/ Interview 2)

Similarly, Jessica was able to access counselling services through her husband's place of work.

"I've actually had some counselling through my husband's work. That's been very helpful. He told me that I shouldn't be blaming myself and he's taught me how to think more positively. I think counselling has been really good. I think everyone who goes through this loss should do counselling." (Stillbirth, 20 weeks/ Interview 1)

Amanda attended a wellness course in addition to a couple of counselling sessions at a community-based bereavement counselling service.

"I did a course which was really good, which focused on my emotions...and that linked in really well with the guilt I was feeling. Some of it was a bit over the top, but you can take it or leave some of the stuff...but it gave me a lot of peace. It also gave me some tools to recognise how my behaviour affects other people..." "I also had two sessions with SIDS and KIDS which tied in really well with it...I realised I had a tendency to push people away...which helped me put things into perspective. It also helped me feel the sadness." (Stillbirth, 26 weeks/ Interview 2)

## The Significance of Familial Support

Nearly all the women expressed how important it was to have their family and friends physically and/or emotionally present to provide support following their loss. This was especially true in the initial period following loss when the women did not want to be alone after losing their baby. The women wanted and needed to be surrounded by the love and support of those closest to them. On the whole, many women reported that their immediate family members and close friends came to be with them during their stay at the hospital, and at home in the initial days and weeks following the loss. Often, this support

was practical as well as emotional (e.g., assistance with household chores, child-care, funeral arrangements) and was described by the women as invaluable. In many instances, the women reported that these family and friendship bonds were strengthened after their loss as a result of this unconditional support from those closest to them.

Maternal support: 'I needed my Mum and my sister'. The majority of women reported that their immediate family were their primary source of support. Many of the women turned to the females closest to them in their time of need, especially their own mothers.

"Mum's been really great. She's taken two months off work and we see each other every day and talked about Noah." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"Mum's been fantastic. She's one of my closest confidantes." (Eveline/ Stillbirth, 21 weeks/ Interview 1)

Ruth conveyed how she was especially appreciative that her in-laws had made the trip to be with them following her loss, as she and her husband were migrants to Australia and all the family resided overseas. The familial support helped to ease the sense of isolation Ruth felt immediately following her loss.

"My husband's parents flew over to be with us and that was really good. But it was so hard when they went back home and we were alone again..." (Stillbirth, 31 weeks/ Interview 1)

Sibling support was also greatly valued, particularly in the first few days and weeks following loss. Sometimes this support was more instrumental, as Chloe shared:

"My brother came to the house and cleared out the bedroom so I wasn't confronted by his [the baby's] things..." (Stillbirth, 39 weeks/ Interview 1)

In other households this support was both instrumental and emotional, where the sibling took over the women's housekeeping duties in addition to providing much needed emotional comfort. Many of the women shared how important they felt this support was to them, especially considering how tasks as simple as getting out of bed each morning were often difficult for them over the first few weeks post-loss. Grace stated:

"My younger sister who has four kids actually stayed with us for the first few days." She was an amazing help for both of us, helping us to adjust to coming home without Charlotte...I don't know how we would have coped without her." (Stillbirth, 41 weeks/ Interview 1)

Jenny also commented on the quality of support she received from her sister, particularly her efforts to acknowledge her baby as a 'real' human being.

"My sister got me a bracelet for Christmas with both my children's initials on it, so that was really nice. It's so nice to have Rose acknowledged, and that's what I want everyone to do, acknowledge that she existed. She's my daughter and always will be." (Stillbirth, 21 weeks/ Interview 2)

Whilst family support was mostly reported as positive, there were instances where women described that they did not receive the support they needed. Instead of the family coming together in a time of need as one would expect, some of the women reported that the loss of their baby tended to exacerbate the relationship problems within the family unit. This generally occurred when women felt that their family members were unsupportive in terms of not validating the grief experience or offering unhelpful advice. As a result, these women felt angry and isolated.

"My own family's not supportive at all. I mean, my mum said 'why does this always happen to me?' And I'm like what happened to you Mum? It happened to me! And then when I told my brother we lost our son he turns around the next minute and says he has some good news for me...that his Mrs is pregnant! So I don't even bother with them anymore. Seriously, they have no idea." (Stillbirth, 40 weeks/ Interview 1)

Chloe shared a similar unsupportive experience when her baby's father's family was informed about the loss. Although already estranged from her ex-boyfriend's family, Chloe expected some sympathy and support but instead was met with heartless disregard and hostility.

"What made me so angry was the day Jasper passed away my Mum called his family to tell them. She thought they deserved to know despite all that had happened and the way the whole family treated us. Can you believe, I didn't get one call or SMS from anyone in the family? Not one condolence! How can people be so heartless? ... And then a few weeks later she [ex-boyfriend's mother] did finally call and I told her how broken I was. She couldn't have cared less and went on to blame me for why my ex had cheated on me whilst I was pregnant...I couldn't believe it! I was so angry and hurt." (Stillbirth, 39 weeks/ Interview 1)

The significant other: 'Losing our baby strengthened our bond'. The greatest source of support for most women following their loss came from their partners. Many women described the extent to which they felt their husbands/partners provided the support they needed, and many revealed that they didn't know how they would have survived the experience without this crucial support. In particular, having a supportive husband who listened and enabled the women to openly express their feelings of hurt and sadness was greatly valued, where the women felt comfortable to mourn in their own way. For example, Grace stated:

"My husband's been fabulous. Thankfully he's not one of those people that likes to bottle everything up and not talk. He always wants to talk everything through with me, you know, we sit and cry together." (Grace/ Stillbirth, 41 weeks/ Interview 1)

#### Similarly, Ruth conveyed:

"I've got a really good husband. If I need to cry he tells me to let it all out. And he knows when to give me space or when to let me cry." (Stillbirth, 31 weeks/ Interview 1)

Whilst many of the women described their experience of loss as challenging, and at times a source of tension in their relationships, the experience of having endured a common grief brought them closer as a couple. Many women felt incredibly lucky to have such a supportive husband, and several reported that if there was anything positive to be gained as a result of having experienced their pregnancy loss, it was the strengthening of their relationship.

"My partner and I have become a lot closer since losing Sia. We're a lot stronger now." (Mary/ Stillbirth, 24 weeks/ Interview 1)

"It definitely brought my husband and I closer together." (Jenny/ Stillbirth, 21 weeks/ Interview 2)

"As terrible as it was, it really brought out the best in our relationship. The ability to support each other and just be there, even without having to speak. You know, we would ask each other how he was or I was, but mostly just sit there and hug each other, not needing to say anything." (Eveline/ Stillbirth, 21 weeks/ Interview 2)

It appears that these relationships were strengthened, because the women felt supported in their grief. Furthermore, the women appeared to have close relationship with their spouse prior to their loss, and were able to retain a certain level of physical and emotional intimacy despite their grief.

"We've always been each other's best friends. We moved in together after two weeks of dating, and we've been inseparable since. He's really been there for me. I mean there have been days when I didn't even want to get out of bed. And he was there giving me a kiss and helping me brush my hair. This whole experience has definitely brought us closer...going through something like this definitely brings you closer as a couple."

(Phoebe/ Stillbirth, 40 weeks/ Interview 1)

"It actually brought me and Steve really close, and we're close anyway but it really brought us closer. He's generally not very good at talking about things, but this has made him open up a bit and allowed me to see his vulnerabilities." (Paige/ Miscarriage, 7 weeks/ Interview 1)

Emily shared how it was the little things her partner did to acknowledge their son that fostered their relationship closeness.

"We talk about Noah all the time...and he will do things like give me a kiss on the cheek and say 'that was from Noah.'" (Stillbirth, 40 weeks/ Interview 2)

For others like Jessica, physical intimacy was suspended for a period of time following loss, but the fact that the husband understood and remained caring and supportive facilitated relationship closeness.

"Afterwards I found that I didn't want anyone touching my stomach. And my partner and I are generally pretty close. But I didn't even want him touching me. Like holding hands or kissing. I just wanted to be alone. And that must have been hard on him...not being able to have sex with me or get close to me, but he understood that." (Stillbirth, 20 weeks/ Interview 1)

This sense of relationship closeness was somewhat of a surprise to women, as they had assumed that the strain of grief would have a negative impact on their relationship. As Rachael divulged:

"A lot of people said to me 'don't let this experience tear you apart', but it hasn't. It's actually brought us closer." (Stillbirth, 21 weeks/ Interview 2)

# Similarly, Grace shared:

"We're definitely a stronger couple now as a result of this experience. And I know you hear that a lot of couples go through a very hard time, and it can go the other way. But for us we're even stronger. Which I didn't even think was possible. Before this I thought we were close as it was, but then you go through a tragedy like this and you think well we could survive anything now." (Stillbirth, 41 weeks/ Interview 2)

Emily admitted that while the whole experience of loss was indeed challenging, it served to strengthen her husband's affections for her and vice-versa.

"It's definitely been tough, but we always say that Noah's the glue that glued us together. And we've always been sweet and affectionate with each other anyway, but since Noah died he's become even more caring and affectionate towards me. He's so protective now too actually it's very sweet. Like the other day we were walking and there was a baby in the distance and he put his hands over my eyes like a shield!" (Stillbirth, 40 weeks/ Interview 2)

## **Advice for Others: How To Support My Grief**

Women's experiences of support from their social networks were varied, with both positive and negative attributions of support being mentioned. These attributes shared many common elements, and the women described a number of supportive behaviours they felt were helpful in assisting their grief journey. Namely, these included categories of emotional support such as being physically and emotionally present following the loss, listening and providing the women the opportunity to express their feelings, and acknowledging and validating the loss and associated grief feelings. Within these descriptions, the women also

discussed forms of emotional support that they wished they had received as well as unsupportive emotional support that they did not find helpful. This generally consisted of avoidance behaviours, lack of acknowledgment/ minimisation of the loss, and giving unhelpful/hurtful advice.

Acknowledge my loss and don't avoid me. Many women felt that their social networks were unsure how to respond to the news of the loss, so they avoided talking about the loss, or avoided them altogether. This was perceived as hurtful, because not only did the women feel let down and abandoned by this lack of support, but it also conveyed to the women that their friends did not recognise their pain. What the women needed was for their friends to be there for them in their time of need, even if they didn't know what to say. As Stephanie shared:

"There were lots of people who didn't know what to say to me, and that was okay. As long as they wrote that in a card or told me that they didn't know what to say. But there were also lots of people who just didn't say anything to me and that just hurt so much more." (Stillbirth, 39 weeks/ Interview 1)

Similarly, Eveline also acknowledged it was a difficult situation and that people often didn't know how to respond, but she conveyed how the act of just being there to offer support was what mattered.

"Some people decided to stay away and I know it's hard for people because they don't know what to say, but they have to realise that they don't have to say anything. All they need to do is just give us a hug. You can't take away the hurt and grief, but just being there for us helps us get through it."

(Stillbirth, 21 weeks/ Interview 1)

For many women, the experience of being avoided led to feelings of anger and hurt, as the women wanted the loss of their baby recognised. As Alyssa conveyed:

"I feel like, why can't you just ask me how I am? Stop avoiding me. Avoidance makes me angry. It's a big deal for me so acknowledge the loss, don't minimise the loss by not talking about it." (Stillbirth, 38 weeks/ Interview 1)

Jenny also wished that people would acknowledge her daughter:

"Some people just don't know what to say and they kind of avoid talking about it. Whereas I want people to recognise that I lost my daughter, that I love her, that she was here." (Stillbirth, 21 weeks/Interview 1)

It was evident that the women had a strong desire to talk about their loss and for their loss to be acknowledged and respected.

"I tell you what, we want to talk about it. So don't be scared about bringing it up or whatever." (Audrey/ Miscarriage 15 weeks; Stillbirth, 25 weeks/ Interview 1)

"You know what got me upset? I had to fill out the census form which asks how many live births in the household. I spoke with my friend about it who had also lost and she was also upset by this question. It's like they're not acknowledging they were our children." (Jenny/ Stillbirth, 21 weeks/ Interview 2)

"It's really strange when people come over for the first time and they don't acknowledge it! I know it's because they don't know what to say or don't want to bring it up...but these friends of ours sent us a message to say how sorry they were, and then a few weeks later came over for dinner and didn't even ask how we were going. And I really wanted them to mention it and say something! I was waiting for the moment the whole night and it was just so awkward. But some people still think well, it happened early so it's not that bad. But I just want people to ask me how I am and not act like it's nothing." (Paige/ Miscarriage, 7 weeks/ Interview 1)

**Don't minimise my grief.** Women's experiences of minimisation were also evident in their descriptions of other's interpretations and attitudes towards their loss. In general, many women felt their extended family, friends, and wider community lacked understanding of the impact of their pregnancy loss, and did not perceive it as significant or painful as other deaths. This occurred regardless of gestational epoch, but appeared more prominent among those who experienced either a first or second trimester loss. Several women felt that society did not conceptualise the loss as a 'real baby', because it was not yet born.

"Everyone feels that it's so much worse when you lose somebody you know. No one seems to understand this type of grief. And you shouldn't compare them. They're all grief, none of it's easy." (Amanda/ Stillbirth, 26 weeks/ Interview 1)

"Well my Dad actually said to me, 'Well, it's not as if you lost a child or anything, it wasn't born yet. You know, it's not a baby until you actually have it, it's just cells'. And yes he's very pragmatic and not religious at all I know but he just

doesn't know how to say things tactfully. I mean, what is it then if you don't think it's my baby? It just makes me feel really shit."
(Maria/ Miscarriage, 8 weeks/ Interview 1)

Such negative comments and disregard for the loss left the women feeling incredibly hurt, as though they had no right to grieve. Furthermore, this often led to an isolated grieving experience where the women were forced to suppress their grief, or grieve in private, because they felt that others did not understand or tolerate their grief. As Rachael conveyed:

"I try to have a cry in private, like when I'm in the shower or something. Or my husband will find me crying in bed. I feel weak when I cry, so I try not to let other people see how I feel, I just go away and feel it. I guess I'm worried that other people will think that I'm not coping." (Stillbirth, 21 weeks/Interview 1)

When listening to the women's accounts of their grief, it was clear that they felt restricted in their grief, and typically expressed their grief behind closed doors. In public, they put on a brave face so that others would not construe them as weak, as they felt as though society at large did not give them permission to grieve. This was discouraging and frustrating for the women concerned, as Audrey and Amanda conveyed:

"We may look fine and have a smile on our face. But that's just a façade. It doesn't mean we feel okay on the inside. But if I cried all the time in front of people they would think that I wasn't coping, that there was something wrong with me! Because after a few weeks you're expected to have gotten over it."

(Audrey/ Miscarriage 15 weeks; Stillbirth, 25 weeks/ Interview 1)

"Sometimes people only hear what they want to hear. Like I just finished telling my friend the other day how I wasn't doing so great and then the next time she saw me I was having an okay day and she assumed I was over it! It's like sometimes I feel like I need to pretend I'm good cos of people's expectations. They don't get it." (Amanda/ Stillbirth, 26 weeks/ Interview 2)

All the women felt it was very important that others accepted their loss as real. However, instead of having their loss validated and sympathised, women felt that their loss was often minimised and disregarded.

"People talk about it like it wasn't a baby. Like the loss is just a piece of sh\*t. But for me it feels different. I feel like I've lost a part of my family. To me, I lost a child of mine. Even if she wasn't really born, I see her as complete, and she was." (Olivia/ Miscarriage, 18 weeks and 12 weeks/ Interview 1)

"I think it's especially hard when people say things that minimise the loss. Like 'Well at least you've got three kids'. Yes I'm definitely lucky to have three children but I still feel sad because I lost my fourth child. Like if someone lost their older child you wouldn't say to them, well, at least you've still got your other son and daughter! People just don't get it." (Jessica/ Stillbirth, 20 weeks/ Interview 2)

"Some people just have no idea. Like I was at the hairdresser the other day and I told her my story. And her response was 'Well, think yourself lucky, cos my friend can't even get pregnant she's having IVF!' And I just thought, how can you even compare the two?! They're two totally different situations, it's completely insensitive." (Amanda/ Stillbirth, 26 weeks/ Interview 2)

Don't mask my grief with unhelpful comments. In a similar vein, the women spoke about unhelpful or hurtful comments made by family and friends, which made the experience of loss more difficult. In particular, several women felt it was unsupportive and irritating when family and friends made comments they perceived as inappropriate and dismissive. Although these comments were often made with good intentions, they were perceived as hurtful. For example, comments such as "Don't worry, you're still young, you can always have another one," and "It's okay, you will get over it," were prevalent. These comments appeared to invalidate the grief experience for the women and did little to ease their pain. As Stephanie articulated:

"Yes I'm sure I can still have another one, but my little Jack still died and he's not coming back!" (Stillbirth, 39 weeks/ Interview 1)

Grace also expressed her frustration and hurt over such insensitive comments:

"They talk about Charlotte as if she's replaceable!" (Stillbirth, 41 weeks/ Interview 1)

Ruth and Jenny were greatly upset by the assumption that they would eventually 'get over it'.

"But I will never get over him! He will always be there in the back of my mind. I mean, a year or two from now it will probably get easier, but I will never forget him. People who say this really don't know what it's like and it makes me so angry." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

"Many people just don't know how to handle it. Sometimes they just stop talking to you or they apologise for asking, other times they say stupid things like 'Oh my God, how did you get over that?' And I think to myself well no you don't get over something like that, I'm not over her. I lost a child, but many people don't seem to see it like that." (Jenny/ Stillbirth, 21 weeks/ Interview 2)

Other insensitive comments relayed by the women's support networks included statements which tried to rationalise the loss. "Things happen for a reason" was another common remark, which infuriated the women and caused a lot of distress.

"I hate it when people say to me 'everything happens for a reason'. What reason? The universe hates me and doesn't want my baby to live? And I know they are only trying to help but it doesn't. It gets me very angry. And I hate when people try and enforce their religious beliefs on you like 'god needed another angel up in heaven'. I try to ignore the words and just look past all that and remember that they are trying to be nice. But it still gets me upset." (Emily, Stillbirth, 40 weeks/Interview 1).

"Don't tell me things happen for a reason. I was so angry I just said to her 'and what reason would that be? That's pretty fucked up!' It was a bit harsh and she was so upset and apologetic... I know she meant well but people just don't think before they speak." (Eveline/ Stillbirth, 21 weeks/ Interview 1)

Other women were confronted by members of their family and friends trying to make sense of their loss by offering reassurance. As Rachael stated:

"Of course everyone keeps telling you that you'll fall pregnant when the time is right. That your body knows what to do. But the fact is, my body didn't know what to do. It didn't finish the job! I get so sick of people saying stuff like that, I don't want to hear it. I know they are saying it to try and make you feel better but seriously. I actually told my husband I was going to get a shirt that said 'don't tell me my body knows what to do cos I'll hit you!"" (Stillbirth, 21 weeks/ Interview 1)

Maria also shared her experience of a friend's failed attempt to provide comfort.

"My friend came over and she said, 'Well, at least you've had one healthy baby so you know you can have another one'. And I'm like thinking well how the hell is that meant to help?! How do you know that? You don't!" (Miscarriage, 8 weeks/ Interview 1)

By all accounts, the women would have preferred their family and friends to have not said anything at all, if they didn't know what to say.

"Don't try to fix the situation, you can't fix it. All I need is for people to say 'I heard what happened, and I'm so sorry that you lost your son'. I don't want to hear that I can have another one. I'm grieving for my son. It's just about acknowledgement at the end of the day. He was here, he was a real, beautiful person."

(Emily/ Stillbirth, 40 weeks/ Interview 1)

"I get sick of people telling me that it's going to be okay. It's not okay right now, and I don't want to hear that. I'm a very rational person and I know that eventually things will be okay but right now it's not so don't tell me that!" (Paige/ Miscarriage, 7 weeks/ Interview 1)

Overall, the women perceived that most of the hurtful comments made were attributable to society's ignorance and ambiguity surrounding the context of their loss, and that they were "only trying to help". Consequently, on most occasions, they were able to engage in a filtering process, which enabled them to excuse the hurtful comments and actions of others

Just listen and let me talk. Many women described their need to talk about their experience of loss and to have others listen to them. They recognised that most people who had not had a similar experience didn't really know what to say, but this was acceptable, as long as others just listened and provided them with the opportunity to express their feelings.

"Even though my friend didn't really know what to say... she asked a lot of questions, and she listened. I found that really helpful that she was interested and asking lots of questions." (Jessica/ Stillbirth, 20 weeks/ Interview 2)

"Of course, none of them have gone through this so they can't relate in any way. But they listen, they have cried with me, and they are there to talk to me if I need to talk." (Grace/ Stillbirth, 41 weeks/ Interview 1)

Support was perceived as most helpful when family and friends were sensitive and empathic towards their loss, especially when they allowed themselves to show their emotions. As Susan stated:

"My best friend and I cried together...she's been good." (Stillbirth, 20 weeks/ Interview 1)

This wasn't necessarily always the closest friend or relative, but the individual who was perceived to be the most supportive and understanding. For example, following her loss Emily reported that she chose to spend more time with certain friends and avoided others because she felt they would be better to talk to and support her grief.

"I find it helpful when people just sit with me and cry. Or just listen. And I know it's really hard for people to talk about death and that's why I needed to be really selective who I chose to hang out with. Cos some people you know are just going to be better to talk to than others." (Stillbirth, 40 weeks/Interview 1)

Many women spoke about the importance for family and friends to wait until they were ready to talk. Particularly in the initial stages following loss, women became emotionally exhausted if they had to re-tell their stories over and over again. It was greatly appreciated when friends and family were patient and tolerant, being there for them to talk when the need arose. As Eveline commented:

"The support was there. We asked for our space initially and they respected that. But I found talking to people about it on the phone was really quite therapeutic. I had several girlfriends who I explained the whole thing to, and it was really good talking to them about it. It was like I was accepting it through talking about it. But also, talking about it helped to make it real." (Stillbirth, 21 weeks/ Interview 2)

Family and friends who were able to respect the women's need to talk and be heard were considered an important source of support for the women following loss. Having friends who were able to just sit and listen, conveyed to the women that they were cared for and understood.

Don't offer advice unless you've been there. Many of the women received advice and guidance from family and friends following their loss. This advice and guidance was only perceived as helpful if it came from others who had endured a similar grief experience. Several women reported that they were able to turn to their own mothers or siblings

following their loss, whose own experiences of pregnancy loss helped them to feel that it was normal to feel grief and anxiety. This was especially true when family members encouraged the women to openly express their grief feelings, as Leanne stated:

"My mum said to let it all out, and that was really good because up until that point I felt like I had been trying to keep it all together. To be strong." (Miscarriage, 18 weeks/ Interview 1)

However, many women reported that they also received advice that was unwarranted and not supportive. Advice and guidance was not appreciated when it came from others who had no experience of loss, as such individuals were perceived to have no understanding of the grief it entails.

"I know how you feel'. No you don't, so don't pretend to know. That's when I get angry... people offering me advice when they have no idea..." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

"What annoys me is that everyone feels it's their business to tell us what to do. When who went through it? Just me and my husband, that's who! They make it sound like it's all nothing, they don't understand how difficult it is." (Olivia/ Miscarriage, 18 and 12 weeks/ Interview 1)

Show you care, but don't treat me differently. While there were many aspects within the women's support networks that were reported lacking, there were also many gestures of support the women recalled as helpful. For most women, the initial task of informing family and friends of the loss was difficult. Several women chose to notify others through emails, text messages, or on social media sites such as Facebook. In response, women were overwhelmed by the flowers, cards, and personal messages of support they received, which showed that other people cared.

"When we lost Noah I actually put a message up on FB telling people what had happened, and also not to call me at the moment because I was very emotional. And that was really good. I received a lot of private messages of support, and cards and flowers with some nice messages. It was just so important that people still got in touch. It didn't matter what they said, just to know they were thinking of me when I was in my world of grief. That they cared. It also helped because I wanted people to acknowledge that Noah was a real person. He was my son."

(Emily/ Stillbirth, 40 weeks/ Interview 1)

"Work's been really good...I gave everyone instructions before I came back, I sent an email out and explained in detail what had happened so that no-one needed to ask. I asked everyone just to treat me as normal. And they did which was good. I got a lot of support." (Susan/ Stillbirth, 20 weeks/ Interview 1)

In addition, several women described how they were really touched by family and friends' show of support through their attendance at funeral services or personal contributions in the baby's memory. As Susan shared:

"The memorial was nice because all our family, parents, in-laws, kids were there...we turned it into this big event, even though we didn't have to. My boss also came down from work as well which was really lovely."

(Stillbirth, 20 weeks/ Interview 1)

Emily shared how she was surprised and grateful for the generous support of her work colleagues, following a collection for charity in her son's honour.

"I did some fundraising and was able to raise \$3000... I actually sent an email around at work with a photo of my son...and people were just so generous. And even though they had a lot of trouble coming up to me in person, this was a way they could show that they cared. And I was quite overwhelmed by all their support." (Stillbirth, 40 weeks/Interview 2)

Although women appreciated actions of support from their social networks, they did not want people to treat them differently. Whilst they wanted their grief acknowledged, they did not want others to dramatise their loss. As Rachael stated:

"I get sick of people asking 'how are you?' You know, not the general 'how ya going' sort of thing but the dreary tone, the insinuation behind it. I'm still the same Rachael, just talk to me how you used to. I'm still me." (Stillbirth, 21 weeks/ Interview 1)

Several women described feeling as though their family and friends were "walking on egg-shells" around them to protect them from all things pregnancy related. The women were able to understand why this was happening, and that their friends meant well, but the result was still a feeling of irritation and frustration. They wanted their friends to realise

that they were still the same person, and they didn't wish to be treated with such caution.

### As Rachael expressed:

"It's like my best friend was too scared to call me up and tell me she was pregnant. I don't want people to feel guilty, like they can talk to me cos they're having their fourth child or whatever and I still don't have one. I'm coping alright...just be yourself." (Stillbirth, 21 weeks/ Interview 2)

### Eveline shared a similar experience:

"It's the same with people who avoid telling me about other pregnancies. I mean, my boss and his wife fell pregnant, and everyone in the office knew and kept it a secret. And that was really hurtful. I felt really insulted by that cos I thought, god damn it I'm going to have to deal with it sooner or later! It's not going to fix the situation by not telling me, I just feel like an idiot." (Stillbirth, 21 weeks/ Interview 2)

The women conveyed that they still wanted to go about their normal routine and enjoy life, not wallow in their sadness. Consequently, those family and friends who encouraged the women to get out of the house and keep up with their normal routine were greatly valued.

"My friends have been fabulous. Every week we generally organise a lunch date with the girls, we go and do a bit of shopping and whatever. So they've been really good at keeping that whole social side of things up." (Grace/ Stillbirth, 41 weeks/ Interview 2)

#### **Seeking a Shared Grieving Experience**

Whilst the women typically described their spouses as their closest sources of support, they also noted clear differences in grieving styles, which made the experience of loss more difficult. Consequently, their desire to achieve a shared understanding of each others grief proved difficult at times, and the women engaged in practices to ensure they were grieving together, not apart. This effect was also mediated somewhat by the women's support seeking behaviours outside of the relationship. The women actively sought support from other women who had experienced a pregnancy loss, as they felt that these women could better relate to their grief and provide them with the support and reassurance they needed.

Grieving together as a couple. Although women reported that the experience of pregnancy loss strengthened their marital bond and they described their spouses as supportive, they did not feel united in their grief. In particular, women reported feeling compelled to talk about their loss frequently, whereas their partners seemed to be happy to talk about their grief for the first few weeks following loss, and then preferred to stop talking about it and 'move on' with their lives. These differences in grief responses were often misconstrued at times, when women perceived that their partner did not care about the loss as much as they did. For example, Amanda reported her frustrations with her husband because he suddenly didn't feel the need to talk about his emotions anymore.

"Well, you know what all the literature says about how we will grieve differently and all that, but you're still not prepared for it. I mean, we started to argue...tearing each other apart, when you're torn apart yourself...I kept saying to him 'what's wrong?', he'd say 'nothing'. And I'm like, 'no really, what's wrong?', and he'd still say 'nothing!' We both grieved differently and I wish someone would have told us what to expect. Geoff [husband] was quite emotional those first few weeks and then just appeared to move on...and now I know that's just what men do but I wish I'd really understood those differences earlier!" (Stillbirth, 26 weeks/ Interview 2)

Susan conveyed a similar experience, whereby she became frustrated by the manner in which her husband was coping with his grief:

"He always just says that he's ok with it, that it's not an issue. Like for him it's done! But sometimes that makes me angry because he doesn't ask how I am, if I'm ok, or if I'm thinking about it. If I'm down he thinks it's just hormonal, you know, just PMS, like a typical male! But I'd like to know more about what he's thinking..." (Stillbirth, 20 weeks/ Interview 1)

Susan strongly felt that she would have benefited from a workshop or counselling session to enable her and her husband to openly explore and discuss their grief.

"Maybe there should be compulsory workshops for couples to attend so that he will talk and discuss his emotions with me. Something maybe with direct questions that target specific things, because he's not going to offer up anything otherwise. And something to teach him how to be more tolerant and patient. Something that helps us communicate with each other. I think it would be quite valuable to have something like that..." (Stillbirth, 20 weeks/ Interview 1)

In Stephanie's case, it was her husband's frustration that created some challenges.

Stephanie described how her husband was frustrated with her for supposedly 'choosing' to be consumed by her grief.

"A friend of mine bought me a magazine article about losing a baby, and it was quite good. And I was just sitting outside reading the article when my husband saw me and said 'What are you doing? Do you want to sit here and keep dwelling on it?' And I said to him well I want to work through this now rather than fall pregnant again and have to deal with it later. He doesn't quite understand the process...he just thinks I want to feel sad. But it's not about that. For me it's something I just need to go through." (Stillbirth, 39 weeks/ Interview 2)

Audrey felt that she couldn't really communicate with her partner about her grief, as she felt that he was reluctant to talk about it.

"I can't really talk to my partner about it much...he says it's too upsetting. I grieve, he blocks it out..." (Audrey/ Miscarriage 15 weeks/ Interview 1)

When relaying their experiences of spousal support, it was clear that not only were the women aware of the gender differences in their grieving experiences, but they accepted them and were able to empathise how difficult the loss must have been on their partners. Many recognised that their partners were not only sharing the grief experience as they too had lost their baby, but they were also expected to be the strong one in the relationship and support their wives.

"He was going through a lot. I mean he was trying to be there for me because I was going through the physical side of things but he was also going through his own stuff as the father. He shed a lot of tears too, but for me the grief was quite different having lost a physical being within me. Whereas he lost an emotional being." (Eveline/ Stillbirth, 21 weeks/ Interview 2)

"It's been really hard on Gary because he's been there through it all...watching me give birth to our son, helping me through it...dealing with it in his own way. He took a lot of time off work, but that was mostly for me. He's the strong one." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

Chapter Five: Experiences of Support 161

In addition, the women expressed how they could not expect their partners to fully understand their grief, as their attachment to their unborn child was different. As Audrey explained:

"The first few weeks he was really supportive, but then it just stopped. And I actually think it's because it's a very different experience for the mother than it is for the father. They haven't carried the baby, felt it move, or given birth to a dead baby." (Audrey/ Stillbirth, 25 weeks/ Interview 2)

#### Similarly, Emily shared:

"We've both got very different ways of grieving, but we both grieve. Like he likes to visit the grave regularly, for me it's still too painful."
(Emily/ Stillbirth, 40 weeks/ Interview 2)

Perhaps this insight and awareness was linked to the distribution of the 'She cries, He sighs' pamphlet in hospital, as several women mentioned the usefulness of this information. However, some women also sought additional information to facilitate their understanding, Stephanie was one of these women:

"I found that pamphlet from the hospital quite good... 'She Cries, He Sighs'. I even went and looked up the differences in grieving patterns on the Internet and found them quite interesting. Everyone expects men to grieve in a certain way and show their emotions, but it's not true. I mean I was carrying Jack for nine months, he wasn't. It's not the same experience." (Stillbirth, 39 weeks/ Interview 1)

It was evident that women felt that they had suffered enough by losing their baby that they didn't want their relationship to suffer as well. Several of the women shared how they made a concerted effort to communicate with their partner in order to better understand their grief. For example, Stephanie described how she and her husband encouraged open communication by writing their feelings down on a piece of paper and sharing them with one another.

"What I found quite useful was to put our thoughts together in Jack's box. We both did this. When I read my husband's it made me realise how much further he was than me. I was more self-centred, trying to figure out why me and that sort of thing. Whereas he wrote things like how sad he was that he wouldn't see Jack grow up,

but that he knows he'll be safe with grandma and that type of thing. And that really helped me understand him a lot better." (Stillbirth, 39 weeks/ Interview 1)

Ruth's husband also expressed his emotions by writing a letter to their deceased son. Ruth described how this simple act of writing down thoughts really helped her husband to open up and enabled her to better grasp what her husband was enduring.

"My husband actually wrote a letter to our son. It basically said that now there is a new star in the sky, and that he must be good in heaven and play with his grandfather (who has also passed) and that he is now with the angels. And that letter really helped me to understand what he was going through. Because he really didn't talk about it, but writing this helped me to understand how he was feeling. And that really helped us to connect. Because before that, I'd always ask him to tell me how he feels and he wouldn't answer. And finally one day he just burst out that he felt so angry, so angry that he felt like punching a wall. He just burst into tears. And I was so thankful that he was honest with me and told me how he was feeling." (Stillbirth, 31 weeks/ Interview 1)

Although some women conveyed that they wished that maybe their partners had been a bit more patient with them and understanding, they still felt adequately supported. The important thing was that their partners were physically present and made themselves available to talk whenever the need arose.

"He doesn't want to talk about it very much, but every day, I will talk about him. And he understands that, and he listens to me talk about him." (Ruth/ Stillbirth, 31 weeks/ Interview 1)

"My husband and I talk about it. Well I talk about it to him but he doesn't really say much. He's very supportive but he just doesn't seem to want to talk about his feelings about it. His way of coping is very different to mine. He's not one to cry." (Jenny/ Stillbirth, 31 weeks/ Interview 1)

"If I want to talk about Max he will listen to me. We both cry together too sometimes. He's a strong support... if it wasn't for him I don't think I'd be as strong as I am. He doesn't always get it that I am upset though...sometimes I have to point it out. But he's there." (Rachael/ Stillbirth, 21 weeks/ Interview 1)

Accessing other women who have lost a baby. To increase their sense of social support, the bereaved women turned to other women with similar bereavement experiences. In some cases, women were able to confide in close friends or relatives who had also

Chapter Five: Experiences of Support 163

experienced death in their lives, and were therefore better able to provide the support and empathy required. For example, Emily revealed:

"I have a few close friends whom I speak to about Noah. One of them is especially good to talk to as she lost her father at a young age so she knows about grief. And another friend has a young daughter and was with me throughout the whole pregnancy. So she shared the pain when I lost Noah and she was very supportive." (Stillbirth, 40 weeks/ Interview 2)

### Similarly, Jessica shared:

"Since I lost I've had a few people come up to me and share their experience about their losses, and that's been amazing." (Stillbirth, 20 weeks/ Interview 1)

Confiding in others who had been through a similar experience enabled the women to feel comfortable expressing their feelings about the loss. Furthermore, confiding in others who had been through a similar experience helped to promote a sense of empathy and understanding.

"I think the most compassionate people are the ones who've experienced loss. And that's just the nature of the experience. Because you can't really feel that kind of empathy unless you've experienced some sort of loss.... because they have that understanding of how painful it really is. I mean, my other friends are great, but they don't understand it. They feel sad for me, but they don't feel sad for my son. And that's understandable because I want them to grieve for my son but they didn't know him so how could they?" (Emily/ Stillbirth, 40 weeks/ Interview 2)

Hence, a connection and special bond was formed because women who had been through a similar loss were able to relate in a way that was recognised as real and authentic. In addition, the women described that they found talking to other women who had experienced loss and then gone on to bear a subsequent child especially beneficial. Speaking with other mother's who had coped with pregnancy loss provided the strength and hope they needed to believe that they too could get through their loss.

"It's good to talk to other women who've been through the same experience. Like my friends Mum had three losses, she phoned me up and said how sorry she was. She said my time will come, she had three losses and look at her now. She has been blessed with four healthy children so that helps."

(Chloe/ Stillbirth, 39 weeks/ Interview 2)

Emily described how conversing with other women who had been in her position helped her to see that she wasn't alone, and provided her with the support she needed on her grief journey. Talking with one woman in particular gave her a whole new perspective on her life and her future.

"A friend of mine lost her son almost full term like me. And shortly after she lost him she found out she couldn't have any more children. And that just made me think, fu\*k, everything can always be so much worse. When I feel sorry for myself I think about the fact that at least I can try again, but she will never be able to. She actually got into contact with me and sent me the DVD 'Losing Layla'. There was a note saying that she was there if I needed to talk and that's how we met. And she's just such a calm and peaceful person, a really beautiful person. She was so inspiring and gave me hope that I could get through it when before that I just wanted to die. But hearing her story, how she survived and got through it, just gave me strength." (Stillbirth, 40 weeks/ Interview 1)

These supportive peers were accessed via a number of means, such as through existing friendship networks, support groups, or 'friends of friends'. For the majority of women however, support was sought from external support networks, such as online pregnancy loss forums. Many women accessed these Internet support groups because they were easily accessible and they were able to talk with women who had been through a similar grief experience of losing a baby. Despite the physical distance (women accessed via online support forums were often located in another state or overseas), talking to other women who had experienced pregnancy loss helped these women as they were able to connect with someone who really listened and understood.

"I actually joined a group on Facebook called 'parents advice page'. There's a lot of Mums on there who have also lost babies. And one of the ladies on there sent me out a memory box, it was really sweet. I'd never met her or anything. And it was so nice talking to someone who had also been through it. I also joined an online forum called 'angel babies' which was also good to share stories with other Mums. It helped to show me I'm not alone." (Emily/ Stillbirth, 40 weeks/ Interview 1)

"I'm actually on a miscarriage website. I've talked to a few people on there, which has really helped. We share similar stories. And it's made me realise how lucky I

Chapter Five: Experiences of Support 165

am as well. There's this one lady on there who had like 13 miscarriages...I couldn't imagine going through that." (Jessica/ Stillbirth, 20 weeks/ Interview 1)

"I like to go on the internet and read what other people have written who have also lost. And the good thing is I have made some new friends through this. I met a friend in Adelaide that had lost two babies, and another friend in Sydney who lost three babies. And we're all very close now." (Ruth/Stillbirth, 31 weeks/Interview 1)

Chloe described how online forums were not only a good way of connecting with other bereaved mothers, but provided her with hope and reassurance that she too could one day overcome her grief.

"I've been on YouTube looking at videos of stillborn babies. I've been on different blogs...I've joined so many and share my story with other mothers. It's very touching and I feel very connected to those mothers. I found the online chat sites really useful. When I was questioning if I'd ever be able to get through this, and get my life back to normal...it was good to talk to other women who'd been through it."

(Stillbirth, 39 weeks/ Interview 1).

Although websites varied, the connections established assisted the grieving process by helping to legitimise and normalise the women's experiences. Women were able to connect with others and talk about feelings and experiences that they were often unable to share with others in their non-virtual lives.

#### **Summary**

The findings in this chapter illustrate the significance of support, both positive and negative, on women's bereavement experiences. In terms of interpersonal support, women value the support and concern of their family and friends who acknowledge and respect the emotional significance of the pregnancy loss. In particular, behaviours such as listening, empathising, and showing genuine concern were most helpful, especially when they were able to share their experiences with friends and family who had endured a similar experience. In addition, a strong supportive relationship with one's significant other also positively affected women's emotional health following the loss. Conversely, women felt

Chapter Five: Experiences of Support 166

that friends and family who ignored them following their loss, offered unwarranted advice, or who failed to recognise the legitimacy of the grief experience, made the experience of loss more difficult.

In terms of professional support, caregivers who listened, conveyed sensitivity, and who understood the emotional significance of the loss were deemed the most helpful. Overall, the midwives who assisted in labour and birth were able to provide this relationship, and women were generally satisfied with the services they received as a result. In contrast, inappropriate and insensitive comments experienced by some women negatively impacted their perceptions of care, as did care that did not meet their expectations.

In the following chapter, women's experiences of pregnancy subsequent to loss are explored. This chapter focuses on the immense anxiety women experienced in the subsequent pregnancy, and how this interfered with their ability to bond with their new baby.

### **Chapter 6: The Subsequent Pregnancy**

This chapter explores women's experiences of pregnancy after pregnancy loss. The analysis yielded four superordinate themes and fourteen subthemes within this domain.

These emergent themes are presented in table 6.1. The superordinate themes include: The Psychological Complications of Trying Again; The Subsequent Pregnancy: The Dark Cloud of Anxiety; Coping with Anxiety During the Subsequent Pregnancy; and The Subsequent Birth: A Bittersweet Reality.

The findings indicate that the subsequent pregnancy is a time of immense anxiety and emotional distress. The decision to try to conceive again is emotionally confusing, and is complicated by feelings of continued grief. The subsequent pregnancy is a period during which anxiety escalates, whereby women undergo the difficult task of balancing hope and fear. As a result, the women engage in a series of compensatory behaviours to enable them to cope with this anxiety during pregnancy. Grief feelings continue beyond the subsequent birth, a time where sadness and joy collide.

### **Emergent Themes**

Table 6.1 Structure of Emergent Themes

Superordinate Themes and Subthemes	Participants Endorsing Theme (n)
Psychological Complications of Trying Again	
Emotional and physical readiness	7
Over-compensatory behaviour and self-blame	6
Timing and the ticking of the biological clock	4
Filling the void	5
The Subsequent Pregnancy: The Dark Cloud of Anxiety	
I was robbed of the joy of being pregnant	11
The 'safe' point? Just wake me up at term!	8
Elevated anxiety following multiple losses	4
An emotional rollercoaster	9
Coping with Anxiety During the Subsequent Pregnancy	
Looking for reassurance	10
Trying to gain a sense of control	5
Reluctance to bond with the unborn baby	4
Withholding preparations and celebration	6
The Subsequent Birth: A Bittersweet Reality	
Continuity of grief and attachment	7
A mixture of happy and sad	5

# **Psychological Complications of Trying Again**

All the women who completed the study (n = 14) wanted to try to conceive again following their pregnancy loss. For each of these women, deciding on the right time to start trying again was difficult. Many women questioned whether or not they were ready, or whether they could endure another pregnancy following such a painful loss. Complicating this emotional response was the fact that the women often received conflicting advice from

their support networks, both solicited and unsolicited. A common response from medical professionals was to wait until at least three menstrual cycles had passed, in order to give the body time to physically heal. Others suggested waiting at least six months, while some advocated that there was no medical reason to wait, but that women should wait until they were emotionally ready for another pregnancy. The opinions of family and friends were often given with good intentions but were ineffective and conflicting. Some advised the women to get pregnant straight away so they could 'forget about' or 'get over' their loss, others suggested waiting a year, as they felt that it was much too soon to even contemplate having another baby. Others suggested the women should consider adoption rather than go through another pregnancy after what they had endured. Being confronted with so many conflicting opinions was confusing for women at a time when they were emotionally vulnerable. Furthermore, perceived time restrictions such as the ticking of the biological clock meant that women felt pressured to conceive again sooner rather than later.

**Emotional and physical readiness.** Women's decisions to try again were primarily based on their sense of feeling emotionally and physically ready to endure another pregnancy, rather than a specific time frame. This was common across gestation, and many women struggled with their own personal turmoil of wanting to get to a point in their grief that they felt ready and able to try again. As Emily stated:

"We want to let ourselves heal emotionally first. He or she deserves us to be strong parents. I mean, they are a tiny helpless baby. They shouldn't have some grieving mess of a parent to take care of them. So I really want to make sure I've worked through my grief enough with Noah before we start trying to have another one." (Stillbirth, 40 weeks/ Interview 2)

### Similarly, Paige declared:

"I'm looking forward to trying again. I know we have to wait a few cycles, more to be emotionally ready than anything else. But I feel ready to start trying again soon. New year coming up, new fresh start." (Miscarriage, 7 weeks/ Interview 1)

Grace also referred to this sense of being 'emotionally ready'. She shared how her decision to start trying again was influenced by the advice of a supportive friend.

"A good friend said to me that when the fear of losing another child is less than the hope of another child, you should start trying again. I'm not there yet, I want to be in that head space where I can start thinking about and emotionally planning for a new baby. At present, I'm still way too fearful." (Stillbirth, 41 weeks/ Interview 2)

Although recommendations varied, most women were advised by medical professionals to wait approximately three to six months. With this in mind, the women focused on preparing themselves physically and mentally for conceiving again. As Emily stated:

"We're trying to get ourselves physically, as well as mentally ready for the next pregnancy." (Emily/ Stillbirth, 40 weeks/ Interview 2)

Physically, this process entailed looking after their body by eating well, sleeping well, exercising, and taking the necessary precautions to ensure there were no underlying health problems. For example, Susan and Olivia both shared how they consulted with certain specialists following their pregnancy loss for a comprehensive medical examination.

"After he died, I ended up seeing a specialist at a wellness centre to get my body right. He was great, I walked in there and told him my story and he did every test possible. He tested my blood, did ultrasounds, tested for chemical poisoning, cut chunks of my hair, I mean, silly tests but it made me feel better knowing there was nothing physically wrong with me. He was very thorough and gave me all the attention I needed, I've never seen anyone like that. And there was a six month waiting list to see him, but I'm so glad I did." (Susan/Stillbirth, 20 weeks/Interview 3)

"And so it came back that my protein and everything was ok, and my haemoglobin was returning back to normal...I had no problem. But I'm still left wondering why all this was happening if everything was normal. How can I stop it from happening again? They said it could be something wrong with the baby but it could also be something wrong with me. So I saw this specialist who gave me increased progesterone. She said it could be something to do with my progesterone levels... so I want to do everything I can to make sure I have the best chance that it doesn't happen again. I don't want to go through another miscarriage." (Olivia/ Miscarriage, 12 and 18 weeks/ Interview 2)

Overall, it appeared that women who experienced a stillbirth needed more time to prepare themselves emotionally for a subsequent pregnancy than those who endured a miscarriage. Women who experienced a stillbirth required more time to emotionally heal than those who experienced a miscarriage. For example, Emily who experienced a full-term stillbirth shared:

"I'm really glad that I gave myself the time to grieve. I went through so many different stages of thinking. At first I didn't ever want to be pregnant again because I knew it wasn't my son. Then I was able to get emotionally ready to try again." (Stillbirth, 40 weeks/ Interview 3)

This is a markedly different experience to Leanne, who focused on physical readiness:

"We're just waiting on some test results to make sure everything is ok. But the doctor has pretty much given us the go ahead. Nothing wrong physically." (Miscarriage, 18 weeks/ Interview 1)

Becoming pregnant sooner than planned was a shock then for women who wanted the extra time to prepare themselves physically and mentally for the next pregnancy. For example, Grace unexpectedly fell pregnant within six weeks after her loss.

"It was a real shock and I wasn't prepared for it. And to be honest, I didn't want to be pregnant again so soon. I mean, I was still grieving, I wasn't ready" (Stillbirth, 41 weeks/ Interview 2)

Conceiving again so soon after loss served to complicate the experience for Grace, who at times found herself thinking she was carrying the same child, and she had difficulty separating the two pregnancies.

"Because I fell pregnant again so soon, sometimes I feel it's all merged together." And going through this pregnancy reminds me so much of my pregnancy with Charlotte. I mean, essentially it's like I've been pregnant for two whole years, like one continuous pregnancy. You know, like an elephant or something!" (Stillbirth, 41 weeks/ Interview 2)

Over-compensatory behaviour and self-blame. During women's accounts of wanting to feel physically and emotionally ready for another pregnancy, it was evident that they engaged in specific over-compensatory behaviours. Such behaviours included:

increased exercise, adhering to a more restrictive diet, reducing work hours, and altering daily bathing routines. These behaviours appeared to be in response to an underlying sense of responsibility and self-blame the women felt for their baby's death. Many women still felt that they must have somehow contributed to their loss, or that their body had failed them. As a result, they were taking extraordinary measures to prepare themselves physically in an attempt to ensure that the same thing didn't happen again.

"The cord being hyper coiled may have been a result of not doing enough exercise and not drinking enough water, which may have not kept the blood flowing as it should have been. So this time I'm trying to keep myself fit and prepare myself physically. I try to swim three times a week, and I've been drinking lots of water." (Stephanie/Stillbirth, 39 weeks/Interview 2)

"I'm eating very healthy, not drinking, not much soda and things like that. My Mum thinks I'm going overboard...but you know, I'd rather do everything right. I'd never forgive myself if I did something strenuous, pulled a muscle, and then something was wrong and it was my fault. I feel guilty enough that I got out of bed wrong, that I must have squeezed on the waters... I'm being super careful this time. I'm making sure my stress levels are down, I'm not doing much housework, I'm going to cut my work levels down to four days...I'm not bathing, I'm only taking showers. You know, cos you hear all these stories about bacteria." (Susan/ Stillbirth, 20 weeks/ Interview 2)

"I have so much guilt and blame. Even since knowing it was a chromosomal abnormality I've been researching what causes it. And I quit smoking, I didn't take any pain killers before falling pregnant, but I did drink. And if you want the best chance to be healthy you should do all the right things at least three months before falling pregnant. I think what if it affected my eggs, what if it affected my husband's sperm...I convince myself that one day they will find the research to show that my drinking before pregnancy caused the loss." (Paige/ Miscarriage, 7 weeks/ Interview 1)

Women's efforts to deliberately make specific behavioural changes in the subsequent pregnancy and the belief that these changes would influence the outcome of any future pregnancies appeared to be a misguided attempt to try and instil some control. The women felt that maybe if they were extra careful this time, and were doing all that they could, they would give the next baby the best chance at survival.

**Timing and the ticking of the biological clock.** In addition to the importance of feeling emotionally and physically prepared before trying to conceive again, many women spoke about how the concept of timing also influenced their decision. The right timing appeared to depend on each woman's individual journey, including their maternal age, their desire to start a family, and perceived disruption to their 'life plan'. Some women shared how this decision was based on certain time pressures, such as the ticking of the biological clock or the ages of other living children.

"The problem is I'm not getting any younger. I'm going to be 36 this year, and I don't want such a big age difference between the next one and my daughter." (Olivia/ Miscarriage, 12 and 18 weeks/ Interview 1)

"The idea is not to replace him but the reality is I'm getting older. I'm 33 now, the other children are 7 and 4, we don't really want to wait too much longer. I mean, I don't want teenagers and a baby! So all those things are kind of forcing things along a bit. I mean, even the house we're building, and that's why it's also so sad. The only reason we were building was to have more room for the third baby. All these things were put in place for the new baby but it just didn't happen. So that's very hard, and I guess that's why we're very eager to move on and get the family started again, hopefully." (Susan/Stillbirth, 20 weeks/Interview 1)

Older women appeared to put more pressure on themselves to conceive quickly after their loss because they feared their childbearing years were nearing an end and they knew the risks of childbirth increased with age. They were also mindful of not having too much of an age gap between siblings. For younger women such as Ruth, it was not so much a factor of the pressures of maternal age but the desire to become a mother and start a family. This longing to become pregnant again and move forward created additional stress for her when she failed to do so in her expected timeframe.

"I'm still not pregnant. We're still trying. It's very hard. All we want is a family, and every month it's negative, and it reminds me of the one we lost. And I got all excited because I didn't get my cycle for three months but then we did a test and it was negative. Heartbreak all over again." (Stillbirth, 31 weeks/ Interview 2)

**Filling the void.** For women who conceived again soon after loss, the reality of being pregnant again was reported quite positively despite some initial uncertainty. In particular, the women described how being pregnant again provided a welcome "distraction" from the all-consuming grief they felt, and reinstated a sense of purpose and hope.

"The further along I progressed in the pregnancy, the more comfortable I became with it. It helped me to heal. Being pregnant again provided me with the hope I needed of being a mother. It taught me that Charlotte wasn't my only chance...I had another chance. And in this way it also helped me with the grief I felt for Charlotte, it was a distraction from the grief. Something to look forward to again." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"Being pregnant again is a very big distraction. Even though you are panicky throughout the next pregnancy, I wouldn't have wanted to wait all these months, thinking about it all now. The whole time waiting to fall pregnant, even though it wasn't that long, all I could think about was wanting to be pregnant and have something to look forward to again. I think I would have been in a depressed rut if I had waited 12 months before trying again as some people suggested. I mean, I know it's different for everyone, but I would tell people to go with what they feel. If they feel ready to start trying again then they should. Why wait? You're still gonna be thinking about the loss regardless of being pregnant or not, but at least you have something to distract you and look forward to." (Susan/ Stillbirth, 20 weeks/ Interview 2)

Several women felt that waiting would have prolonged the intensity of grief they were feeling, and that being pregnant again served to distract them from the depths of their despair. Some women suggested that a short conception period served to enhance their emotional recovery because conceiving again meant they were no longer preoccupied with the emotional and physical void.

"I think I really started to come to peace with it [baby's death] over the first couple of months [during the subsequent pregnancy]. I don't really know when it happened, but I remember a certain point where I could think about him without being sad. Where I could just be glad that he was here [deceased baby] and look forward to this one [new baby]" (Stephanie/ Stillbirth, 39 weeks/ Interview 3)

"We didn't expect to fall pregnant again so quickly, but when I find out I was really happy. I smiled, for the first time in a long time. And I didn't expect to react that way. I wasn't prepared. I mean, I only just lost my daughter so that was a lot to deal

with. But it didn't matter. I'll never get over it [losing her]. I can't change what happened. I just had to get on with it. And at least now I was excited again, I had something to look forward to." (Jenny/ Stillbirth, 21 weeks/ Interview 2)

"I'm glad I fell pregnant again so quickly. I think I still would have been deep in the grieving process otherwise. I felt so empty." (Grace/ Stillbirth, 41 weeks/ Interview 2)

### Pregnant Again: The Dark Cloud of Anxiety

Upon finding out they were pregnant again, the women described feeling mixed emotions. There was excitement, happiness, and gratitude that they were expecting another baby. At the same time, there was immense sadness over the baby they lost, together with intense fear and despair about the future and the prospect that it could all happen again. It was clear that the women experienced immense anxiety during their subsequent pregnancy, which impacted on their ability to fully commit to and enjoy their subsequent pregnancy. Ruth's feelings reflect how many women felt during their experience of pregnancy after loss

"I was happy with the news. But I was also very scared. My immediate thought was what if it happens again? And of course all the memories come flooding back. I still miss him and think about him all the time. It's been really hard." (Stillbirth, 31 weeks/ Interview 3)

I was robbed of the joy of being pregnant. All of the women in the study who endured a subsequent pregnancy (n=14) reported elevated levels of anxiety, regardless of the gestational trimester in which their loss occurred. This often led to strong feelings of panic and distress during the subsequent pregnancy, and many women described how they felt this overwhelming anxiety deprived them of the joy of being pregnant.

"I feel very cheated of the enjoyment of pregnancy now. Especially because I lost him full-term. There is no safe period. And I think that's one of the unfairest things about having experienced this loss. I loved being pregnant. And yes I'm very excited about being pregnant again, but I'm also terrified." (Emily/ Stillbirth, 40 weeks/ Interview 2)

Anxiety was particularly heightened in relation to specific areas of concern that were associated with the previous loss. For example, following two successive miscarriages, Olivia experienced intense anxiety when she started spotting within the first trimester and immediately feared the worst.

"The whole experience has been horrible, you can't imagine. About four weeks after I found out I was pregnant I started to get a brownish mucus again. I started to feel dizzy every time I walked and every time I saw the mucus I was in panic. All the memories came flooding back. I can't relax. I'm constantly worried." (Miscarriage, 18 and 12 weeks/ Interview 2)

For Grace, each ultrasound during her subsequent pregnancy was a traumatic and anxiety provoking experience. Every examination she was worried that she might be told there was no heartbeat. She was also deeply concerned about her baby's umbilical cord in light of the fact that her previous baby's death was attributable to difficulties with the absorption of nutrients to the placenta.

"It was a very anxious pregnancy. Every check-up, every scan. I was always worried. Hoping that everything would be ok. Especially the extra scan I had to check the placenta to make sure the baby was getting enough nutrients." (Stillbirth, 41 weeks/ Interview 3)

Anxiety was not limited to specific areas of concern related to the women's previous loss. It was evident that women had lost their sense of naivety surrounding pregnancy loss and they now felt vulnerable to the multitude of issues that could complicate their pregnancy. Consequently, their subsequent pregnancy was fraught with constant fear that death could reoccur. As Olivia and Grace's accounts demonstrate:

"I worry about issues like difficulties with the placenta, like in my first miscarriage, and then what else can go wrong." (Olivia/ Two miscarriages, 18 and 12 weeks/ Interview 1).

"I'm so aware now of all the things that could go wrong. So anything that's a slighter variation on last time, I think oh my gosh, this could be a sign that something's wrong! I start thinking what does this mean and I jump to all these conclusions. Sometimes to the point where I can't stop thinking about it and feel like I'm going to have a breakdown. I'm super anxious about this pregnancy. Last

pregnancy I was blissfully happy, ignorant, whatever you want to call it. This time I'm extremely cautious, anxious, constantly worried that something could go wrong." (Grace/ Stillbirth, 41 weeks/ Interview 2)

The 'safe' point? Just wake me up at term! When comparing pregnancy anxiety responses among gestational epoch, there were clear differences between the two groups. For women with a history of miscarriage), anxiety in the subsequent pregnancy appeared more elevated in early pregnancy (the first trimester), and lessened as the pregnancy progressed. In general, these women's anxiety decreased significantly once they made it past the first trimester or the 'critical point' of their previous loss, which once passed, provided an enhanced sense of security.

"I actually thought the anxiety would be a lot worse than it was. But once I got past that first trimester I was fine. I really started to enjoy my pregnancy." (Paige/ Miscarriage, 7 weeks/ Interview 2).

"Those first few months were definitely the hardest. Especially coming up to the point where I lost her. That was really difficult. I was really focused on making it past that half way mark... I don't know why I had it in my head but when I was half way I felt like right, it's going to be ok now." (Leanne/ Miscarriage, 18 weeks/ Interview 2).

The opposite effect occurred in terms of pregnancy related anxiety for women who had experienced a stillbirth. For these women, there was no 'safe' point. Anxiety persisted throughout the pregnancy and increased as the pregnancy progressed. There was no sense of relief until the baby was born healthy and alive.

"I was always worrying right up until the moment she was born. I was completely stressed even on the table giving birth to her, even though it was a caesarean. Until she actually came out and was crying and breathing, it was still panic station." (Susan/ Stillbirth, 20 weeks/ Interview 3)

"The pregnancy itself has been really hard. I've been for regular scans and every time they check the heartbeat I get a sinking feeling and I start to panic. I'm always worried that there will be no heartbeat that it could happen again. But when I hear it and they tell me it's all ok, I can relax a bit. But I can't completely relax until she's here kicking and screaming. And she will be here in just over 6 weeks. Then I can take a breath when she is here and healthy with us." (Ruth/ Stillbirth, 31 weeks/ Interview 3)

"It's still a week by week process. Every week I progress in this process and I feel another step closer to the end. But the thing is, I was full-term when we lost Charlotte, I was a week overdue even. We got to the end. There is no safe point." (Grace/ Stillbirth, 41 weeks/ Interview 3)

"I never felt comfortable or safe until the moment the baby was born. The anxiety never went away. I always felt like the baby was going to die. Yeah, it was only when they gave me the epidural that I kind of felt that maybe this baby was going to be ok." (Emily/ Stillbirth, 40 weeks/ Interview 3)

Not surprisingly, the point at which pregnancy related anxiety was described as most intense was approaching the anniversary of the loss, and this was true for both gestational groups. This was a point in time whereby the women experienced a complex interaction of grief and anxiety, which culminated in some sense of relief as this date passed.

"We are now at the stage where we lost him. It was 31 weeks, 2 days. Now I am at 31 weeks, 5 days. So the last two weeks have been extremely hard." (Ruth/ Stillbirth, 31 weeks/ Interview 3)

"I was very worried, highly anxious. Constant thoughts about what if I lose this one too? How I would cope. I thought it would be worse at the start of the pregnancy, but it actually got worse the further I went along. Especially as I got closer to the anniversary of when we lost our daughter [referring to passing gestation of stillborn baby's death at 21 weeks]. The day came, and I was very upset of course. But I actually felt quite a sense of relief when I actually reached the date [21 weeks]. My aim was to get to 23 weeks though because they told me that at least if he was born then he would be viable. So once I got to 23 weeks I felt a huge sense of relief." (Jenny/ Stillbirth, 21 weeks/ Interview 3)

Although some of the women who experienced stillbirth expressed relief at passing the critical point of their loss in the subsequent pregnancy, at no time did they feel completely safe. For example, Emily explained how being confronted with statistics suggesting the unlikelihood of another loss did nothing to ease her anxiety which persisted right up until the moment her son was born.

"I don't care about the chances of it not happening again, I don't care about stats." There is only a small percentage chance of something like this happening, yet I was the one with the rotten luck! And who's to say I won't have the rotten luck again? It was nine months of constantly being on the edge, fearing he was going to die." (Stillbirth, 40 weeks/ Interview 3)

Similarly, Audrey's frustration at others suggesting she was 'safe' was also evident.

"One of the nurses actually said to me, you're over your danger period now, everything will be ok. I thought are you serious? How can you even say that? There are no guarantees. I was totally baffled. She had no idea. It was such a stupid thing to say." (Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 2)

Among women who experienced a stillbirth, the anxiety felt was so intense that several women mentioned that they wished they could just fast forward or bypass the pregnancy journey so they didn't have to endure the anxiety on a daily basis.

"I wish I could just go to sleep and wake up again two years later and have a healthy baby. Or I wish I could just see some psychic who could tell me exactly what was going to happen and that it will all be okay. Especially because I lost full-term. There is no safe period. And I feel like punching anyone who tells me otherwise that it will all be ok...because they don't know that!" (Emily, Stillbirth, 40 weeks/ Interview 2)

"You know, I just want someone to put me in a coma and wake me up after the caesarean! Fast Forward!" (Grace, Stillbirth, 41 weeks/ Interview 2)

Elevated anxiety following multiple losses. Among those women who had suffered multiple losses, an even greater sense of anxiety was clearly evident during the subsequent pregnancy. These women were all too aware that it could indeed happen to them again. For example, Olivia described how the trauma and distress of her previous miscarriage impacted on her subsequent loss:

"I lost my first baby in the toilet...there is no way I can forget that image. And with this second one, imagine, every time I went to the toilet I was looking in the bowl, every time. And one day I started pouring blood, like an open tap... I rushed to go to the toilet and that was it. I knew at that time it was finished, it was over. My heart sank." (Two miscarriages, 18 and 12 weeks; Interview 1)

Having had the experience of two previous miscarriages, Olivia had reservations about the reality of ever being able to have any more live-born children. The fact that she had a healthy baby girl as her first born did nothing to ease her level of distress or anxiety.

"The truth is that there could be something wrong with me. I mean, the time I am losing is getting shorter and shorter. The first time I lost was at four and a half months, the second loss at three months...I may lose the next one at 6 weeks..."

(Miscarriage, 18 and 12 weeks/ Interview 1)

Maria experienced a subsequent loss during the course of the interview process, a second miscarriage at seven weeks. This reality made her question whether or not her first child, her daughter, would be her only chance at being a mother. She rationalised that the first time was just an unlucky occurrence, but the fact that it happened again was a real shock.

"I wanted to focus on preparing myself for the next pregnancy, so I tried to put it [the miscarriage] out of my mind and focus on the future. Then it happened again, I couldn't believe it." (Two miscarriages, 8 and 7 weeks/ Interview 2)

Maria described how her fourth pregnancy was subsequently burdened with anxiety, as she was now concerned that there may have been an underlying factor which was accounting for her losses.

"The pregnancy with Ava was riddled with stress because of the previous miscarriages. I thought whatever made me miscarry might also affect that pregnancy too. I was so stressed and anxious until about 30 weeks...because then I knew the baby would be safe if I had to deliver early for some reason." (Interview 3)

Having suffered a previous miscarriage at 15 weeks and a stillbirth at 25 weeks, Audrey commented that she never fully entertained the prospect of giving birth to a healthy child as she was always fearful the baby wouldn't make it. Influencing this belief was a recurring dream Audrey had that something would go wrong at 36 weeks, so when she gave birth to a healthy son at 38 weeks the experience was quite surreal.

"The whole pregnancy I was really anxious. I mean, I'd had two losses now, and none of my pregnancies have been easy. I also had a dream that at 36 weeks I had a baby boy that was dead. So I couldn't get excited about the pregnancy. I mean, my intuition, I really believed within myself that everything would be ok. But inside my head I felt something would go wrong...the anxiety and the stress was horrible. It consumed me. That innocence is gone. So it wasn't until I was actually being induced that I actually realised I was going to have a baby. I know that sounds weird, but I actually remember looking at my partner and saying to him oh my gosh, we're actually having a baby!"

(Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 3)

**An emotional rollercoaster.** The subsequent pregnancy was not only a time of immense anxiety and fear, but it was also a time of continued grief. The women reported that they were anxiously anticipating and trying to be happy about the new baby that was coming, whilst they were continued to mourn the baby that they lost.

"For some reason I thought that as soon as I would be pregnant again things would be easier...but funnily enough it's not. I still have the grief, I still feel really mad at losing [baby]...I still hate pregnant women and babies...I'm still on this up and down rollercoaster." (Emily/ Stillbirth, 40 weeks/ Interview 2)

"It's always there [the grief], it's ongoing. I'm always thinking about it." (Susan/ Stillbirth, 20 weeks/ Interview 2)

"I'm nearly 6 months pregnant now and I still think about Charlotte a lot. And I still cry a lot. It doesn't seem to take much to bring it all back. It's a bit of a strange situation, I still have all this grief and this loss, but I also have this hope." (Grace/ Stillbirth, 41 weeks/ Interview 2)

This complex interaction of grief and anxiety was difficult and upsetting for the women who were actively trying to remain positive and optimistic about the expectant baby. The women described a myriad of mixed emotions, as the following excerpts illustrate:

"I feel like my hormones are all over the place, which is normal so they tell me. But I just find myself crying for no apparent reason. Standing in the shower, crying. Crying whilst I'm driving. Either thoughts of losing Charlotte, missing Charlotte, what it would have been like if she was in the car with me now. Then there are thoughts of losing this one. Thinking how I would cope. My mind just races." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"It's still hard. I still think about him and miss him a lot. She's doing well and I'm happy but also very scared. I'm scared it could all happen again. And then I'm also very sad because we had really hoped for a boy and I still miss my son. Every time we go to Target I will always have a look at the boys stuff as well and think about him. But we're also very excited about having a girl" (Ruth/ Stillbirth, 31 weeks/ Interview 3)

"I've been so up and down during this pregnancy. I'm really happy that I'm pregnant, but there's a lot of mixed emotion there. I've been going to counselling every two weeks now to help me deal with it. She's been helping me a lot with my anxiety issues in addition to my grief with Christian." (Phoebe/ Stillbirth, 40 weeks/ Interview 2)

In addition, many women carried a lot of anger and resentment with them through the subsequent pregnancy. They remained angry at their loss, angry at others who they perceived as directly or indirectly responsible for their loss, and angry at the situation in general – to have to endure a pregnancy all over again.

"I'm still so angry at that lady in emergency, I still blame her for my second miscarriage. She turned me away... And I know there are problems against them, there's not enough space and beds and whatever. But she knew my history and she still turned me away. And had my husband not been there, I probably wouldn't be here today. And now I'm going through all this again..." (Olivia/ Two miscarriages, 18 and 12 weeks/ Interview 2)

"I still feel a lot of anger towards pregnant women, and those with healthy babies. I have a lot of trouble dealing with that. In the sense that they have what I didn't have. And everyone loves you when you're pregnant. It's such a special time and they're excited for you." (Emily/ Stillbirth, 40 weeks/ Interview 2)

### **Coping with Anxiety During the Subsequent Pregnancy**

When reflecting upon their experiences of anxiety in the subsequent pregnancy, it was clear that the women engaged in a number of self-protective behaviours in order to reduce their anxiety. These behaviours restored a sense of control over the pregnancy, as the women tried to do all they could to give their baby the best chance of survival. The anxiety specific behaviours are grouped into four separate subthemes: looking for reassurance, trying to regain a sense of control, reluctance to bond with the baby, and withholding preparations and celebration. These are described below.

**Looking for reassurance.** A major underlying theme was the tendency of the women to continually seek reassurance that everything was well with their baby during their pregnancy. To achieve this, the women engaged in a number of proactive behaviours such as increasing the frequency of ultrasound checks, purchasing a Doppler for home usage, and consulting with specialists. The overall aim of these behaviours was to gather

evidence that all was progressing well with their unborn baby, and consequently, alleviate the anxiety they were feeling at the present time.

"We bought a little heart monitor so we can listen to the heartbeat ourselves at home. Every once in awhile we take it out just to see that it's all okay." (Ruth/ Stillbirth, 31 weeks/ Interview 2)

"Each ultrasound that is normal gives me some relief. My last one was at 16 weeks and they also checked my cervix and there were absolutely no problems. They told me not to worry... I also have an appointment with my specialist every month, just for my own piece of mind. Financially it's quite expensive, I can only just afford seeing the specialist but it's important and I will continue to see them." (Olivia/ Two miscarriages, 18 and 12 weeks/ Interview 3)

"I asked at the ultrasound if they could take a special close-up of the cord...just for a piece of mind." (Stephanie/ Stillbirth, 39 weeks/ Interview 3)

For those women who endured a previous stillbirth, the desire to experience foetal movement in the subsequent pregnancy was a common occurrence. This was interpreted as a sign that all was well with the baby for the time being, as Phoebe's statement demonstrates:

"I'm really looking forward to when this baby starts moving. And I hope it moves a lot cos Christian really wasn't much of a mover. So I hope that will be different this time." (Stillbirth, 40 weeks/ Interview 2)

Jenny and Grace shared a similar experience during their subsequent pregnancy.

"Luckily this pregnancy is very different to the last one. I wasn't as sick this time, he moves a lot, he's bigger than she was...he's very active and he lets me know all day that he's here! (Jenny/ Stillbirth, 21 weeks/ Interview 3)

"I think I have to remind myself that this one's not Charlotte. And this one's like a little spider monkey, she moves all the time, all over the place! Very different to Charlotte, so that's been good" (Grace/ Stillbirth, 41 weeks/ Interview 2)

"I was pretty reserved to begin with, then I was happy for awhile, before the fear set in again and I felt it was all going to be too hard... Then the baby started kicking which helped me calm down a bit. He kicks a lot which makes me think 'this one is strong! He can look after himself!" (Stephanie/Stillbirth, 39 weeks/Interview 3)

Consequently, when foetal movement was absent or different from the norm, the women were notably concerned and sought immediate reassurance.

"I need to feel him move in the morning and at night, and then I'm happy. I mean, I didn't feel him move the other night and my immediate thought was that he's dead. So I'm straight to the hospital to find out whether or not he's still alive." (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 3)

"When this one doesn't move as much as she usually does, I get worried and begin to ask questions. Recently she's begun to move differently, it feels more like a poke than a kick now. And I asked the Doctor why that was because I was concerned. He said it was nothing to worry about as she is getting bigger and has less room to move which is normal." (Ruth/ Stillbirth, 31 weeks/ Interview 3)

Following a previous stillbirth, the women were routinely assigned a label of 'highrisk' on their medical records, which meant that they now received an elevated level of care. Having the acquired label of 'high-risk' was viewed as positive, as the women were encouraged to seek greater access to desired health care services (such as more frequent ultrasounds, access to the 'gold team' at the hospital). Importantly, the women reported that they were never made to feel silly for feeling overly anxious, and that medical personnel were accommodating to their needs for reassurance.

"We had a lot of trips to the hospital in the middle of the night. Because every time I didn't feel him move as much I was worried. But they were great, they knew my history and understood why I was there." (Emily/ Stillbirth, 40 weeks/ Interview 3)

"My doctor has been very good. He's been monitoring me and reassuring me that everything will be ok. He's very supportive." (Jenny/ Stillbirth, 21 weeks/ Interview 2)

"I saw my obstetrician every two weeks for 5 months. And she was so lovely. If I wanted an ultrasound she would let me have one. And I asked for many ultrasounds, just to assure myself that my baby was alive. And it was never a problem." (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 3)

Overall, the women spoke positively about the level of care they received in the subsequent pregnancy as 'high-risk' patients.

"They explained that now because I am high-risk I will be getting more frequent scans and I'll also get swabs in case of infection...all those things will be monitored on a weekly and fortnightly basis. So I know we are going to be well looked after." (Susan/ Stillbirth, 20 weeks/ Interview 2)

"The doctor we have is really great. When I ask questions she explains things to me at length, and if she can see that I'm still not quite getting it, she explains it again. And now it's every two weeks that I have a scan and blood test to make sure everything is fine. That may seem like a lot but I'd rather have too many, than not enough. And she really cares. She told me that anytime I have any questions or need to speak to her I can just call her. Every time I have a blood test she will go through everything with me and explain the results." (Ruth/ Stillbirth, 31 weeks/ Interview 3)

"My obstetrician has been really good. Even when I've been completely irrational he's been able to calm me down. And he knows my history, he has that understanding of what I've been through." (Grace/ Stillbirth, 41 weeks/ Interview 2)

Consequently, for some women there was almost an underlying sense of resentment that they did not receive such thorough care during their previous pregnancy. This prospect led to a lot of 'what if' questions, that maybe if they had "just been for more frequent scans" the outcome may have been different. As Ruth's comment demonstrates:

"I'm still very upset that it took losing him first, to get the care we are receiving now. Why didn't we have more routine scans just to make sure everything is fine? I know it's not going to bring him back now but I can't help wondering if things would have been different. I mean, I come from overseas and over there we have a check-up every 4 weeks when we are pregnant. Australia is so advanced, yet the medical system leaves a lot to be desired." (Stillbirth, 31 weeks/ Interview 3)

#### Susan shared similar feelings:

"When they found out my history, there was definitely a turn around. The care and attitude changed. I'm a lot happier with the standard of care now...they are willing to monitor me more closely now that I'm higher risk. I've joined the Gold Team now so to speak! And this time around I've been for more frequent scans to make sure everything's alright and it's never been a problem. Very different to last time when I was concerned and they wouldn't even look, they wouldn't even do a scan! I had to wait until the appointment with my obstetrician. And you know, there are at least six different scanning centres I know of so surely they could set up some appointments at other clinics? I know that seems excessive, but it would be piece of mind to have the option there." (Stillbirth/ 20 weeks/ Interview 2)

Trying to gain a sense of control. Considering the heightened sense of vulnerability the women felt following their loss, many became preoccupied with doing all that they could to control the outcome of their subsequent pregnancy. Some researched on the Internet what they could do to help minimise their chances of another loss, whilst others consulted with medical specialists to ascertain whether or not there was an underlying problem that could be rectified. For example, Phoebe did some research on how she could reduce her chances of stillbirth and shared the following:

"Did you know that you're more likely to have a stillbirth in the final stages if you're laying on your right side? Because you're laying on the main vain that supplies your uterus. That was in the British Medical Journal... And another piece of research I found... that your chances of having a stillbirth are also higher if you fall pregnant in the warmer months...because of the air-conditioning and all the germs you're exposed to." (Stillbirth, 40 weeks/ Interview 2)

Susan was also familiar with stillbirth research and altered her sleeping behaviour accordingly.

"I try to make sure I only lie one way, because I don't want to put pressure on the waters at all. And it's very uncomfortable on my side like that and I don't sleep very well because of it. So I'm very tired. And the Doctor told me to take Temazepam...but I don't want any medication whilst I'm pregnant. I've even gone off my other medication because one of the side effects for it is blindness! I mean, if it can affect me like that don't tell me it can't affect my baby. Whatever goes through my blood goes through the placenta into the bloodstream." (Stillbirth, 20 weeks/ Interview 3)

Susan also took extra precautions to ensure that she was doing all that she could to give her unborn baby the best chance of survival. She was conscious that she was going to the extreme now but didn't want to take any chances.

"I said to my husband...you're going to buy me that special chair for the computer now...all these sort of things, extra precautions. I'm on all these vitamin tablets too just to boost everything...visiting the wellness centre to check my protein levels, make sure I'm eating the right things...yes I've gone to the extreme now. I'm also going to cut down my working hours, go on to lighter work duties... I don't know if I was working too hard during the last pregnancy." (Interview 2)

This also included the decision to change hospitals this time around (from private to public) as Susan felt that the standard of care she received at the public hospital was much better, and consequently felt they would be more able to respond to her needs as a high-risk patient.

"I've changed my hospital to [public] now for the next pregnancy because I'm a lot happier with the standard of care and at least I know I'll be looked after there. They've old me I will have more regular check-ups and scans, you know, they will monitor me a lot more closely now that I'm high risk. Whereas if I go private, none of that will happen. My loss will be treated as an unfortunate event, like don't stress about it, it's an unlikely event that will never happen again, cos you know I've had two successful pregnancies and they'll just treat me as normal. I don't want that. I'd rather be swabbed every week or whatever...I'm high-risk now and want to be treated that way and know what to do. To be sitting there for nearly a week, when my life was at such high-risk, that's just not good enough." (Interview 2)

Further control behaviour was apparent during women's accounts of their desire to deliver early in the subsequent pregnancy. This often occurred at thirty-eight weeks gestation, the point in time when the baby was considered to be fully developed and the procedure relatively safe. For those women who scheduled a Caesar section or opted to be induced early, this was their preferred option. They did not want to prolong the agony and anxiety of carrying to term if they did not have to.

"I'm getting induced at 38 weeks. They said that from 38 weeks the baby is viable. And we don't want to wait any longer than we have to. We don't need the extra worry." (Ruth, Stillbirth, 31 weeks/ Interview 3)

"I've already booked myself in for a Caesar. I want a completely different experience this time. I mean, emotionally going into labour again, and not knowing how the baby is responding...I don't want to do it again." (Grace/ Stillbirth, 41 weeks/ Interview 2)

Reluctance to bond with the unborn baby. During women's accounts of the anxiety they experienced in the subsequent pregnancy, it was evident that anxiety very much interfered with the intensity of attachment they felt for the developing foetus. Many women revealed a tendency to withdraw emotionally from the baby they were carrying, and several expressed a conscious effort to maintain an emotional distance 'just in case' they were to lose this baby as well. When discussing their difficulties investing emotionally in the subsequent pregnancy it became apparent that most women were engaging in this

behaviour with the intent to protect themselves from the pain and hurt of a potential future loss.

The women were extremely forthcoming about their difficulties attaching to their unborn baby. It was clear that they delayed preparations for the coming baby (such as postponing nursery preparations, refusing to buy clothes and toys, not selecting baby names), as well as restricted their emotional investment in the child (such as thinking about the baby, talking to it, visualising its future).

"I'm ten weeks pregnant now...I'm having a lot of trouble getting connected now. I want to give it all that I have like I did with Christian but I just can't. I was really attached to Christian and I lost him, and somehow I've got to figure out how to get that attachment back." (Phoebe/ Stillbirth, 40 weeks/ Interview 2)

"I'm trying not to get too excited, too attached, just in case. Even though the doctors have pretty much assured me it's going to be fine. I don't want to buy any toys just yet. I mean, with the other one I was feeling very attached, you know, we were already thinking of names and everything. Whereas with this one I just want to get past the 22 weeks, that's my focus at the moment. So yeah, I'm very nervous, so I'm holding back a bit." (Susan/ Stillbirth, 20 weeks/ Interview 2)

There's no planning for the future with this one...no planning a room, washing clothes, getting excited. Unfortunately something might go wrong, and I'd prefer to try and protect myself. It's always in the back of my head that something could happen." (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 3)

Withholding preparations and celebration. In addition to restricting emotional bonds with their baby during the subsequent pregnancy, the women attempted conceal their pregnancy and delay preparations for the baby's arrival. For example, several women described the extraordinary lengths they went to to hide their pregnancy, and how they withheld the news from family and friends for as long as possible. For example, Emily shared:

"It was kind of almost a sense of denial that I was even pregnant. I didn't want to talk about it. We tried to hold off telling people for as long as we could, we only told close friends. I just kept on wearing really baggy clothes! I also didn't put up on FB this time that I was even pregnant. So when I started putting pictures up of my son once he was born I had this whole bunch of people shocked saying 'wow I didn't even know you were pregnant!' It was quite a shock for people." (Stillbirth, 40 weeks/ Interview 3)

### Similarly, Audrey shared:

"I never wore anything tight around my tummy with him. Thinking about it now I think it was my way of protecting myself. He wasn't real in a way. I mean, I didn't even tell my mother's group that I was pregnant again. It wasn't until I only had 10 weeks to go that they noticed and actually said something!" (Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 3)

Several women shared their discomfort over others getting excited about their pregnancy. This was particularly true among those women who had experienced a previous late-term loss (stillbirth). These women were uncomfortable with the prospect of celebrating the impending birth, hence were reluctant to accept gifts or enjoy preparations for their baby's arrival. The women would have preferred for their pregnancy to have passed unnoticed, and that celebrations be suspended until the baby had arrived. In fact, celebrating the pregnancy often annoyed and upset the women, as the following excerpts illustrate:

"My friends bought a lot of little outfits and things, and honestly, I really wasn't very happy about receiving them. I felt quite upset, quite a weird sensation really. I mean, they're happy for you all over again but don't really understand my anxiety about this pregnancy. I wanted them to wait until she had actually been born. Because it's guaranteed then, she's here. For me, it's a week by week existence. Yes she's fine now, but that doesn't mean she'll be fine in a month's time. I feel it's a bit premature to start celebrating. Until this baby is in our arms." (Grace/ Stillbirth, 41 weeks/ Interview 2)

"My girlfriend organised a surprise baby shower for me at 28 weeks. And I was quite annoyed at her for organising it. And other people warned her against it, and I wish she had listened. I mean it was a great day but if it had been my decision I wouldn't have had one... And my Mum was going on about getting organised for the baby and making sure the clothes were washed and ready, and I was like no! I don't want to!" (Audrey/ Stillbirth, 25 weeks; Miscarriage, 15 weeks/ Interview 3)

"I'm very upset and angry when people are happy and excited for me! I just want them to hold off on the congratulations until the baby is here." (Emily/ Stillbirth, 40 weeks/ Interview 2)

Several women acknowledged that their refusal to engage in preparations for the baby's birth was contrary to their pregnancy experience before loss. They now felt vulnerable, that life could be taken away at any minute, and that conceiving again did not necessarily equate to a healthy baby.

"This time around I didn't buy anything for her until she was physically here. I had a lot of things on lay-buy. And also, I didn't talk about her as much as I normally would have. The excitement wasn't there as much. I was looking forward to having her but in the back of my mind I was always thinking of the possibility that something could go wrong." (Susan/Stillbirth, 20 weeks/Interview 3)

"So yes I'm pregnant again but I can't even comprehend that at the end of the pregnancy I might actually have a child. I'm taking each day as it comes. Whereas before when I was pregnant I was always thinking about my life 'when the baby comes'. Everything I did became about the baby, for the baby. But the baby did come and nothing changed." (Emily/ Stillbirth, 40 weeks/ Interview 2).

"This time I didn't get anything ready until 37 weeks. Only at 37 weeks did I get ready for him. Painting the walls, washing the clothes, I put it off for that long. Whereas with my daughter I was doing all of that at 20 weeks." (Audrey/ Stillbirth, 20 weeks/ Interview 3)

### The Subsequent Birth: A Bittersweet Reality

During the final interview period, several women experienced the labour and birth of their subsequent baby. The experience was described as bittersweet, and evoked many mixed emotions for the women. In particular, the women described continued mourning for their deceased baby. They spoke of longing and sadness, and their continued efforts to ensure their baby would never be forgotten. In addition, they described happiness and joy, and a strong sense of gratitude for their new baby.

**Continuity of grief and attachment.** In the initial months after they had given birth to their subsequent baby, several women spoke of an unexpected recurring sadness they felt for the baby they lost. The women did not expect that their grief would suddenly disappear after having another baby, but they were surprised at how much they continued to long for and mourn their deceased baby. In particular, spending time with their newborn

made them think about all the moments they had missed out on as a mother with their previous baby, and all the memories that would never eventuate.

"When she was born, it was funny because I really started to miss Jack. I missed holding and cuddling him. I thought about what he would look like now. It has eased a bit over time but I still think about him. And she looks so much like Jack did when he was born." (Stephanie/ Stillbirth, 39 weeks/ Interview 3)

"There was a point maybe a month after Elijah was born that I got really emotional about Noah. I think it was because I was just reflecting about the last month with Elijah and I realised that I had missed out on all this with Noah and I felt so sad. I cried a lot during that first month." (Emily/ Stillbirth, 40 weeks/ Interview 3)

"And there still isn't a day that has gone by where I don't think of him. He still pops into my head, he's always there. And I'm definitely not sad when I look at my daughter. I'm very grateful. But sometimes I do think about how different things would have been had my son still been here. I think about him nearly being a year and a half now. He'd be walking, all that stuff. But I also think about that my daughter wouldn't be here now if he was still here. So there's a lot of mixed emotions." (Susan/Stillbirth, 20 weeks/Interview 3)

"I think a lot about Charlotte now still, and that surprises me. I think about what she would be doing now if she were still here, she would already be a year old. But then I remind myself that Macey wouldn't have been created if Charlotte was still here because I wouldn't have started trying again after 4 months!" (Grace/ Stillbirth, 41 weeks/ Interview 3)

"I still wake up every morning and think about her. What she would be like if she were here with us now, probably crawling. I also look up at the picture of her in our bedroom and I say good morning to her in my head and smile. I don't cry much anymore, but some nights I still do cry and can't get to sleep because I miss her so much. I'll never get over it, and I can't change what happened, but I just have to try and get on with things." (Jenny/ Stillbirth, 21 weeks/ Interview 3)

Although the women continued to grieve for their deceased child, this did not appear to have a negative impact on their emotional wellbeing. In fact, the women appeared quite comfortable in their grief and sadness, and they did not consider it was necessary or even possible to ever 'get over' the death of their baby. Although upsetting, thinking about 'what could have been' was a way in which the women could keep the memories of their baby alive. Hence, the women made special efforts to ensure continuing bonds with the

baby they lost and were adamant that this would never change. They felt they would always acknowledge the child as part of the family, no matter how much time passed.

Indeed at 13-18-month follow-up interviews, several of the women who now had another baby conveyed how their new son/daughter would always know of their siblings' existence:

"He will always be our first baby, our first son. He will always be here in our thoughts. And that won't change no matter how many children we have." (Ruth/ Stillbirth, 31 weeks/ Interview 3)

"We will always grieve for our first born son...And Elijah will know one day that he has an older brother." (Emily/ Stillbirth, 40 weeks/ Interview 3)

"I still really miss Charlotte. And Macey is never going to be a replacement child for Charlotte. Macey will always know that she has an older sister and every year we will go to her memorial" (Grace/ Stillbirth, 41 weeks/ Interview 3)

"I finally found the right urn for her ashes, and she has her special spot. And her brother knows where she is as well and often points to her, saying proudly 'that's Rose up there!' He knows that's his sister. And that's what I want my family to do, acknowledge her existence. She's my daughter and always will be." (Jenny/ Stillbirth, 21 weeks/ Interview 3)

A mixture of happy and sad. Although the women commented that they would give anything to have their deceased baby back, having a new baby enabled them to reach a greater state of acceptance and resolve some of the bitterness they were feeling.

"I thought my life was over before. I thought I'd always feel as sad as I was. But having Elijah has been very healing. He's such a special boy. Once I had Elijah all my anxiety disappeared, all my bitter thoughts have gone about other women with babies. I no longer feel that jealousy. Before when I saw a pregnant lady I was just so angry at all these other pregnant women, but now that's all gone." (Emily/Stillbirth, 40 weeks/ Interview 3)

"It's just amazing. I finally feel like I have a family now, my own family. I'm not so angry anymore...this is what I wanted and I can't stop smiling every time I look at her!" (Phoebe/ Stillbirth, 40 weeks/ Interview 3)

In addition, the women reported that they felt immense happiness and gratitude following the birth of their subsequent child. The women described how they cherished every moment with their newborn baby, and how lucky they felt to have a healthy newborn.

"Having Luke has been the most amazing, surreal, exhilarating experience of my life. I can't imagine a day without him and it's such a joy being his Mum. If only I could slow down time. It all goes so fast and I'm trying to savour every moment." (Paige/ Miscarriage, 7 weeks/ Interview 3)

"When I look at Macey, she's just an absolute blessing. I'm very content now. I'm so grateful. And I catchmyself sometimes when I'm getting annoyed that she doesn't sleep straight away, or she's being grizzly, and I just remind myself how lucky I am to have her here." (Grace/ Stillbirth, 41 weeks/ Interview 3)

"I can't stop looking at her. I could look at her all day. All these cute little faces she pulls...I'm afraid if I look away for even a second I'll miss out on something!" (Phoebe/ Stillbirth, 40 weeks/ Interview 3)

### **Summary**

The findings in this chapter demonstrate that the subsequent pregnancy creates immense psychological distress for women who have experienced a previous pregnancy loss. Specifically, the subsequent pregnancy is characterised by intense anxiety, together with enduring grief. The anxiety experienced is a result of the continual fear of a recurring loss, leading to increased hypervigilent behaviour and a constant need to have everything under control during pregnancy. At the same time, women continue to grieve for the baby they lost and they have difficulty investing emotionally in their subsequent child during pregnancy because they want to protect themselves from further grief. The result is ambivalence towards wanting to be happy and hopeful for the expectant child, while still grieving for the previous child and being afraid that it could all happen again.

The following chapter will discuss the findings that emerged from the analysis in light of existing research.

Chapter Seven: Discussion 195

#### **Chapter 7: Discussion**

The women in this study described their experience of pregnancy loss as a painful and life-altering event. Unsurprisingly, for the majority of women this experience included the experience of a subsequent pregnancy, and for some, the experience of postpartum delivery of a healthy baby. In many ways, women's experiences reiterated those of previous studies, including; the incidence of perinatal grief and psychological distress (Hughes & Riches, 2003; Murphy et al., 2014; Radestad et al., 2009), the importance of spending time with the deceased baby and creating mementoes (Cacciatore, 2010; Gold et al., 2007; Klass, 1999; O'Leary & Warland, 2013; Radestaad & Christoffersen, 2008; Schott et al., 2007), the influence of milestones and anniversaries (Armstrong, 2001; Cote-Arsenault & Mahlangu, 1999; Rando, 1993; Robertson & Kavanaugh, 1998), the need for emotionally sensitive and appropriately responsive support (Gold et al., 2007; Hughes et al., 2002; Koopmans et al., 2013; Peters et al., 2014; Pullen et al., 2012; Saflund et al., 2004) and immense anxiety in the subsequent pregnancy (Amato, 2008; Armstrong, 2006; Bergner et al., 2008; Caelli et al., 2002; Cote-Arsenault, 2003; Craig, Tata, & Regan, 2002; Franche & Mikhael, 1999; Gaudet et al., 2010; Hunfield, Wladimiroff, Verhage, & Passchier, 1995; Lok & Neugebauer, 2007; Mevorach-Zussman et al., 2012). However, women's experiences also contribute some new information on these perspectives, and in some cases, contradict the findings of previous research.

The findings of this study challenge what has previously been reported about the trajectory of grief following pregnancy loss, the negative impact of bereavement on the spousal relationship, and the timing of the subsequent pregnancy. The study also uncovered new information, including; the need to consider meaning-making and investment in pregnancy as a crucial indicator of bereavement response, the potential disregard of

posttraumatic stress, the need to offer extended continuity of care that considers both medical and psychological aspects, the incidence of post-traumatic growth, and the reintegration rather than resolution of grief. In this chapter, each of these considerations are examined and critiqued in the context of existing research.

## Grief and Pregnancy Loss: Beyond the Dominant Discourse

Consistent with existing perinatal literature, grief was a significant component of the bereavement experience among women who experienced pregnancy loss (Badenhorst & Hughes, 2007; Boyle et al. 1996; Gaudet et al., 2010; Kersting & Wagner, 2012; Lang et al., 2011; Lin & Lasker, 1996; Murphy et al., 2014; Neugebauer & Ritsher, 2005; Radestad et al., 2009). When confronted by the news of their baby's death, women experienced profound shock, numbness, and disbelief as they struggled to grasp the series of events that unfolded. This grieving experience was accompanied by marked psychological distress, and women encountered strong feelings of anxiety, despair, anger, isolation and guilt (Cacciatore, 2010; Campbell-Jackson & Horsch, 2014). In addition, the grieving experience was distinct in its presentation compared to other child losses. Rather than grieving for a piece of their past, women were predominantly grieving for their loss of future, that was now irrevocably changed (Bennet et al., 2005).

The experience of pregnancy loss was complex, and comprised of many supplementary losses, including the loss of self-esteem, aspirations of parenthood, loss of pregnancy, and a loss of naiveté that transpired into fear over the ability to create another life (Lamb, 2002). In comparison to other forms of bereavement, women conveyed a disenfranchised grieving experience where they struggled to cope in a society where their loss was viewed as less significant than other forms of bereavement (Froen et al., 2011; Vance et al., 1995). Consequently, women felt largely isolated and invalidated in their

grief, a reality that appeared to impede the grief process and make the experience of loss more difficult.

Whilst these psychological responses to pregnancy loss have been recognised previously, the literature has predominantly focused on making comparisons between miscarriage and stillbirth, specifically, on the impact of gestation on attachment and grief intensity (Cuisiner et al., 1993; Goldbach et al., 1991). Although it is recognised that women can form attachments early in pregnancy (Gold et al., 2010), it is widely accepted that the further along the pregnancy has progressed, the more severe the grief reaction (Goldbach et al., 1991). Whilst this conclusion may hold some truth, comparing miscarriage to stillbirth does little to promote understanding of the grief process specific to pregnancy loss, and only serves to perpetuate the stigma that often leads to fragmented maternity care (Brownlee & Oikonen, 2004). Accordingly, it is a contention of the current study that the experience of maternal bereavement following pregnancy loss is a vulnerable time for all women who experience pregnancy loss, and care needs to be taken to ensure that the experience is wholly understood so that all bereaved women receive adequate support. In particular, consideration needs to be given towards the distinctive trajectory of grief following pregnancy loss, and the elements that serve to shape and define this unique bereavement experience. These include: meaning making and investment in pregnancy, post-trauma distress, reintegration not resolution of grief, and an altered sense of self.

#### **Meaning Making and Investment In Pregnancy**

Because of the strong emphasis upon how gestation affects the emotional intensity of grief, there is often a misconception that the degree of loss experienced is in proportion to the length of the pregnancy. However, what seems far more relevant is the loss of an expected child. The findings of the current study indicate that regardless of the type of

pregnancy loss (i.e., miscarriage or stillbirth), the women spoke of their loss as the loss of a person. Lindemann (2014) described this reality as the activity of 'calling the foetus into personhood', which simultaneously acknowledges the pregnant woman's identification of herself as a parent. On this basis, it is presumed that women interpret and make sense of their pregnancy loss, through the value and meaning they ascribe to their pregnancy (Stoyles, 2015). In other words, a woman's investment in her pregnancy contributes to her experience of psychological distress.

In the immediate aftermath of loss, women commonly described the same range of feelings reported in other bereavement situations, such as denial, anger, sadness, emptiness, guilt, blame, and preoccupation with the deceased (Adolfsson et al., 2004; Archer, 1999; Barr, 2004; Holland, Neimeyer, Boelean, & Prigerson, 2009; Maciejewski et al., 2007; Shuchter & Zisook, 1993; Stroebe, Hansson, Schut, & Stroebe, 2008; Stroebe, Abakoumkin, & Stroebe, 2010). Furthermore, feelings of anger, guilt, failure, and jealousy appeared especially elevated, and were complicated by feelings of inadequacy, doubts about femininity, and lowered self-esteem. Such consequences of bereavement appear unique to women who experience pregnancy loss, and appear to reflect the mother's grief over the loss of her much loved and anticipated child.

The devastation and hurt over the loss of the much-wanted child was notably apparent in women's descriptions of anger. Women professed a profound sense of anger directed at themselves, their peers, service providers, God, and other pregnant women. They described a great sense of injustice at not being able to fulfill their desire for a muchwanted child, and statements of "why me?" and "It's not fair" were prevalent. Being confronted by other pregnant women and babies was especially difficult, and resulted in feelings of sadness, envy and resentment. Internal projections of anger were just as

destructive, and often led to feelings of failure and shame. Such reactions feature prominently in the perinatal loss literature, which suggests that it is not at all uncommon for women to blame their pregnancy loss on themselves (Berg, Wilson, & Wingarter, 1991; Brkovich & Fisher, 1998; Lindsey & Driskill, 2013).

The assumption that pregnancy loss may threaten a woman's self-identity as a mother (Amato, 2008; Hsu et al., 2004) was also supported by the current findings.

Motherhood was described as a major life goal for many women, and women appeared to convey a strong sense of failure and shame that this life goal was not successfully attained. What appears so easy for other women was not, and the women felt incompetent in comparison. Thus, women may feel enormous guilt and shame for failing to meet the expectations of themselves and others, and may feel inadequate as a woman and mother, by not bringing a pregnancy to a complete and healthy outcome.

The findings suggest that the emotional impact of loss and therefore the grief experienced appears to be based on women's expectations and hopes for the wanted child. Regardless of whether women experienced a miscarriage or stillbirth, they still grieved for the loss of their baby. The baby was perceived as a much-wanted child, and for most women, was considered a 'real being' from conception. This suggests that the degree of investment in the pregnancy, or the value or the meaning of pregnancy loss, may be a much more important consideration than gestational influences alone (Robinson et al., 1999; Stoyles, 2015).

#### **Post-Trauma Distress**

The reality of grief reactions following pregnancy loss is corroborated by studies that report significant deterioration in health and psychological functioning among women who experience loss (Beutel et al., 1995; Blackmore et al., 2011; Brownlee & Oikonen,

2004; Grekin & O'Hara, 2014; Hughes et al., 1999). Often, these reactions are enduring and can lead to prolonged psychological distress (Brier, 2004; Geller et al., 2004; Klier et al., 2000; Swanson, 1999; Turton et al., 2009). In the current study, the women spoke of significant sleep disturbances such as nightmares and flashbacks over the events leading up to their baby's death, and waking up hoping it had all been a bad dream. They described difficulties falling asleep or waking in the early hours of the morning as they recounted traumatic memories of their loss or wondered what they could have done differently. Such ruminative activity was also present during waking hours and the women described feeling consumed by their grief and that it was difficult to focus on anything else.

Such findings are consistent with indicators of post-traumatic stress disorder, where re-experiencing the trauma in the form of nightmares and flashbacks is a common occurrence (American Psychiatric Association, 2013). Indeed, many women described symptoms typical of post-traumatic stress disorder such as: continual re-living of the event (being told there was no heartbeat), the need to avoid stimuli that reminded them of the event (pregnant women, babies, baby-related items), as well as significant emotional distress (emotional numbing, yearning, fear, anger, guilt, shame).

This finding suggests that women who experience pregnancy loss may be at high risk for developing posttraumatic stress or posttraumatic stress disorder, but are not being identified. Indeed, a recent systematic review exploring posttraumatic stress (PTS) and posttraumatic stress disorder (PTSD) following pregnancy loss suggested that despite growing evidence of adverse psychological states associated with pregnancy loss, PTS and PTSD have not been well recognised amongst this population (Daugirdaite, Akker, & Purewal, 2015). Other studies have concurred, reporting high percentages of women

meeting partial or full criteria for PTS or PTSD following miscarriage or stillbirth (Forray, Mayes, Magriples, & Epperson, 2009; Gold & Johnson, 2014).

The high risk of posttraumatic distress among women who experience pregnancy loss was particularly evident in their descriptions of labour and birth. This experience was described as immensely traumatic and distressing, and was a time of momentous grief. The women had to endure the physical and emotional experience of labour and birth with the full knowledge that there would be no healthy newborn at its completion. Several women described how the process was so immensely painful and exhausting that they dissociated during labour and birth. Dissociation occurs when an individual experiences disruption of consciousness, memory, identity, or perception (American Psychiatric Association, 2013). It may encompass an array of responses, including disturbances in experiences of time and place, a sense of detachment from oneself, and perceptual or memory distortions (Bui et al., 2013).

Although little is known about the role of dissociation experienced during or immediately after the loss of a loved one (Bui et al., 2013), recent research in the field of trauma has indicated that 'peritraumatic dissociation' is associated with increased risk for the development of post-traumatic stress disorder (Bui et al., 2013; Ozer, Best, Lipsey, & Weiss, 2003). In addition, dissociative reactions reflect one of the intrusive symptoms required for a diagnosis of posttraumatic stress disorder, along with the marked alterations in arousal, reactivity and mood state as described above. Hence, consideration and exploration of women's dissociative experiences, and assessment of posttraumatic stress, may be an important function of intervention practices designed to target emotional processing of the baby's death.

## **Reintegration Not Resolution of Grief**

In terms of the course of their grief, the women described oscillating between their emotions rather than following a linear progression of stages. In addition, they reported certain days and dates where they experienced greater grief intensity, which reflected the ongoing nature of their grief. Frequently described as 'anniversary reactions', these upsurges in grief intensity are common and have been referred to in the literature as STUG (Subsequent Temporary Upsurges of Grief) (Rando, 1993).

This notion of fluctuating between emotions is consistent with Stroebe and Schut's (1999) Dual-Process Model and Rubin's (1999) Two-Track Model of bereavement, which emphasise the non-linearity of grief. Furthermore, this representation depicts grief as a continuous process of emotional adjustment rather than a recovery from grief per se. The women conveyed that whilst they would never "get over" the loss of their baby, their grief did become "easier" over time. They learnt to cope through a process of reintegration and adjustment, and as time passed the experience of loss became more bearable.

The women's continuous efforts to purposely integrate their deceased child into their lives in a meaningful way, is also consistent with a reintegration rather than resolution model of grief. Described in the attachment literature as 'continuing bonds' (Field et al., 2005; Klass et al., 1996; Ronen et al., 2010), maintaining an emotional sense of connection with the deceased (e.g., thinking about the deceased, holding onto positive memories, feeling their presence, and cherishing the deceased's belongings) appeared to bring a sense of comfort to the bereaved. Such bonds do not represent denial of the reality of the death, but offer an ongoing, renegotiated relationship with the deceased (Capitulo, 2005; Klass et al., 1996). This finding is in contrast to earlier models of bereavement which stipulate that the overall goal of grieving is to free oneself from the emotional attachment with the

deceased, whilst working towards its eventual resolution (Bowlby, 1961, 1980; Gorer, 1967; Kubler-Ross, 1969; Lazare, 1979; Lindemann, 1944; Parkes & Weiss, 1983). It also contests previous research that implies an association between continuing bonds and difficulties recovering from loss (Boerner & Heckhausen, 2003; Stroebe et al., 2012; Stroebe & Schut, 2005). Instead, maintaining a sense of emotional attachment with the deceased baby appeared to facilitate adjustment among the majority of bereaved women in the current study.

The women spoke openly about their experiences of thinking about what their baby would look like, or what their life might look like if their baby were here today. In addition, they found peace in ensuring these connections were maintained and looked for meaningful ways in which their deceased baby could be remembered. They purchased special items such as jewelry or other memorabilia to honour their baby's memory, held vigils, shared mementoes, or engaged in other practices to ensure their baby's presence was acknowledged. This positive association between continuing bonds and adaptive coping is underreported in existing literature, and there remains controversy over whether continuing bonds are maladaptive or integral to successful adaptation (Field et al., 2013; Klass, 1996; Ronen et al., 2010; Stroebe et al., 2005). However, recent research suggests that the manner in which continuing bonds are expressed (comforting compared to distressing in nature), and the experience of personal growth as a result of loss, may be indicative of more adaptive coping (Field et al., 2013; Stroebe, Schut, & Boerner, 2010). Consequently, further research on the influence of continuing bonds on grief reactions is warranted, to ascertain how enduring connections with the deceased may best facilitate mourning.

Chapter Seven: Discussion 204

#### **An Altered Sense of Self**

Women's accounts of their bereavement experiences revealed an inherent transformative process of both positive and negative change. The women spoke of positive growth as an outcome of their bereavement experience, reflected in the themes of acceptance and spiritual growth, and empathy and gratitude. In particular, they described increased personal strength, a greater appreciation for life, improved intimacy with significant others, enhanced coping, greater empathy for others who have experienced loss, and spiritual development as positive characteristics of their bereavement experience. Such findings are not unusual in the aftermath of loss, and descriptions of psychological growth, spirituality, and positive health outcomes following bereavement are becoming increasingly common (Balk, 1999; Bray, 2013; Bogensperger, & Lueger-Schuster, 2014; Calhoun & Tedeschi, 2004; Gerrish, Dyck, & Marsh, 2009; Grof & Grof, 1990; Shaw, Joseph & Linley, 2005; Sormanti & August, 1997).

Specifically, the findings of the current study are consistent with the dimensions of posttraumatic growth identified by Calhoun and Tedeschi (2004) and Grof and Grof's (1990) model of psycho-spiritual transformation. Tedeschi and Calhoun's model of posttraumatic growth reflects the bereaved individual's struggle with existential questions, change, and meaning making as they manage their emotional distress in the aftermath of loss. Through intense cognitive processing (i.e., rumination, writing, and talking), the bereaved individual begins to acquire new wisdom and understanding that alters their worldview and leads to a spiritual awakening and a greater appreciation of life (Bray, 2013). Grof and Grof (1990), described this psycho-spiritual transformation as 'spiritual emergence'.

In the current study, many women reflected upon how they engaged in meaning making and rumination as a fundamental part of their 'grief work'. For some, engagement within the spiritual domain facilitated this adjustment, as the belief in a higher power and the idea that the death was 'God's will' helped to ease the pain and foster acceptance (Davis & Noelen-Hoeksema, 2001; Davis, Wortman, Lehman, & Silver, 2000). For other women, consideration of contextual factors appeared to enhance coping and facilitate acceptance of loss. Chloe (23) was young, single, living at home, and her pregnancy was unplanned. Whilst she did cry most days during the first few weeks following her stillbirth, she was focused on remaining strong and putting things into perspective. She reminded herself that she was still young, had her whole life ahead of her, and would get a second chance when she was ready and in a stable relationship. This rationalisation appeared to aid her in making sense of her loss, and assisted her to process her grief.

Such 'sense-making' and interpretation appeared to assist women in accepting and adjusting to their loss. Indeed, as Bonanno (2009) suggests, reactions to grief are almost purposely designed to help individuals' "accept and accommodate losses relatively quickly" so that they can "continue to lead productive lives" (p.7). The underlying assertion is that individual's who are able to find meaning and/or 'positives' in their loss, will be better adjusted (Balk, 1999; Calhoun & Tedeschi, 2001; Schaefer & Moos, 2001). Furthermore, some theorists have advocated that meaning-making is an essential component of 'successful' grief (Currier, Holland, & Neimeyer, 2006; Davis et al., 2000; Gamino & Sewell, 2004; Polatinsky & Esprey, 2000).

In addition to positive growth, the bereaved women also described an acquired vulnerability and perceived loss of control in response to their baby's death. Both of these attributions were interpreted negatively as they served to complicate the grief experience

and made the experience of loss more difficult. In particular, women described feeling increasingly vulnerable to future adversity, as a result of their previous assumptions being violated. This concept of vulnerability has been acknowledged in other literature, as the bereaved become aware of the discord between their previously-held beliefs about the world being predicable and the reality of their sudden bereavement experience (Vickio, 2000).

Janoff-Bulman's 'Assumptive World Theory' (1992) proposes that prior to the experience of a traumatic event (i.e., death), individuals maintain positive perceptions of themselves and others, and believe in a just, meaningful, and benign world. Following a traumatic event, an individual experiences the shattering of these fundamental assumptions and begins to question themselves and the world around them (Janoff-Bulman, 1992). Hence, when a mother is not able to have a baby when and how she chooses, her world view may be altered as she comes to realise that the world is not predictable. Pregnancy no longer automatically equates to a healthy baby at the end of nine months, and this awareness may result in immense vulnerability and distress for women who formerly perceived themselves to have control over their reproduction (Lindsey & Driskill, 2013; Weisman et al., 2008). In particular, pregnancy loss may lead to insecurity over future childbearing outcomes and feelings of depression, anxiety and despair (Jaffe & Diamond, 2011).

This perceived loss of control and vulnerability over childbearing outcomes may extend to concern over other living children. For example, the bereaved women described being overprotective of their other children subsequent to pregnancy loss, as they now realised that "life can be taken away so easily". They described being "extra clingy" and hypervigilent in order to protect their children from harm. Similar overprotective and

reassurance seeking behaviours have been identified in other research. For example, Theut and colleagues (1992) explored the effect of pregnancy loss on subsequent parenting and found that women who had experienced pregnancy loss needed constant reassurance regarding the physical health of their subsequent child, out of fear that they might miss a medical problem which may cause their child to die. Warland, O'Leary, McCutcheon, and Williamson (2011) expressed similar concerns, their findings concluding that women engaged in a "paradoxical parenting style" following pregnancy loss where they tried to parent using several "diametrically opposed unsustainable options" (p. 163). This included trying to hold their subsequent child close, while holding them at arm's length; taking control whilst feeling out of control; loss of confidence in parental decision making, whilst feeling empowered to make decisions; and excessive checking on their child whilst at the same time trying to refrain from checking (Warland et al., 2011). Although bereaved parent overprotection and anxiety has not been specifically examined in the perinatal literature, these have been associated with a range of negative child outcomes, including externalising problems (Holmbeck et al., 2002), eating disorders (Shoebridge & Gowers, 2000), and anxiety and depression (Herbert & Dahlquist, 2008; Yahav, 2006).

## **Perceptions of Support: A Critical Catalyst**

While the bereavement experience is influenced by numerous factors, one of the most significant is the level of support one receives following bereavement (Cacciatore et al., 2009; Dimond, Lund, & Caserta, 1987; Dyregrov & Dyregrov, 2008; Egan & Arnold, 2003; Flannery, 1990; Hutti, 2005; Kavanaugh et al., 2004; Kohn et al., 2013; Sherkat & Reed, 1992). A support network relates to the supportive resources one has available, or turns to in times of need (Kavanaugh et al., 2004). Supportive behaviours consist of emotional, practical, material, behavioural, and social aspects, the outcome of which

depends on the quality and quantity received, as well as the manner in which a supportive behaviour occurs (Vaux, Reidel, & Stewart, 1987). However, supportive behaviours must be perceived as helpful by those receiving it for it to be beneficial (Kavanaugh et al., 2004).

The women in the current study described several examples of positive and negative support, during both their experience of pregnancy loss and in the subsequent pregnancy. These are divided into three distinct categories of support – caregiver, interpersonal, and social. With respect to caregiver support, the women identified caregiver attitudes and communication, preparations for labour and birth, the experience of giving birth, support to facilitate contact with the deceased baby, and the lack of continuity of care, as meaningful components of their bereavement experience. Interpersonally, seeking a shared grieving experience was pivotal, as indicated by the impact of partner support, and the women's efforts to access support from credible sources. On a social level, the women described the importance of facilitating, rather than constraining, grief expression.

# Caregiver Support: The Importance of Empathy, Guidance, and Respect

Caregiver Attitudes and Communication. Women's experiences of professional care indicate that they valued care that they considered was emotionally sensitive and appropriately responsive. When women consulted their general practitioners or other service providers to express their concerns, they expected these concerns to be addressed and further assessment to take place. Conversely, low levels of satisfaction were reported when women perceived their service providers to be dismissive, flippant, incompetent, neglectful, or lacking compassion. Such dissatisfaction with has also been documented in other research, specifically, the discontentment and frustration that occurs when health care providers do not pay enough attention to women's expressions of alarm and concern (Cuisinier et al, 1993; Geller et al., 2010).

Delays and ambiguity in informing women about the news of their baby's death were also experienced negatively. At the time of diagnosis, several women reported distressing encounters with ultrasound technicians whom they felt were extremely uncomfortable giving or confirming the news that their baby had died. Due to this apparent discomfort, they delayed breaking the bad news to women or requested the assistance of colleagues. These findings of discomfort and inappropriate communication are generally consistent with those of other studies (i.e., Peters et al., 2014; Turton et al., 2001), and suggest that some healthcare providers may be inadequately skilled or prepared to deliver news sensitively to bereaved women (Kavanaugh & Paton, 2001; Romm, 2002). Likewise, the manner in which the information was conveyed appeared to impact on women's experiences of distress. Blunt and disengaged communication when confirming the loss were described as cold and insensitive, whereas healthcare providers who conveyed empathy and sensitivity were described as caring and supportive. In particular, women appreciated when the news of their loss was delivered in a gentle, compassionate, and sympathetic manner that conveyed genuine empathy and warmth. They spoke positively of healthcare providers who took the time to sit with them by their bed to comfort them, and explain what had happened in language they could understand.

Another potential rationale for poor communication regarding death may be attributable to the routine of the hospital environment and the associated medicalisation of pregnancy loss. In other words, some caregivers may consider the pregnancy loss as a diagnostic outcome of the task they routinely perform, rather than an unusual and unexpected tragedy. As a result, many women felt their grief was often minimised or dismissed by attending physicians. Similarly, consultations with their healthcare specialists to discuss the results of medical assessment and autopsy were often described as insensitive

and impersonal. Several women described feeling an attribution of responsibility for their baby's death, when doctors proposed that the women's weight was a contributing factor. In addition, doctors were criticised for their use of medical jargon, the use of inappropriate terminology to refer to the deceased baby, and the matter-of-fact manner in which they communicated test results. These forms of communication were perceived as confusing and insensitive by the women and contributed to their feelings of distress.

These findings suggest that healthcare providers can potentially over-medicalise the pregnancy loss experience, by not attending to the emotional experience of stillbirth.

Healthcare providers need to be vigilant of the language they use, and medical terms that refer to the baby's death as an outcome rather than a human being should be avoided. In addition, care needs to be taken to ensure that probable causes of death are conveyed in a sensitive manner that does not infer blame. Healthcare providers dealing with grief and loss need to remain sensitive and professional at all times, and communicates in a manner that recognises the value of the loss of human life.

Preparations for Labour and Birth. The importance of sensitive and succinct communication was also emphasised in women's experiences of labour and birth. Women described their healthcare providers as helpful and supportive when they explained the process of labour and birth, using clear, concise, and sensitive language. Conversely, women reported that they felt distressed and unprepared for birth when they were unaware of what to expect or when information was provided in a manner they interpreted as overwhelming and confusing. This finding suggests that the emotional state of women following news of their loss may make it difficult for them to comprehend and process information. Hence, care needs to be taken to ensure that information is communicated in a coherent and sensitive manner. Healthcare providers may need to break down information

into more digestible portions and reiterate the information several times, to ensure that it is understood. This includes careful explanation of the reasons for vaginal birth over caesarean section (Dahlke, Mendez-Figueroa, & Wenstrom, 2014), and the course of induction and birth. In addition, healthcare providers should not make assumptions that women who have experienced a previous live birth know what to expect, as the experience of giving birth to a stillborn baby is indeed very different.

Among women who experienced a stillbirth, feelings of disbelief, anxiety, and confusion were particularly amplified when they were informed that they must still endure the lengthy process of labour and birth. This was an initially daunting and incomprehensible experience, and many women described needing time to process and prepare for the reality of giving birth to their stillborn child. Several women described how they appreciated the choice to go home as it helped them to process their loss and prepare themselves psychologically for the birth. This finding is consistent with Trulsson and Radestad's (2004) conclusions on women's experiences of stillbirth – they found that women might benefit from time to psychologically and physically prepares themselves for labour and birth. Specifically, they reported that several women in their study valued time between diagnosis of foetal death and induction of delivery because they needed time to rest and take in medical information, to prepare themselves psychologically for vaginal birth, and to prepare themselves psychologically to meet and say farewell to their long-awaited baby (Trulsson & Radestad, 2004).

On the other hand, some women in the current study preferred to have labour induced as early as possible, and perceived lengthy delays as distressing. Although they were informed about the physical and psychological benefits of vaginal delivery, they found this prospect horrifying and meaningless. Similar findings have been documented by

Malm, Radestad, Erlandsson, & Lindgren (2011), who described that women may feel confused by the decision not to induce birth immediately, and that delaying labour may be perceived as unnecessarily prolonging their distress. Trulsson and Radestad (2004) also reported that some women saw no meaning in giving birth to a dead baby, and just wanted "to get rid of the dead child immediately" (p. 191).

Such findings illustrate the importance of collaborative decision making with women regarding their birthing options, and ensuring that women are provided with sufficient information to make an informed decision (Peters et al., 2014; Ryninks, Robert-Collins, McKenzie-McHarg, & Horsch, 2014). The optimal duration between diagnosis of stillbirth and induction of birth may vary according to each of the women's needs, and care should be taken to ensure these needs are met. Likewise, women need to be more carefully informed of the psychological benefits of allowing time to process the information given to them so that they do not view the delay as pointless (Pullen et al., 2012).

Women's experiences also suggest that clear, descriptive, and accurate information regarding what to expect in regards to the physical condition of their stillborn baby may also be important to lessen their fear. For example, several women reported being concerned that their baby would look deformed and that this image would be morbid and disturbing. For some, this fear made them think twice about whether or not to see and hold their stillborn baby, a finding also documented in other research (Ryninks et al., 2014; Sun, Rei & Sheu, 2013). In reality, the women reported that their stillborn baby looked normal apart from some discoloration in skin tone and coldness to touch, and that the experience wasn't as frightening as they anticipated. Hence, healthcare providers need to be forthcoming, yet sensitive with their descriptions pertaining to the likely physical condition

of the stillborn baby, so that they do not needlessly escalate women's fear (Dyson & While, 1998; Ryninks et al., 2014; Trulsson & Radesaad, 2004).

The Experience of 'Giving' Birth. Despite the emotional and physical distress the women endured during labour and birth, the experience was also perceived as meaningful and empowering. In particular, the women felt that it was important that they could give their baby "something", and seemed to feel proud that they had accomplished giving birth. It seems plausible to assume that this "something" was a culmination of all the physical and emotional strength the women could garner to give birth. The commitment to labour and birth reflected the mother's love and affection for her baby that might be interpreted as: "You were real, you mattered, and I want to do all I can for you as your mother." As difficult as the process was, the women felt that it helped them to connect emotionally with their baby, as well as validate and process their grief. Perhaps if women are presented with this information prior to labour and birth, they will feel more prepared, less distressed, and interpret the experience as more meaningful.

The overall experience of labour and birth was greatly facilitated by the emotional support of attending midwives. Midwives were commended for their remarkable sensitivity, their warmth and affection, and their words of encouragement and reassurance throughout the experience of labor and birth. They were described as being emotionally present and responsive, and knowing exactly what to say at the right time to assuage women's fears. This suggests that midwives are in an important position to mitigate the psychological experience of pregnancy loss, through their provision of compassionate support (Leyland, 2013).

Other elements that contributed to women's satisfaction with caregiver support throughout the experience of labour and birth were associated with the hospital

environment. Foresight that the maternity ward may not be conducive to women's emotional needs following stillbirth meant that the majority of women were relocated to other wards away from crying babies. Indeed, previous research suggests that one of the biggest complaints by women who have experienced loss is that they were located on the maternity ward (Lasker & Toedter, 1994). Consideration was also given towards including the father and provisions were often made to ensure the women's partners could stay with them overnight. These actions were interpreted positively and led to feelings of increased satisfaction.

Support to Facilitate Contact with the Deceased Baby. The presence and actions of midwives were also an important determinant of women's satisfaction with caregiver support. In particular, midwives appeared to play a prominent role in supporting women's decisions about whether or not to see and hold their stillborn baby. The women reflected favourably upon midwives gentle persuasiveness and encouragement to see and hold their stillborn baby, an experience they were initially hesitant and fearful about. They felt that the midwives helped to alleviate their fear and discomfort, and assisted them to make a decision that they would have otherwise regretted. Similarly, the opportunity to take photographs of their stillborn baby and create special memories was an experience they treasured immensely.

The findings concur with existing research that has shown that women appreciate their healthcare providers taking the lead in supporting them to see and hold their stillborn baby. Many women reflect positively on the experience of being able to see and hold their stillborn baby, and view the experience as meaningful because of its importance as an action of validating their parenthood and their baby's existence (Cacciatore, 2010; Radestad & Christoffersen, 2008; Schott et al., 2007). In addition, they found that having visual

memories and the opportunity to create tangible tokens of remembrance assisted them to come to terms with their baby's death. Several women revealed that they might have expressed regret at not seizing the opportunity to engage in this important experience.

These findings do not support the conclusions of Hughes et al. (2002), which suggest that seeing, holding, and spending time with a stillborn baby results in greater distress. Instead, the findings are consistent with the notion that spending time with the stillborn baby may facilitate the mourning process, and that not doing so could lead to regret and make mourning more difficult (Cacciatore et al., 2008; Erlandsson et al., 2013; Radestad et al., 2009). Hence, creating multiple opportunities for women to see and hold their stillborn babies should be encouraged, as it may provide women with concrete memories and special keepsakes which may serve to validate their grief. Healthcare providers should also be mindful that women may initially decline the opportunity to see and hold their stillborn baby, but may later change their mind. Irrespective of which option they choose, it is important is that women are guided to make informed choices about whether or not to see and hold their stillborn baby, with full awareness of the potential risks (Koopmans et al., 2013; Schott et al., 2007).

The Lack of Continuity of Care. Upon leaving the hospital, the women found it painful and difficult to leave their baby behind. Coming home was a time when they felt immensely vulnerable as the support of the hospital was abruptly removed, and they experienced great distress and loneliness upon returning home with empty arms. As one participant noted, "that's when the wheels fall off", as the gravity of the loss sinks in. The emotional burden continued for women when they faced the dreaded task of informing family and friends about their baby's death. This was especially difficult for women who lost a full-term baby as family and friends were eagerly anticipating the baby's arrival.

Women's feelings of abandonment and vulnerability upon leaving the safety of the hospital environment indicate the need for improved and continued support. Although the women received an information and support pack following their discharge from hospital, they described this information as insufficient. They wanted more information regarding referrals for further psychological support, and they wanted further guidance and support as to what they could expect in the aftermath of their pregnancy loss. In particular, the women felt that they would have benefited from extended midwifery care, or support provided by psychologists, counselors or social workers trained in perinatal bereavement. They felt that these healthcare providers could have assisted them to manage their anxiety and grief symptoms, and improve their ability to cope.

The potential value in extending continuity of care has also been recognised by other researchers (Bangal et al. 2013; Brier, 2008; Kohner, 2001; Peters et al., 2014). Women appear to have many concerns and unanswered questions and they may benefit from the opportunity to have these concerns addressed (Lee et al., 2013). In addition, women may desire continuity of care with the same healthcare providers who were involved in the birth of the stillborn baby because rapport and trust has already been established (Peters et al., 2014). This may assist women to avoid having to retell their story to successive care providers, which may be emotionally taxing and counterproductive. However, this option may not be logistically or financially viable and policy makers must also consider alternative options when engaging in decision-making affecting women's care.

Research regarding the specific components of care to be targeted is limited, although a few conclusions may be drawn. Specifically, a recent qualitative study examining the effects of physical activity on women's emotional functioning following stillbirth, found that physical activity helped to mediate depressive symptoms (Hubert et al.,

2014). Thus, women who experience stillbirth may benefit from intervention that promotes physical activity as a tool for managing grief and associated distress. Furthermore, Kersting et al. (2011) provided evidence for the efficacy of internet-based cognitive behavioural therapy in improving psychological outcomes among women who had experienced stillbirth. This suggests that cognitive behavioural therapy may be an effective treatment modality, and online support systems should not be discounted. Additional treatment recommendations to facilitate continuity of care are discussed in the following chapter.

### **Interpersonal Support: Seeking A Shared Grieving Experience**

Consistent with other research on pregnancy loss, the family was often the most immediate and consistent source of support for the bereaved, and close family relations appeared to greatly assist the women in their grieving process (Kavanaugh et al., 2004). In particular, parents and siblings played a fundamental role in the days and weeks following pregnancy loss by keeping the bereaved company, preparing meals, and looking after the other children in the household (Kohn et al., 2013). Many women described how they relied upon the closest females in their family (e.g., mothers, sisters, grandparents) for emotional and practical support, as these were the women they felt most comfortable talking to. In addition, women turned to online bereavement support forums in order to access women whom they felt could better understand their bereavement experience and share their grief. However, the closest form of support appeared to come from the women's partners, and the experience of bereavement served to strengthen these relationships.

The Impact of Partner Support. All of the women in the current study who were in relationships at the time of loss described their partner as the most influential and important source of support. Several women shared how they felt loved and supported by their partners who they described as caring, affectionate, understanding, and emotionally

resent. They valued the opportunity to express their grief and loss to their partner, and to "let it all out", in a safe and supportive environment. The ability to communicate without words was also emphasised, and the women reflected favorably upon their partner's ability to "let me cry", "cry together" and "hug each other, not needing to say anything". This perceived emotional availability appeared to strengthen women's relationships with their partners, and they felt a lot closer as a couple as a result of the shared bereavement experience. In particular, several women described how the bereavement experience was the hardest thing they had ever endured together as a couple, and if they could get through this, they could get through anything. Thus, the experience of pregnancy loss appeared to reiterate the strength of the relationship and the couple's ability to withstand difficult times.

These findings suggest that following pregnancy loss, women appear to have a strong need to express their emotions in order to feel close to their partner. Conway and Valentine (1988), and Gilbert (1989), reported similar findings on the importance of communication in facilitating relationship closeness following pregnancy loss. Gilbert (1989) reported five aspects of communication that couples found helpful in decreasing conflict and improving understanding following pregnancy loss. These included: exchanging information, expressing opinions, listening, non-verbal communication, and code words and signals. By communicating with each other in meaningful ways, couples were better able to support and understand each other, thus developing a greater sense of connection.

This sense of relationship closeness following the death of a child is underreported in the literature. The literature is dominated with reports of relationship distress following bereavement (Gold et al., 2010; Lang & Gottlieb, 1993; Oliver, 1999; Shreffler, et al., 2012) and suggests that even the closest of relationships may suffer under the strain of grief

(Rosenblatt, 2000). However, in the current study many women were quite aware of the gender differences in grieving, and consequently, were more understanding of their partner's grieving than the literature suggests. Furthermore, it appears that they strived to find ways in which they could understand and support their partner's grief, which served to strengthen the relationship rather than tear it apart.

This sense of relationship closeness does not mean that couples did not face any challenges in coming to terms with their bereavement. Indeed, the women described that they grieved very differently to their spouse/partner, which often cultivated some tension within their relationships. In particular, women felt that they were often more expressive and forthcoming with their grief than their partners, who were more inclined to suppress their grief in an attempt to move on with their lives. These differences in grieving responses tended to be misconstrued at times, when women felt that perhaps their partners didn't care about the loss as much as they did, because their partners were no longer talking about it. This finding is consistent with stereotypical notions of grief often reported in the literature, whereby women possess a clear need to talk about their emotions and process their grief (Cacciatore et al., 2008; Fish, 1986; Rando, 1985), whereas men typically deal with their reactions internally and therefore feel less compelled to talk about it than their female counterparts (Cacciatore et al., 2008; Kohn et al., 2013; Wing et al., 2001).

Such diverse grieving patterns can often create tension and conflict among couples, particularly when the differences in grieving are interpreted negatively by one partner as being unsupportive or not caring about the death (Wing et al., 2001). In addition, the grieving discrepancy may be misconstrued by one partner as the other half having 'gotten over their grief', which can fuel anger and resentment (Archer, 1999; Gold et al., 2010; Lang et al., 2011). In actuality, it may be that men felt the need to suppress their feelings of

grief, in order to be strong and supportive for their partners. Indeed, Murphy (1998) advocated that cultural norms may lead men to portray a strong front in order to protect their partner from additional emotional burden. This finding highlights a potential need for service providers to assist couples to open communication channels and gain an understanding of each other's needs following loss, so that they are better able to avert misunderstanding and support one another in the aftermath of pregnancy loss.

Accessing External Support from Credible Sources. Whilst the women described interactions with their significant other and their closest female confidantes as their primary sources of support, it was evident that they also sought help from external sources. These sources were often female peers, colleagues, 'friends of friends', or strangers with a history of pregnancy loss, whom the women felt they could relate to because of a shared bereavement experience. In particular, the women accessed online pregnancy loss support forums in order to connect with women who had experienced loss. They described these forums as helpful in terms of reducing the sense of isolation they felt, as it enabled them to openly express their grief in a baby-loss community that provided them with the empathy and understanding they needed. In addition, these forums provided the women with information and guidance from credible sources (i.e., women who had also lost a baby). This was beneficial as it helped to provide women with the sense of reassurance they needed, as they were able to connect with women who had experienced similar pain and suffering, and survived. Similar findings on the positive effects of online peer-to-peer interactions have been identified in other research (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

In addition, participants discussed reading materials or becoming educated about their grief following pregnancy loss. They described reading pregnancy loss books, reading

magazine and journal articles, researching online websites, and reading online pregnancy loss blogs, in order to access information that could facilitate their adjustment to loss. They wanted to become self-educated about their experience so they could learn how to cope. These practices were not always helpful, as women would also source reading materials that provided them with 'evidence' over causes of death. However, it did help women to understand more about the frequency with which these losses occur, and that they were not alone in enduring such a painful experience.

Not-withstanding the importance of familial support and self-help, several women appeared to benefit from external support services. In Western Australia, the organisation SIDS and Kids provides women with counseling and bereavement support as a couple, in a group, or on an individual basis. Women who utilised the service found the support helpful, and spoke positively about their experiences. In particular, they found it beneficial to talk about their grief in a supportive environment where facilitators had also experienced pregnancy loss. This gave them the confidence and assurance they needed to trust that they too would learn to cope with their grief, and enhanced the programs credibility. Others reported how the support they received helped them to better understand their grief, and they benefited from information and strategies that helped them to cope with their anger, guilt, and anxiety. However, only a small number of women reported that they utilsed available support services, and this is concerning. In particular, a common complaint was that the women did not find the services accessible. They attributed this to either logistical or emotive issues (i.e., it was "too far away", it was "too hard" [emotionally] to make the call) or misinformation about the organisation itself (i.e., "I know that we can access SIDS and Kids...but that's not specific to losing a baby"). Hence, care should be taken to ensure

that services are accessible to women, which needs to go beyond the provision of self-help pamphlets.

## **Social Support: Issues of Avoidance and Minimisation**

With respect to women's experiences of social support following bereavement, perceptions were varied. Certain behaviours were acknowledged as supportive and helpful, whereas others were deemed as unsupportive and disruptive. Determining what women perceive as positive support following pregnancy loss is essential, as this can have an important mediating effect on their associated grief response (Kavanaugh et al., 2004). Furthermore, a lack of social support has been linked to complicated and chronic grief among this population (Janssen, Cuisinier, de Graauw, & Hoogduin, 1997; Lasker & Toedter, 1991).

Results of the current study indicate that although women were generally appreciative of the care and support they received from their social networks, there were also many encounters with family and friends that led to negative perceptions. In particular, women described behaviours such as being avoided or ignored, as difficult and upsetting. It was especially challenging when family and friends did not understand or acknowledge their feelings of grief and loss, and dismissed their baby's death as insignificant. In addition, they reported feeling angry when given unsolicited advice about how to feel or act by family and peers, who themselves had not experienced the loss of a baby. They strongly felt that others could not relate to them or provide the necessary empathy and understanding they required, unless they too had experienced a pregnancy loss. These experiences often led to feelings of isolation and abandonment, a finding which has also been documented in other perinatal research (Kavanaugh et al., 2004; Malacrida, 1999; Rajan, 1994). The findings also concur with theoretical conceptualisations of disenfranchised grief, whereby

grief that is not understood or recognised by others is often dismissed or ignored (Boss, 2004).

It seems plausible to assume that society's ambiguity over how to respond to the death of a baby fuelled their avoidance behaviours. Ambiguity leads to discomfort, and family and friends may have unwittingly minimized the loss because they didn't know what else to say and were attempting to offer words of encouragement. Furthermore, the bereavement experience following pregnancy loss is one that is seldom talked about, and resultantly, mourning expectations are ill-defined. In order to improve the bereavement experience for women affected by pregnancy loss, it would appear that there is a strong need to increase awareness of grief following pregnancy loss and what women perceive as helpful and unhelpful in terms of support. The current study adds to an existing body of literature, which recognises that women value emotional support that facilitates grief expression (Corbet-Owen & Kruger, 2001; Hutti, 2005; Kavanaugh et al., 2004; Peters et al., 2014; Sejourne et al., 2010; Wong et al., 2003). Women appreciate the opportunity to talk about their bereavement experience and have someone listen, even if they don't know what to say. The ability to listen and sympathise is reported as most valuable, and is preferred over intended words of comfort and encouragement that commonly serve to minimise the loss. Advice is only beneficial when it comes from others who are truly able to empathise with the bereaved mother, and this person is typically another bereaved mother who has experienced pregnancy loss. Similar findings have been documented by Rajan (1994), who reported that support is perceived as most helpful when it comes from someone who has had a similar experience.

## The Subsequent Pregnancy: The Need for Guidance and Reassurance

Consistent with the literature, the vast majority of women who experience pregnancy loss fall pregnant again within a twelve-month period. Deciding to try and conceive again following pregnancy loss often triggers conflicting emotions, doubts, and insecurities, and women often feel anxious about the prospect of enduring a subsequent pregnancy (Cote-Arsenault & Marshall, 2000; Lamb, 2002). Once pregnant again, women describe feelings of having lost their innocence and being robbed of the blissful joy of being pregnant (Bergner et al., 2008; Lee et al., 2013; Cote-Arsenault & Mahlangu, 1999). The experience is one of immense anxiety, whereby the mother engages in a process of balancing fear and hope whilst continuing to grieve for the baby she lost. In the following section, women's experiences regarding decision-making and timing of the subsequent pregnancy are discussed, along with their experiences of coping with anxiety during the subsequent pregnancy. Possible treatment initiatives for assisting women to better manage their psychological distress are also explored.

#### Is There A Right Time to Try Again?

Throughout history, women have been encouraged by healthcare providers and society to put pregnancy loss behind them, and attempt to conceive again as soon as possible after loss (Franche & Mikail, 1999). Over the past few decades, increasing awareness of grief following pregnancy loss has resulted in a gradual shift towards encouraging extended time between pregnancies to process this grief (Turton et al., 2001). Researchers have cited increasing complications when pregnancy occurs within twelve months post-loss, such as complicated grief (Kersting & Wagner, 2012), depression and anxiety (Hughes at al., 1999), and posttraumatic stress disorder (Turton et al., 2001). However, other researchers (e.g. Franche & Bulow, 1999; Franche & Mikail, 1999) have

documented positive outcomes, citing lower levels of distress among women who conceive within a shorter time frame after loss, compared to women who are not pregnant.

Deciding on the right time to try again following pregnancy loss is further complicated by the provision of contradictory advice from healthcare providers and the women's own conflicting emotions, insecurities, and self-doubt following loss (Lee et al., 2013). In the current study, women struggled to define the 'right time' to begin trying to conceive again after loss. For some, the decision to start trying again sooner rather than later reflected an overriding sense of urgency, attributable to either advanced maternal age or preoccupation with the desire to become a mother. For example, several women made reference to the ticking of the biological clock, suggesting that they were mindful of time slipping away. This finding is consistent with Phipps (1985) who found that some women possess a strong desire to conceive again quickly due to fertility concerns or fear that they are running out of time. For these women, aspirations to become a mother meant that efforts to conceive again commenced as soon as their physician told them they were physically able to do so.

For other women, timing was based on feelings of physical and emotional readiness – when women felt that they were physically and emotionally prepared to begin trying again (Lee et al., 2013). As such, women focused on preparing themselves physically and mentally for the subsequent pregnancy, especially upon giving themselves 'enough' time to grieve.

Complicating such physical and mental preparation were attributions of failure and self-blame. It was clear that women felt an underlying sense of responsibility for their baby's death, and consequently, they engaged in a number of compensatory behaviours in an attempt to prevent loss from occurring gain. In particular, they made conscious efforts to increase their exercise and eat well, as medical reports had indicated obesity and/or

gestational diabetes as a potential contributing factor to their loss. In addition, they altered their sleeping and bathing routines, in an effort to reduce their chances of sustaining bacterial infection or placental dysfunction. This finding suggests that women are especially sensitive to information surrounding the probable causes of death, and more care needs to be taken to diffuse any resultant self-blame. Despite being told that they are not to blame, women may attribute the pregnancy loss to their own behavior in an attempt to make sense of what happened (Callander, Brown, Tata, & Regan, 2007).

In terms of wanting to wait until they were emotionally ready to try again, the women spoke of their efforts to work through their grief in order to get to a point where their desire for another baby outweighed their fear of another loss. This concept of enabling 'enough' time to grieve and 'waiting' to feel ready before trying to conceive again following pregnancy loss, has also been recognised in other research (Lee et al., 2013). In a study exploring women's decision making and the experience of subsequent pregnancy following stillbirth, Lee et al. (2013) found that women tended to contemplate the emotional challenges that might occur in the subsequent pregnancy and evaluated their ability to cope with these challenges, before embarking on a subsequent pregnancy.

However, consistent with Lee et al. (2013), the women in the current study also spoke of an instinctual yearning and desire to want to become pregnant again, and needing to replace the loss with something positive. They came to the realisation that the void they felt could only be filled by a subsequent pregnancy, as their aspirations to become a mother or have a family (including adding to their existing family), remained unchanged.

This notion of wanting to conceive again soon after loss to 'fill the void', has been reported in the literature as a risk factor for complicated grieving and for what has been described as 'replacement child syndrome' (Anisfeld & Richards, 2000; Cain & Cain,

1964; Robertson & Kavanaugh, 1998), or 'vulnerable child syndrome' (Green & Solnit, 1964). Both these concepts express concern about the need to either replace the deceased child with a live one or the mother's inclination to view their subsequent child as needing specialised care and attention to protect them from harm, with potentially negative consequences. 'Filling the void' may also be interpreted as 'avoiding the grief', when the subsequent pregnancy occurs too soon after loss. Indeed, the women in the study reported that the subsequent pregnancy acted as a "distraction" from their grief. This is concerning as some researchers have identified that grief avoidance may be detrimental if it results in delayed or obstructed grieving (Cote-Arsenault & Dombeck, 2001; Field, 2006; Hughes et al., 1999). 'Unresolved' or 'maladaptive' grief has also been reported to interfere with parenting of the subsequent child (Lamb, 2002; Warland et al., 2011). However, in the current study the women described that their intention was not to create a 'replacement child', but to fulfill their own desires to "have a family", or provide a much wanted sibling for their son or daughter. Furthermore, the notion of the 'replacement baby' did not seem to fit with women's accounts of acknowledging their deceased baby as a sibling to any future children or their continued efforts to memorialise and maintain connections with their deceased baby. Instead, the women appeared to recognise the potential danger of needing to replace their new baby, and they were accordingly cautious in approaching their new baby.

Such findings suggest that concepts such as the 'replacement child', or 'vulnerable child' may not be applicable to women who experience pregnancy loss.

Instead, mothers should be understood as experiencing a complex dual parenting role, where they are trying to continue their parental bond with their deceased child, as well as formulate a new bond with the baby in their current pregnancy (Gaudet et al., 2010; O'Leary, 2004). In the current study, many women rejected the idea of the replacement

child, and spoke fondly about their continued efforts to integrate their deceased baby into their lives in a meaningful way. Connections were maintained through memorial behaviour, such as family photographs, mementoes, and anniversary rituals, which honoured their baby's existence. Likewise, many women ensured that other children would know about their deceased sibling, and they were encouraged to ask questions. Thus, the concept of a replacement child does not do justice to the complexity of the bereavement experience, nor does it account for the many conduits of grief that are not necessarily pathological (Grout & Romanoff, 2000).

In summary, the current study confirms that the majority of women who endure a pregnancy loss become pregnant again within twelve months (Cuisinier et al., 1996).

Precisely how long women should wait to try and conceive again remains inconclusive, and consensus on the appropriate time interval has not been reached (Hughes et al., 1999;

Phipps, 1985; Turton et al., 2001). It appears that the 'right time' to try and conceive again will vary according to women's individual needs, and an optimal waiting time seems questionable. Furthermore, the current study concurs with existing research which suggests that anxiety and grief is elevated during the subsequent pregnancy, irrespective of the time interval between pregnancy loss and subsequent conception (Chojenta et al., 2014; Gaudet et al., 2010).

Thus, providing women with information about potential risks and allowing them to make an informed choice may be more appropriate than focusing on rigid time frame to delay conception. This may be achieved by the provision of interconceptional counseling as suggested by Wallerstedt, Lilly, and Baldwin (2003), to assist women to discuss their ambivalence, explore their fears and concerns, and evaluate potential risks for the subsequent pregnancy.

Chapter Seven: Discussion 229

### The Difficult Task of Balancing Hope and Fear

During the subsequent pregnancy, the women in the current study described intense anxiety and fear over the possibility of another loss. Women described the pregnancy as being tainted, and themselves as having lost the sense of naiveté that was evident during the pregnancy prior to their experience of miscarriage or stillbirth. A similar loss of joy and naiveté has been expressed in other studies of pregnancies subsequent to pregnancy loss, which have also reported elevated levels of anxiety (Armstrong et al., 1998; Bergner et al., 2008; Lee et al., 2013; Cote-Arsenault & Mahlangu, 1999; Gaudet et al., 2010). In the current study, not even the presence of other living children acted to buffer women's anxiety. All women felt that they were "robbed" of the joy of being pregnant, and were greatly fearful of the possibility of another loss. This finding is consistent with previous research suggesting there is no difference in the level of anxiety experienced by women with children compared to those without living children following pregnancy loss (Woods-Giscombe, Lobel, & Crandell, 2010).

The loss of joy and naiveté in the subsequent pregnancy was common to both early and late pregnancy losses alike, although the women in the current study seemed to support the finding that the greater the gestation, the greater the anxiety and fear during the subsequent pregnancy. Women who experienced a miscarriage experienced profound anxiety in the first trimester, which abated somewhat after this 'safe-point' had passed. Similar findings have been reported in existing research, which state that it is common for anxiety to decrease as the pregnancy progresses, as women grow more confident (Tsartsara & Johnson, 2006; Cote-Arsenault, 2007). Conversely, among women who experienced a prior stillbirth, no apparent 'safe point' was evident. Anxiety appeared to peak as they approached the gestational point of their previous loss, and it remained until the subsequent

birth, when their baby was born alive and well. This anxiety appeared so elevated and distressing that women wished that they could "just fast-forward" their pregnancy, so they didn't have to cope with this agonising emotional experience. Whilst other researchers have also identified the pervasiveness and prolonged nature of anxiety in the subsequent pregnancy following stillbirth, little has been done to curtail this anxiety (Gaudet et al., 2010; Hannah, 2013).

Difficulty in forming attachment to their baby during the subsequent pregnancy was a common occurrence among the women in the study who experienced stillbirth. Due to the immense fear about the potential of another loss, women appeared to try and protect their emotions and avoid prenatal bonding. This construct, known as 'emotional cushioning', appears to be a complex self-protective mechanism used by women to cope with the anxiety, uncertainty, and vulnerability they experience in the subsequent pregnancy (Cote-Arsenault & Donato, 2011; Gaudet et al., 2010). In order to protect themselves from further emotional distress, the women attempted to avoid thinking about their pregnancy, delayed sharing news about their pregnancy and attempted to cover it up, withheld preparations and celebrations for birth, and restrained their excitement. Similar emotional cushioning behaviours have been identified in other research (Armstrong & Hutti, 1998; Cote-Arsenault & Marshall, 2000; Cote-Arsenault et al., 2006).

Women's experiences of curtailing their emotions also appeared to be related to their feelings of continued grief. Following confirmation of subsequent pregnancy, women held back their excitement and emotions because they perceived this to be dismissive of their stillborn baby. Whilst the women wanted to maintain hope that this time everything would be okay, they also wanted to convey the message that their subsequent pregnancy was not a replacement for their stillborn baby. They were still grieving and coming to terms

with their loss and they wanted this reality acknowledged and respected. Such findings are consistent with those of other researchers who have reported that a new pregnancy can often reactivate emotions of grief and loss with the baby who died (Cote-Arsenault & Dombeck, 2001; Franche & Mikail, 1999). Indeed, it was clear that grief intensity remained high during the subsequent pregnancy, with many women reporting feelings of grief and hope at the same time. The experience is complex, as the pregnant woman continues to grieve for her deceased child while wanting to be happy and excited for the new baby coming (Cote-Arsenault & Donato, 2011; DeBackere et al., 2008; Gaudet et al., 2010; Tsartsara & Johnson, 2006).

Negative connotations such as 'unresolved grief' or even 'pathological grief' have been linked to such responses among this population, and researchers have reported detrimental outcomes in the long-term (Hughes et al., 2001; Lamb, 2002). Indeed, research has suggested that certain attachment disorders found between the mother and her subsequent child may be attributable to this unresolved grief (Heller & Zeanah, 1999; Hughes et al., 2002). In addition, unresolved grief has been linked to depression, anxiety disorders, difficulty coping during the subsequent pregnancy, as well as parenting issues with the subsequent live-born child (Lamb, 2002; O'Leary, 2003). However, the phenomenon of 'unresolved grief' has also been referred to as problematic, in that it pathologises a grief response which may be considered a normal part of the bereavement process (O'Leary, 2004). Lin and Lasker's (1996) study on patterns of grief reaction after pregnancy loss echo the results of the current study which suggest that the majority of women do not exhibit 'normal' patterns of grieving. During a subsequent pregnancy, women continue to mourn their stillborn baby and this grief does not appear to decline following live birth. While a subsequent live birth may help appease grief, it does not

appear to resolve it. Likewise, 'chronic' grief throughout the first year post-loss is not necessarily indicative of adjustment difficulties (Holland et al., 2009). Such findings suggest that the 'normal' trajectory of grief following loss may not be applicable to women who experience pregnancy loss. Further longitudinal research is needed, which examines the trajectory of grief following pregnancy loss over time, in order to provide a more accurate representation.

The complex interaction of grief and anxiety in the subsequent pregnancy, and women's attempts to balance their hope and fear, suggests that interventions to target pregnancy specific anxiety are warranted. The anxiety women experience during a subsequent pregnancy is profound and overwhelming, and results in substantial psychological distress (Franche, 2001; Lee et al., 2013; Schott et al., 2007; Turton et al., 2001; Turton et al., 2006). In addition, high stress in pregnancy has been associated with a range of potential negative outcomes for the subsequent child, such as premature birth (Reck et al., 2013; Shapiro, Fraser, Frasch, & Seguin, 2013), low birth weight (Grote et al. 2010), irritable infant temperament (Van den Bergh et al., 2005; Wermser et al., 2006), and parenting and attachment difficulties (Gaudet et al., 2010; Hughes et al., 2001; O'Leary & Thorwick, 2008).

#### **Psychotherapy Treatment Initiatives**

Although research into effective treatment during the subsequent pregnancy is limited and no published studies of psychotherapeutic treatment for anxiety in pregnancy exist (Goodman et al., 2014; Currier, Neimeyer, & Berman, 2008), the results of the current study corroborate with existing research which suggests that healthcare providers need to recognise the psychological impact of pregnancy after loss and respond accordingly to minimise distress (Cote-Arsenault, 2003; Robertson & Kavanaugh, 1998; Wallerstedt et al.,

2003). Care should be tailored to meet the specific needs of women in the subsequent pregnancy, and that interventions are not delayed (Cote-Arseanult & Morrison-Beedy, 2001; Hannah, 2013). This should be continued throughout the pregnancy continuum as psychological distress can occur at any time or gestation (Schott et al., 2007).

Recognising that many women will experience immense fear and anxiety in the subsequent pregnancy, initial intervention might include psychoeducation on anticipatory anxiety so that this distress is normalised. Women need to be given the opportunity to ask questions, and express their worries and fears in a supportive and understanding environment where their opinions and feelings are respected (Schott et al., 2007).

Additional therapeutic considerations might include psychoeducation about the potential risks of emotional cushioning (Badenhorst & Hughes, 2007), to encourage prenatal bonding. Simultaneously, healthcare providers need to address women's extensive reassurance seeking behavior and acknowledge the status of 'high-risk'. Consistent with previous research (e.g., Simmons & Goldberg, 2011), most women in the current study embraced the 'high-risk' label in the subsequent pregnancy, as this meant that they were now eligible to receive an elevated level of routine care. On this basis, several researchers have suggested that increasing the frequency of ultrasound examinations and prenatal visits may be useful, to help confirm the wellbeing of the unborn baby (Armstrong & Hutti, 1998; Schott et al., 2007).

Cognitive processing to assist women to separate the current pregnancy from the previous pregnancy may also be of benefit. This may include a consideration of mindfulness-based therapy to assist women to remain in the present moment. Mindfulness based interventions have been recognised as an effective treatment modality to reduce anxiety, depression and stress in both clinical and non-clinical populations (Keng, Smoski

& Robbins, 2011; Khoury et al., 2011; Kuyken et al., 2010; Toneatto & Nguyen, 2007). In a recent study, mindfulness-based cognitive therapy (MBCT) was demonstrated to effectively reduce perinatal anxiety in a sample of pregnant women who met criteria for generalised anxiety disorder (GAD). The intervention (Coping with Anxiety through Living Mindfully – CALM), incorporated psychoeducation, mindfulness techniques, and cognitive processing exercises over eight weekly two-hour group sessions, along with homework to practice the skills learnt (Goodman et al., 2014). Results indicated that participants who completed the intervention showed clinically significant improvements in anxiety, depression and stress severity, and concurrent significant increases in self-compassion and mindfulness (Goodman et al., 2014). These results suggest that MBCT is an effective treatment for reducing perinatal anxiety, and it may also therefore be an effective treatment for women who are enduring anxiety in the subsequent pregnancy after loss.

There are several reasons to hypothesise the transferability of this treatment: (1) Rumination is a prominent feature of women's anxiety in the subsequent pregnancy and MBCT has been shown to reduce maladaptive rumination (Heeren & Philippot, 2011; Mickalak et al., 2011); (2) Women experiencing anxiety in the subsequent pregnancy engage in future-oriented worrying and therefore training in present-focused mindful awareness may be beneficial (Roemer & Orsillo, 2002); (3) Women experiencing anxiety in the subsequent pregnancy exhibit marked hyperarousal and reassurance seeking behavior, therefore, practicing Mindfulness with a non-judgmental awareness may increase distress tolerance and reduce emotional reactivity (Mennin, Heimberg, Turk, & Fresco, 2005; Tull et al., 2009); and (4) Women experiencing anxiety in the subsequent pregnancy tend to engage in emotional cushioning which results in avoidance behaviour and emotional suppression. Mindfulness practice offers a way to deliberately notice, allow, and accept

Chapter Seven: Discussion

235

painful emotions, to promote greater emotional and behavioural flexibility (Chapleau, Paquin, & Hoffman, 2013; Greeson & Brantley, 2009).

As an adjunct to cognitive-based intervention, an option might be to provide extended midwifery care via home visits during the subsequent pregnancy. This is consistent with the conclusions of Rajan and Oakley (1993) and Cote-Arsenault and colleagues (2014) who identified improved postnatal wellbeing among women who received additional one-to-one midwife or perinatal nursing contact in the subsequent pregnancy after loss. Cote-Arsenault recently published her results of a comprehensive nurse caring intervention (Cote-Arsenault, Schwartz, Krowchuk, & McCoy, 2014), based on Swanson's (1991) Theory of Caring. Via home-based visits, the author provided a tailored intervention to address women's anxiety and distress in the subsequent pregnancy. This included normalising the pregnancy after loss experience, strategies to counter anxiety (e.g., relaxation, positive self-talk, noting foetal movement in a pregnancy diary, and journaling), and strategies to facilitate prenatal bonding. Women's reflection on the home visits intervention revealed that they experienced it as valuable, and that discussions with the nurse helped to reduce their anxiety and increase their self-confidence. However, a reduction in anxiety and depression was not detected, and confidence outcomes were not measured (Cote-Arsenault et al., 2014). The authors attributed this result to the ongoing nature of the subsequent pregnancy (i.e., that the women did not yet have a healthy baby in their arms), but they also indicated that encouraging women to openly talk about their fears rather than suppressing them with emotional cushioning might have contributed to their elevated distress.

This is an interesting assumption and is one that must be interpreted with caution.

Existing literature on psychotherapy for perinatal anxiety (and anxiety disorders in general)

suggests that confronting painful and fearful emotions through a process of cognitive restructuring is an effective treatment modality (Green, Haber, Frey, & McCabe, 2015; Misri, Kendrick, 2007). This suggests that skilled professionals such as psychotherapists and psychologists who are trained in the assessment and treatment of clinical disorders may be better equipped to deliver psychotherapeutic intervention. However, further exploration of this concept is required; as it would appear that no studies to date have been published examining the efficacy of CBT in treating anxiety in the subsequent pregnancy.

Another suggestion proposed by Cote-Arsenault and Freije (2004) might be the inclusion of pregnancy after loss (PAL) support groups. An asset of pregnancy after loss support groups is connecting women who share the same experience (Schott et al., 2007). Historically, these groups are often run by trained facilitators who themselves have experienced pregnancy loss, but this is not a requirement. However, facilitators should be competent in their understanding of the grief and anxiety process that follows pregnancy loss and subsequent pregnancies (International Childbirth Education Association), and should preferably possess skills in counseling (Redman, 2003). PAL support groups have been identified as a valuable source of support in assisting women to reconcile the paradoxes inherent in a post-loss pregnancy, learn new coping skills, choose hope over fear whilst nurturing grief, and feel safe, less isolated, and understood (Cote-Arsenault & Freije, 2004).

#### Summary

This discussion highlights an important clinical disparity within the perinatal literature, whereby women continue to endure substantial psychological distress that remains largely unacknowledged and unappreciated. Consequently, women's expressions of grief are often constrained (by themselves, their social networks, and service providers

alike), which not only exacerbates their distress but also interferes with the process of mourning. This reality needs to change, as women who experience pregnancy loss need to have their bereavement experience recognised and understood in order to facilitate grief expression and optimal care.

The findings of the current study concur with previous research, which has acknowledged the prevalence, uniqueness, and complexity of grief following pregnancy loss. However, the study has highlighted that the trajectory of grief pertaining to pregnancy loss is still largely minimised and misunderstood. First, the strong focus on grief intensity within the existing body of literature and its correlation with gestation has meant that the expression of grief across the continuum of pregnancy loss has been largely ignored. As such, grief following early pregnancy loss (i.e. miscarriage) has been dismissed as less significant, and grief following stillbirth has been largely pathologised. Pregnancy loss is a grief inducing experience for all women, and there are many additional components (other than gestational length) that may shape and define the grieving experience, which need to be considered.

Second, the emphasis on identifying "pathological" or "complicated" forms of grief has meant that normal manifestations of grief are at risk of being pathologised. In the literature, grief that causes functional impairment and lasts longer than expected according to societal norms is typically referred to as "pathological" or "complicated". In the current study, elevated psychological distress such as anxiety, depressed mood, anger, guilt, self-blame, vulnerability, and feelings of failure and worthlessness were common, and continued well into the subsequent pregnancy. In addition, grief was conceptualised by the women as continuous and it did not appear to resolve overtime. Such intense and persistent grief reactions suggest that grief following pregnancy loss differs from the dominant

discourse, and should be treated accordingly. Pathologising normal grief reactions will only serve to perpetuate the stigma that surrounds grief following pregnancy loss, and will do little to facilitate appropriate intervention.

Third, the findings of the current study made reference to the numbness, dissociation, and flashbacks experienced by the women following their diagnosis of pregnancy loss. It is possible that women who experience pregnancy loss may be at high risk for developing posttraumatic stress disorder, but are failing to be diagnosed, and therefore treated. Consequently, this is of great concern and warrants further research attention.

Fourth, whilst the experience of bereavement following pregnancy loss is an immensely painful and debilitating experience for women, it is also one of profound positive growth. The women described increased personal strength, a greater appreciation for life, improved intimacy with significant others, greater empathy, and spiritual development as positive characteristics of their bereavement experience. This is a finding that has been underreported in the perinatal literature and suggests that treatment initiatives might focus on identifying aspects of positive growth to enhance coping among bereaved women.

Fifth, women's experiences of professional and interpersonal support following pregnancy loss suggested both positive and negative aspects of pregnancy loss care. Overall, findings revealed that women felt adequately supported when their loss was acknowledged and others conveyed sensitivity to their grief experience. In particular, women reported that behaviours such as listening, empathising, and showing genuine concern were most helpful, especially when they were able to share their experiences with friends and family who had endured a similar experience. In addition, a strong supportive relationship with one's significant other also positively affected women's emotional health following the loss. Conversely, support was perceived as inadequate when grief was minimised or ignored, or when others responded insensitively to the loss. Several of the women reported feeling ignored, judged, or avoided by others in their social support network, which made the experience of loss more difficult.

In the professional realm, effective support came from those who recognised the needs and expectations of the bereaved woman. Caregivers who listened, conveyed sensitivity, and who understood the emotional significance of the loss were deemed the most helpful. The midwives who assisted in labour and birth were generally able to provide this support and were praised for their authentic and caring nature. However, other health care professionals were viewed in a more negative light, when they failed to recognise the legitimacy of the grief experience and respond appropriately to the women's needs. Inappropriate and insensitive comments experienced by some women greatly affected their perceptions of care, as did perceived systemic inadequacies where the women experienced care that did not meet their expectations. One of the major criticisms identified was the lack of follow-up care available to women upon their discharge from hospital. This was a time when the women felt immensely vulnerable, let down, and unsupported by the system, which led to increased feelings of psychological distress.

Finally, this study provides additional evidence of women's need for continued professional support in the subsequent pregnancy and beyond. The participants encountered immense anxiety prior to and during the subsequent pregnancy, which further complicated their bereavement experience. In terms of the timing of the subsequent pregnancy, women struggled to identify a "right" period of time to wait. They wanted to wait until they were physically and emotionally ready before trying again, however, they were also mindful of

competing age and lifestyle factors (i.e., ticking of the biological clock), which promoted a sense of urgency. Dissatisfaction with advice regarding the "right time" to try again, and enabling sufficient time to grieve whilst recognizing the continuing nature of grief also contributed to women's difficulties. Therefore, identification of a "right" time to wait before trying again seems questionable. Instead, it would appear that women might benefit from further information and support that assists them to make an informed decision based on their individual circumstances.

Throughout the subsequent pregnancy, women experienced continued grief, together with an overwhelming fear that they could possibly endure another loss. Consequently, the subsequent pregnancy was characterised by a process of balancing fear and hope, whereby the bereaved women engaged in a number of self-protective behaviours in an attempt to cope with the immense anxiety they were feeling. Consistent with previous research, emotional cushioning was one of these behaviours, whereby the women attempted to restrict emotional attachment to their new baby as a means of protecting themselves from further pain. In addition, the women displayed marked hypervigilence and reassurance seeking behaviour, together with a strong desire to have everything under control. The central role of caregivers in mitigating this experience was identified, especially the benefits of extending midwifery care and the inclusion of professional support.

The following and final chapter presents the overall conclusions of the current study, and resultant implications and recommendations for future research and practice.

#### **Chapter 8: Conclusions and Implications**

The final chapter provides an overall discussion of the conclusions and implications derived from the current study. First, the broad aim of the research and its phenomenological design are reiterated. Second, a short summary of the findings is provided, with a particular emphasis on the main conclusions that can be drawn from the research. Third, the implications of the research for theory development and service provision are explored. A discussion of suggested avenues for future research follows, including consideration of the current study's limitations. Finally, a personal postscript is provided, whereby the researcher shares her reflections on the research process.

## Research Aim and Design

This study of women's experiences of pregnancy loss was undertaken to gain an interpretative description of the essence of this experience, in order to gain a comprehensive understanding of the phenomena it entails. With this knowledge, a potential explanation of the processes involved and recommendations for practice are likely to be derived. The research question was: "How do women experience pregnancy loss following a miscarriage or stillbirth?"

Using an interpretative phenomenological design, nineteen bereaved women who experienced a pregnancy loss were interviewed. Of these, fourteen women completed the study (participated in all three interviews), and all of these women experienced a subsequent pregnancy during the interview period. With the assistance of a semi-structured interview guide, women were asked to describe their experiences of pregnancy loss.

Naturally, this also included inquiry as to their experiences of support and enduring a subsequent pregnancy. The interviews were transcribed verbatim and written notes were documented immediately following each interview. Using interpretative phenomenological

analysis (IPA), the findings were generated from a constant comparative analysis of the data. Common themes were resultantly identified, as well as variations in the women's accounts.

# **Summary and Conclusions of the Research Findings**

Similar to findings that have been reported by other researchers, the findings of the current study highlight the immense grief and psychological distress incurred by women who experience pregnancy loss. For the majority of women, this distress appears greatest in the first few months following pregnancy loss, but seems to persist for some time. Furthermore, it appears to interfere with the process of maternal attachment in the subsequent pregnancy, and may even affect adaptation to the subsequent child.

The women's diverse experiences of their interactions within the healthcare system, as well as within their social networks, revealed structures of both positive and negative support. Adequate support, particularly from family, partners and attending midwives, appeared beneficial and made the experience of loss easier to endure. In particular, having someone to talk to who shared the same bereavement experience helped to reduce the sense of isolation the women felt, and assisted to validate their grief. In contrast, a lack of perceived emotional support appeared to increase psychological distress. Women's vocalisation of their need for more sensitive and specialised care, across the continuum of pregnancy loss (including the subsequent birth), was a strong emergent theme that arose from the study. This was evident through their requests for greater empathy, reassurance, guidance and control. This finding creates a context within which existing healthcare and support can be examined and improved, so that women's experiences may be applied in practice.

As a result of this study's findings, as well as an examination of those findings within the context of available empirical literature, the following conclusions may be drawn:

- Women who experience pregnancy loss describe a psychologically distressing
  experience that impacts their lives immensely. The experience is painful and
  unexpected, and women feel unprepared for the possibility of loss and the emotional
  processes that follow.
- 2. The marked psychological distress experienced by bereaved women is complex in its presentation, and differs from the dominant discourse. In addition to typical manifestations of grief such as shock, denial, anger, and depression, women who experience pregnancy loss experience enormous anxiety, guilt, self-blame, disruptions to their identity, vulnerability, and post-trauma distress. This psychological distress is often pervasive and enduring.
- 3. The experience of pregnancy loss not only results in immense psychological distress, but also leads to positive growth. Women described greater empathy, increased personal strength, relationship closeness, and spiritual development as positive outcomes of their pregnancy loss experience.
- 4. The experience of labor and birth is significant. Women feel immensely proud of their ability to deliver naturally via stillbirth, but feel unprepared for the process this entails. Women also value the opportunity to spend time with their stillborn baby and create tangible mementoes.
- 5. Women engage in specific memorialisation practices to ensure their connections with their deceased baby are maintained. The baby holds a special place within the family unit, and is considered a sibling to any current or future children. The notion

- of a "replacement child" is considered offensive to women who experience pregnancy loss.
- 6. Women often encountered feelings of disenfranchised grief, whereby their grief was often misunderstood and dismissed. Therefore, emotional validation of the loss is important, that recognises the loss of human life and the loss of the mother's future aspirations. The pregnancy loss should not be viewed as a replaceable outcome.
- 7. Support on a professional level is lacking for bereaved women, particularly in respect to follow-up care. Delays between labour and birth can be perceived as meaningless and distressing, and women need further guidance to enable more informed decision-making. Similarly, women need more information to prepare them for the processes of labour and birth. Following discharge from hospital, women need further guidance and support to promote effective management of grief. Continuity of care, preferably by the same staff who assisted during the process of labour and birth, would be of value.
- 8. Communication is pivotal, and should be warm, sensitive, genuine and reassuring. Language is important, as blunt, ambiguous, and disengaged communication styles can increase women's distress.
- 9. Women seem to experience a powerful urgency to become pregnant again, in order to fulfill their desire for another child. Although they strive to wait until they are emotionally and physically ready to try gain, there does not appear to be a "right time". Hence, the notion of an optimal waiting period is questionable.
- 10. The majority of women who experience pregnancy loss endure a subsequent pregnancy. This is an emotionally laden experience, characterised by continued grief, intense anxiety, and a constant need for reassurance. In an attempt to cope

with this experience and protect themselves from further pain, women engage in emotional cushioning behaviour, whereby they attempt to restrict emotional bonds with their unborn baby. This reality may affect attachment to the subsequent child.

# **Research Implications**

Although the findings of the current study are not generalisable to all women who experience pregnancy loss, they may guide current research upon which to inform clinical practice. Likewise, although this study is not in itself a basis upon which to support changes in practice, the findings generated from women's voices can contribute to policy development in collaboration with existing research.

# Implications for Theory Development and Grief Classification

Pathological Grief or Just a Normal Reaction to Bereavement? For years, there has been considerable debate over what differentiates 'normal' constructions of grief from 'abnormal' constructions, and whether in fact the emotional reaction to the loss of a loved one can ever be considered a mental disorder (First, 2011; Frances, Pies, & Zisook, 2010; Holland et al., 2009; Stroebe et al., 2000; Wagner & Maercker, 2010; Wakefield, 2011). Several theorists have advocated that grief is nearly ubiquitous among all individuals, that grief following bereavement is normal, and therefore, should not be pathologised (Freud, 1917/1957; Greenspan, 2004; Kleinman, 2007). Reinforcing this argument appears to be a concern that the medicalisation of grief would stigmatise and reduce the normalcy of the pain that grieving ensues, and may lead to an over-diagnosis of grief and consequently, over-prescription of psychotropic medication (First, 2011; Frances et al., 2010; Getz, 2012; Wagner & Maercker, 2010; Wakefield, 2011). Other theorists have argued that the conceptualisation of pathological grief as a distinct syndrome would likely result in less misdiagnosis and inappropriate treatment (Horowitz et al., 1997; Shear et al., 2011), and

that a separate diagnostic category is needed to assist in more accurate identification and management of bereaved people (Horowitz, 2005; Lichtenthal, Cruess, & Prigerson, 2004; Momartin, 2012).

Despite such widespread controversy, the push to recognise pathological grief as a formal psychiatric diagnosis has been strong, resulting in the recent inclusion of 'Prolonged Complex Bereavement Disorder' in the appendix of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Although this section contains proposed criteria sets that require further verification, it seems likely that pathological bereavement will be included as a formal diagnostic category in the future. Compared to earlier proposed criteria sets (e.g., Horowitz et al., 1997; Prigerson et al., 2009; Shear et al., 2011), this criteria set has specified an increase in the durational onset of symptoms required for diagnosis (from six months to twelve months).

In light of the current research findings, this modification is an improvement on previous models, as for many women in this study the majority of symptoms required to meet a diagnosis of pathological/complicated grief were still evident at six months postloss. Furthermore, in most cases these symptoms persisted for more than a year. Similar findings have been reported in a qualitative study by Stringham, Riley, and Ross (1982) who found that over half the women interviewed following a stillbirth continued to experience symptoms of distress six months after the loss, and that these symptoms persisted for several of these women one year post-loss.

Evidence for the long-term trajectory of grief was obtained in a qualitative study by Dyson and While (1998), who found that women bereaved by pregnancy loss continued to experience yearning and sadness even fourteen years after loss. Based on this finding, the authors concluded that yearning and sadness might never cease. This finding is also

consistent with women's interpretations in the current study that their grief would never entirely resolve. However, as interview data for the current study was only collected over a 13-18 month time frame, it is acknowledged that this conclusion is only speculative. Regardless, the results do add to the existing body of literature by demonstrating that women continue to experience grief symptoms beyond twelve months post-loss. Grief symptoms not only persisted beyond the six-month 'pathological' cut-off enforced by most diagnostic categories, but were experienced with varying intensity that did not resolve over time. Therefore, the findings challenge the conceptualisation of 'pathological grief' among this population, and the author urges researchers to reconsider the long-term trajectory of grief rather than labeling grief that continues for longer than six or twelve months as 'pathological'.

Currently, there is no robust evidence that symptoms observed in pathological grief are different from normal grief responses that abate within six or twelve months (Bryant, 2013; Holland et al., 2009; Wagner & Maercker, 2010; Wakefield, 2011). Research into grief and loss indicates that grief can be prolonged and debilitating without indicating a psychiatric disorder (Prigerson & Jacobs, 2001). There is also no conclusive data to signify whether pathological grief represents a persistence of symptoms that endure longer than the 'normal' period of adaptation, or is a qualitatively distinct syndrome altogether (Holland et al., 2009). What is clear at this point is that differentiating a pathological grief reaction from a normal one remains difficult, and further evidence as to how pathological grief symptoms are phenomenologically distinct from those of normal grief should be established before pathological grief is recognised as a separate disorder (Holland et al., 2009; Stroebe et al., 2000). Without a greater understanding of the underlying structure of

normal and pathological grief reactions, there are no clear guidelines available to determine what intensity, duration, or type of grief symptomatology can be considered pathological.

Transferability of Current Grief Theories. As Chapter 2 revealed, there is no single theoretical framework that explains perinatal attachment and no current framework that can adequately explain grieving following a pregnancy loss. Existing theories of maternal attachment and perinatal bereavement are based primarily on assumptions of what women experience following a pregnancy loss, rather than on empirically generated data (Wright, 2011). As Brier (2004) noted, the emotional discourse of pregnancy loss has not yet been identified, so intervention in this field is largely operating on the basis of grief theories that are not specific to perinatal grief. This is not only ineffective best-practice, but "the absence of normative information about the possible long-term sequelae of perinatal bereavement only serves to perpetuate simplistic assumptions regarding the recovery process" (Uren & Wastell, 2002, p. 305).

It is clear from the research findings that grief following pregnancy loss is very different to typical manifestations of grief reported in the mainstream literature (e.g., Bowlby, 1961, 1980; Freud, 1917/1957; Kubler-Ross, 1969; Lazare, 1979; Lindemann, 1944; Parkes, 1965; Parkes & Weiss, 1983; Shuchter & Zisook, 1993; Worden, 2009). The dominant narrative which depicts grief as a short-term process consisting of several stages or phases of grief that eventually resolve, was not supported by the bereaved women in this study. Instead, women's experiences were characterised by a process of adaptation and integration, whereby they learnt to accept and live with their grief and loss, rather than recover from or resolve it. This was primarily evident through their conscious efforts to maintain continuing bonds with their deceased baby, and through their incorporation of the baby as part of the family. Whilst this attachment behaviour was most prominent among

women who experienced a stillbirth, many women who endured a miscarriage also ensured these connections were maintained. Women from both gestational cohorts were adamant that their grief would never dissolve and that the bond with their deceased child would never be broken. This reality is underreported in the literature, which suggests that women who experience miscarriage do not grieve as deeply or have such strong connections with their child compared to those who experience stillbirth (Cuisinier, Kuijpers, Hoogduin, de Graauw, & Janssen, 1993).

Losing a child through pregnancy loss presented a unique and complex bereavement experience characterised by immense emotional turmoil and challenges to self-identity — not characteristically representative of stereotypical notions of grief. For the women in this study, attributions of guilt, blame, anger, shame, and vulnerability were significant components of the grief experience. These occurred irrespective of gestational age and resulted in a myriad of secondary losses in addition to the loss itself. The women experienced the loss of naivety, the loss of motherhood, and the loss of their future hopes and dreams. They also experienced significant disruptions in their family relationships and friendship networks, and questioned their roles, identities, beliefs, and priorities in this world. These multiple losses were compounded by a society that largely fails to recognise the incidence and emotional experience of pregnancy loss. Consequently, for women bereaved by pregnancy loss, grieving often occurs behind closed doors and presents an isolated grieving experience (Lang et al., 2011).

To further clarify the disparity that exists between current grief theory and research evidence, it is also necessary to examine the attachment literature in relation to grief and loss. Whilst most of the research focuses on infant attachment directly after birth (Bowlby, 1969; Klaus & Kennell, 1976; Peppers & Knapp, 1980), attachment during pregnancy has

also been addressed (Gaffney, 1988; Muller, 1992; Rubin, 1984). Most of this early research stipulates that attachment begins well before birth, foetal movement has been frequently cited as the time when attachment intensifies (Gaffney, 1988; Heidrich & Cranley, 1989; Lerum & LoBiondo-Wood, 1989; Peppers & Knapp, 1980; Rubin, 1984). For example, Rubin (1984) hypothesised that maternal attachment began with quickening at around twenty weeks gestation, when the mother first perceives foetal movement. If Rubin's theory was valid, women would not be expected to grieve following losses that occurred prior to quickening. However, as the results of the current study and other research demonstrate, women have also described profound emotional responses to early pregnancy loss (Abboud & Liamputtong, 2005; Adolfsson, Larsson, Wijma, & Bertero, 2004; Hutti, 1986; Van & Meleis, 2003). Such findings suggest that attachment processes begin early in pregnancy, and that it is not necessarily gestational age that predicts women's grief responses following pregnancy loss but the woman's investment in her pregnancy.

Given that the phenomenon of perinatal bereavement cannot be understood in relation to current theories of grief and attachment, a new, integrated theory is needed to explain the entire perinatal bereavement process. This needs to include further exploration of maternal attachment processes during pregnancy. Considerations such as the effects of advanced technology such as prenatal testing and ultrasound should also be accounted for, as these may foster earlier emotional attachment (Black, 1992; Righetti, Dell'Avanzo, Grigio, & Nicolini, 2005; Robinson, Baker, & Nackerud, 1999; Stormer, 2003). In addition, any new theory would need to consider a comprehensive analysis of the emotional responses of pregnancy loss identified in this thesis and existing research, so that any principles applied are specific to perinatal grief. Clinical care needs to reflect evidence-

based practice, based upon sound practice models that are supported by the clinical and research literature. Currently, women's accounts of the care they receive following pregnancy loss do not convey wholly effective treatment (Abboud & Liamputtong, 2005; Morrissey, 2007). This is discussed in the next section and has important implications for practice.

## **Implications for Policy Development**

Overall, the findings of the current study indicate that service delivery following pregnancy loss is not sufficiently meeting the specific needs of bereaved women, because women feel that the emotional significance of their grief experience is not fully appreciated or recognised. Women's dissatisfaction with many aspects of their care and support received from healthcare professionals following a pregnancy loss and the potentially negative consequences of this remains under-acknowledged. In addition, the current trend towards pathologising grief reactions on the whole only serves to reinforce the stigma that persistent and enduring grief following pregnancy loss is 'abnormal', and that losing a baby shouldn't be as painful as other losses.

In light of the perceived inadequacies articulated by the women in response to service provision, the implications of this thesis are purposely presented in a format that is most likely to be utilised and incorporated by service providers. These are divided into five major recommendations for practice: (1) Increase public awareness of pregnancy loss and improve grief education; (2) Validate women's concerns and acknowledge the emotional impact of loss; (3) Facilitate support in spending time with and separating from the baby; (4) Establish specialised follow-up care; and (5) Continued professional support in the subsequent pregnancy.

# (1) Increase Public Awareness of Pregnancy Loss and Improve Grief

**Education.** The first major recommendation emerging from the research concerns the provision of grief education. As the findings demonstrated, pregnancy loss results in a unique grieving experience, and its emotional impact is often not recognised by society at large. Consequently, women who endure a pregnancy loss are often presented with an isolated and unprecedented grieving experience, with limited support.

In order to improve the bereavement experience for women affected by pregnancy loss, it would appear that there is a strong need to increase awareness of the frequency of pregnancy loss and the resultant grief experience that ensues. The research findings suggest that support for the bereaved is lacking because the community and service providers are failing to respond with the appropriate sensitivity that the grieving experience requires. Given this perceived lack of support, community-wide education about grief response to potentially increase awareness and understanding of the grief experienced by those bereaved through pregnancy loss is recommended.

At the forefront of this community-wide initiative, should be a focus on increasing public awareness. During women's accounts of their bereavement experiences, it was evident that many women expressed guilt over their ignorance at not knowing the high incidence of pregnancy loss, and consequently, were not aware of some of the warning signs to look out for that something could be amiss with their pregnancy. The women felt that perhaps if they had known what some of the warning signs were (i.e., gestational diabetes, experiencing lack of foetal movement) they would have been more vigilant and attentive during their pregnancy. One possible avenue is the provision of pamphlets on the statistics of pregnancy loss, risks, and some of the common warning signs to look for. Respective healthcare providers, such as GP's, obstetricians, midwives and others, could

distribute these to women. Childbirth educators may also wish to mention the possibility of pregnancy loss during routine prenatal classes. This should be addressed not in a manner that creates alarm, but in a sensitive way that conveys whilst hopefully all will go well with the pregnancy, if there are any complications the support and appropriate services are there if required. As most prenatal classes have access to educational resources, it may be an option to direct women to these resources should they desire or require additional information on the experience of pregnancy loss. This approach addresses the direct concern of women in the current study, without invoking unnecessary fear for those who wish to focus their attention on an anticipated healthy outcome.

In addition to educating pregnant mothers sensitively about the risk of pregnancy loss, it is also necessary to educate women who have lost a baby about the nature of the grief experience. To do this, it is essential that staff working in maternity care are knowledgeable about the grief response, so that they are able to provide appropriate support. In particular, healthcare providers working in maternity care have the ability to facilitate the grieving process by understanding the course of grief and preparing the women for its impact (Kohn & Moffitt, 2005). As the research findings demonstrate, initial grief responses to pregnancy loss include shock, denial, and emotional numbing. This is followed by a phase of acute grief, where the reality of the loss sinks in, and women's grief is arguably at its greatest intensity. Strong emotional and physical anguish is experienced, and the women experience significant disruptions in their sleeping and eating patterns, as well as other aspects of daily functioning. Intense anger, guilt, jealousy, self-blame and shame follow. Over time, this grief transcends in to a more settled phase, whereby the women learn to accept their loss and integrate their deceased child into their lives. The women's grief is not resolved, but is a process of continual adjustment as they slowly begin

to reinvest emotionally in their future. Generally, the grief journey entails a subsequent pregnancy where the women experience resurgence in their grief intensity, together with immense anxiety. Educating professionals about this bereavement response is important because it means that they will be better able to normalise and validate the grieving process for women who experience pregnancy loss. Ultimately, this will help reassure women that their grief is normal and will encourage them to openly express their distress and fears.

In light of some of the bereaved women's accounts of the negative attitudes they experienced through service provision, bereavement education must also focus on service delivery. Although healthcare providers were not interviewed in the current study, the women reported that care providers working in the field need to be better educated on how they can respond more sensitively to pregnancy loss. The use of medical jargon and the callous attitudes displayed by certain care providers were articulated as hurtful and insensitive to the bereaved women's experiences. Likewise, some care providers were criticised for their tendency to become desensitised to the emotional significance of loss. Therefore, it is crucial that care providers working in the field of bereavement receive the appropriate skills and training to communicate and respond more sensitively to the needs of bereaved women following pregnancy loss. Although doctors, nurses, and midwives working in maternity care often receive basic bereavement training as part of standard curricula (i.e., via IMPROVE<sup>8</sup> workshops in Australia), there is a need for further skills training among doctors. The current study and others have identified that nursing and midwifery personnel are best meeting the psychological needs of bereaved women (Cuisinier et al., 1993; Gold, 2007; Peters et al., 2014). A supplementary approach may be to present the qualitative findings of women's experiences within education programs (i.e.,

<sup>&</sup>lt;sup>8</sup> IMproving Perinatal mortality Review and Outcomes Via Education (IMPROVE, Australia and New Zealand Stillbirth

at an undergraduate level at university), beyond what is already occurring. Hence, facilitation of a shared approach to care may lead to greater satisfaction with healthcare provision across the board.

Grief education also needs to extend beyond the personal and professional realm to the wider community. The findings revealed that the nature of pregnancy loss, combined with society's inherent discomfort with grief in general, meant that women's social support networks were often unable to provide them with the appropriate support they needed. As a result, many of the women felt isolated from social networks when their grief was ignored, or when they encountered thoughtless and hurtful comments that served to minimise their grief experience. Thus, it is suggested that education at the community level can also play a significant role in helping the community to provide appropriate support to women following pregnancy loss.

Women's support networks need to be educated about the importance of acknowledging the legitimacy of the death, and validating the grief experience. In Australia, multiple grief support resources for fathers, siblings, grandparents, family and friends exist (i.e., downloadable brochures from sands.org.au), however evidence from the current study suggests that these are currently being underutilised. Perhaps the issue lies within the inherent discomfort that surrounds grief – several women described how they possessed information pamphlets in their grief pack upon their discharge from hospital, but they felt uncomfortable passing these pamphlets on to their family and friends. Thus, an alternative means of communicating such valuable information to peer support networks seems warranted.

In today's age of modern technology, a possible way to open communication channels might be through the use of social media. Many women in the current study highlighted

their regular use of online support forums to increase their feelings of social validation. They also indicated that they used online tools such as Facebook and Instagram as they counted down the weeks until their baby's due date, and again as a means of breaking the bad news to their social networks when they lost their baby. One participant described her use of email to inform her work colleagues of her pregnancy loss and to express her feelings of grief. On this basis, it is plausible to assume that social media may also be a useful tool to inform family and friends how they can best support the bereaved mother. This could involve the mother posting a status update on Facebook for example, with links to supportive electronic resources (e.g., "My precious baby has died – How you can help"). It might also include the opportunity to 'like' a pregnancy loss support page in honour of the baby, which may outline some helpful and hurtful comments and behaviours that either facilitate or hinder the mourning process. Other women may prefer to send this information via email to their family and friends.

(2) Validate Women's Concerns and Acknowledge the Emotional Impact of **Loss.** Several women in the current study expressed dissatisfaction with the manner in which their healthcare providers failed to respond to their initial concerns or show appropriate sensitivity in response to their loss. For example, the women reported feeling angry and upset at healthcare providers whom they felt either ignored or minimised their concerns and distress. Some felt that perhaps their pregnancy loss could have been averted if only their respective doctors had validated their concerns, and responded accordingly by conducting a more thorough physical examination. Likewise, long waiting periods in emergency departments led to heightened feelings of emotional distress. This suggests that healthcare providers need to be more vigilant about the state of distress women are in when they present with concerns, and respond with greater empathy and diligence.

Additional complaints noted by the women related to their experiences of inadequate direction from health care providers in terms of what to expect during labour and birth. In particular, women who had given birth to a previous healthy child in the past felt that healthcare providers often made assumptions that they would know what to expect. However, the experience of delivering a stillborn baby was described as a very different experience emotionally compared to the experience of a live birth. During stillbirth, the women needed to endure labour and birth, with the full knowledge that there would be no healthy newborn at the end. Not only was this a traumatic and anxiety provoking experience, but the women felt that they did not fully comprehend the reasons for a natural birth. In addition, the information that was communicated to them regarding labour and birth was often interpreted as confusing and difficult to absorb. This suggests that healthcare providers need to take the time to carefully and sensitively explain the processes of labour and birth, and provide clearer justification of the psychological and medical reasoning for vaginal birth. Additionally, women need to be given time to process this material, and encouraged to make an informed decision as to the preferred timing between diagnosis of foetal death and induction of labour. Evidence from the current study suggests that women experience delays as meaningless and distressing, as they are provided with insufficient information as to the psychological benefits of enabling time to process the loss.

A further discrepancy highlighted by the women in respect to their experiences leading up to labour and birth was the disconnect that existed between their perceptions of loss and those held by the majority of service providers they encountered. For example, practitioner attitudes in response to miscarriage came across as very 'matter of fact', and the women felt that their loss was treated as a largely trivial event rather than as the loss of

human life. Similar disregard for the emotional experience of pregnancy loss was also reported by women who experienced stillbirth, who felt that their consultants were preoccupied with the medical significance of their loss. This left some women feeling that their healthcare providers did not really grasp the magnitude of their loss, in terms of its intensity and devastation. Such findings reinforce the need for service providers to ensure that they remain attentive and sensitive to the emotional experience of pregnancy loss, and that grief surrounding pregnancy loss is acknowledged and respected.

#### (3) Facilitate Support in Spending Time With and Separating from the Baby.

The quality of support in spending time with the baby following stillbirth, was crucial to the women in this study's bereavement experiences. In contrast to some of the literature which specifies that seeing and holding the deceased baby can intensify women's grief experiences (i.e., Hughes et al., 2002), those who elected to spend time with their stillborn baby reported that the experience had a positive influence on their grieving. Despite being fearful at first, these women were grateful that healthcare providers recognised their initial fear and hesitancy and gently encouraged them to cherish the opportunity to spend time with their baby. Although this precious time was conceptualised as "never enough", all of the women in the study who experienced stillbirth reported how special this time was. Caregivers' efforts in helping with memorialisation and celebration of their baby's short life were especially appreciated. For example, the midwives assistance in taking photographs, handprints, and footprints, planning funeral arrangements, and providing a birth certificate, were all deemed as invaluable gestures of support. Thus, consistent with other research findings which illustrate the positive effect of physical contact with the deceased baby (e.g., Cacciatore et al., 2008; Erlandsson et al., 2013), it is suggested that

caregivers continue to support women in meeting and spending time with their baby, as this seems to facilitate the grief experience.

Equally important is the support required to assist women in separating from their deceased baby once they leave hospital. Whilst the women appreciated their caregivers' efforts to provide resources and explain their use, many had personal difficulty accessing these services or expressed discomfort at using these services. For example, although women found the supportive pamphlets given to them prior to discharge useful, they reported that it was often hard to make the call for help when they were in such a distressed and emotional state. Similarly, although the women knew they were eligible for available support services, they experienced discomfort when trying to access these services. Therefore, it would appear that the women would have benefited from a support service that perhaps could have reached out to them, instead of the other way around. This pivotal recommendation is addressed in the following section on establishing specialised follow-up care.

(4) Establish Specialised Follow-Up Care. A common theme that emerged from the data was the women's dissatisfaction with the lack of follow-up services provided to them following their discharge from hospital. This was evident across gestational cohorts (i.e., among women who experienced miscarriage and stillbirth) and supports previous research outlining the importance of follow-up care (Athey & Spielvogal, 2000; Geller, Psaros, & Kornfield, 2010; Rajan & Oakley, 1993; Simmons, Singh, Maconochie, Doyle, & Green, 2006). Returning home was a time when the women described overt psychological distress. This was a time when the women were not only confronted by the harsh reality of their loss (i.e., that they were no longer pregnant, and were coming home with empty arms to a fully adorned baby room), but was also a time when the comfort and

support of hospital caregivers was abruptly removed. Therefore, instilling adaptive emotional regulation skills that facilitate adjustment for these women upon their discharge from hospital is of utmost importance, and the implementation of a follow-up service that supports women in this transition is recommended.

Providing such a service could be incorporated into a 'continuity of care' model of treatment, whereby the women are provided with a scheduled follow-up appointment after their discharge from hospital. This follow-up needs to extend beyond the brief grief questionnaires and physical check-ups already in place. At present, referral for psychiatric support is only provided if there is clear evidence of a pathological reaction or if the woman is assumed to be at high-risk for psychological morbidity. However, the women reported that they would have benefited from early supportive interventions that could have encouraged and normalised their expressions of grief, and assisted them to better manage their psychological distress, at a time when they felt so emotionally vulnerable. Thus, if the follow-up appointment establishes that referral for counseling may be required, action may be taken to refer the individual to the appropriate psychological service (i.e., individual, group, or couple therapy). At this point, care should be taken not to over reinforce the benefits of professional support, as some women may not feel a need or desire to utilise these services. The important thing is that women are provided with access to supportive resources, and reassurance that help is available should it be required. As one study participant poignantly remarked, there is a wealth of information to assist women to prepare for the transition to motherhood (e.g., book titled, 'What to Expect When You're Expecting'), yet, there is little available for women who experience pregnancy loss. "There is nothing for us. Maybe there should be a book called 'What to Expect When You're NOT Expecting'!"

In terms of professional support, it is suggested that any psychotherapeutic intervention for pregnancy loss should incorporate psychodynamic and cognitive-behavioural elements, as these have been shown to be effective in dealing with reproductive trauma (Bennett, Ehrenreich-May, Litz, Boisseau, & Barlow, 2012; Capitulo, 2005; Kersting, Kroker, Schlicht, Baust, & Wagner, 2011; Stratton & Lloyd, 2008). In addition, the women's experiences have highlighted how professional support needs to take into account the meanings each woman has constructed from her experience of loss, as this will ultimately affect how each woman responds to her loss. Therefore, initial assessment should include an analysis of the personal meaning the woman ascribes to her loss, as well as identification of the supports she has available to her, her current state of functioning, and full medical history (including previous losses).

Identifying how women interpret their loss is important because as the findings of the study have shown, perinatal grief is not necessarily linked to gestational age but more to the woman's investment in her pregnancy. For example, some women may attach to their baby quite early on in pregnancy, and miscarriage may be a very devastating event.

Therefore, healthcare providers must evaluate the personal significance of the loss for the woman before they intervene so that misguided assumptions in care can be avoided. Once the personal meaning of the loss has been derived, the therapist can help the woman to understand her grieving response by educating her about some of the common physiological and emotional reactions to loss. For example, disruptions in sleeping and eating, emotional numbness, frequent yearning for the deceased baby, nightmares, and difficulty concentrating are all likely to be initial characteristics of the immediate grief experience. This is likely to lead to more complex secondary emotions such as guilt, anger, shame, self-blame, anxiety. Thus, the initial focus of assessment might be on increasing the

women's awareness of typical responses to pregnancy loss, and on helping them identify their own personal feelings and responses.

Following identification of the women's emotions, the women might be informed that they will be given some emotional regulation strategies in future sessions to help them manage these intense emotional responses. This could likely be achieved through the practice of adaptive coping skills, such as emotional exposure, mindfulness, and cognitive reappraisal, which have been shown to be effective in reducing post-loss psychopathology (Bennett et al., 2012; Shear, Frank, Houck, & Reynolds, 2005). Therapy should be tailored to the individual needs of each woman, and it is anticipated that a combination of strategies should be employed. Mindfulness practices, which focus on assisting the client to remain in the present moment and express painful emotions with a nonjudgmental awareness, may be useful to encourage women to become more self-aware and less reactive. Cognitivebehavioural techniques may be useful to help women restructure their unhelpful cognitions, such as those focused on guilt, shame, and self-blame. Emotional exposure practices can be gradually integrated into sessions according to the needs and abilities of each woman at certain points in time. For example, narrative exposure (e.g., speaking or writing about the loss experience) may be useful at the beginning of treatment to express particular emotions and to identify negative attributions. This was indeed noted as helpful by several women in the current study who engaged in journaling practices as a form of emotional expression. Situational exposure (e.g., visiting the hospital, going to the baby section of department stores, going to the playground) may be useful to target avoidance behaviours. Imaginal exposure (e.g., visualising the traumatic experience of birth, imagining a live-birth) may be useful to target anxiety specific behaviours and generate a new positive outcome. These emotional exposure practices should enable the women to practice tolerating and regulating

their emotions in a supportive environment, leading to an overall reduction in avoidant coping skills and an improvement in adaptive coping.

In addition to providing the bereaved women with emotional regulation strategies, it is recommended that attending to psychosocial issues could further enhance the management of grief. The women felt that some of the most effective support came from someone who had previously experienced and successfully managed a similar crisis (e.g., they actively sought support from other women who had experienced pregnancy loss). Thus, facilitating access to other bereaved women who are willing to share their stories of grief and loss and provide support to women in need should be considered. Indeed, several women in the current study reported that they would be willing to put their names forward on a register that was accessible to other women seeking support, should this be an option. Similarly, another important source of support indicated by several women in the study is a referral to a pregnancy loss support group. Many of the women in the study expressed that had such a service been available, they would have utilised the service. This finding highlights the importance of educating women about the availability of existing support services to assist their grief. In particular, both SIDS and KIDS WA and SANDS WA bereavement support groups were largely underutilised by the women in the current study. This is likely attributable to the women's misconceptions about the organisation (i.e., that SIDS and KIDS wasn't specific to pregnancy loss) or women simply being unaware of the existence of such groups (i.e., SANDS WA). Hence, care needs to be taken to educate and inform women as to the benefits and availability of existing support services, so that women feel comfortable accessing such invaluable support.

Pregnancy loss support groups might have been especially useful in helping to normalise women's grief experiences, and reduce the sense of disenfranchisement and

isolation that women felt. In addition, they could have provided information on coping strategies and addressed any misconceptions the women may have had. For example, facilitators could provide information on how best to respond to others reactions to their loss (e.g., understanding avoidance, the filtering of hurtful comments, practicing assertive communication), the gender differences likely to be encountered in grieving (e.g., differences in grieving styles, how to communicate effectively with your partner), as well as the factors to consider when deciding to try again (e.g., emotional and physical readiness, the costs and benefits of waiting versus trying again as soon as possible). Indeed, both the findings of the current study and existing research suggest that the decision to try again for another baby is difficult and immensely anxiety provoking. Hence, continued professional support in the subsequent pregnancy is a final recommendation.

(5) Enable Additional Support in the Subsequent Pregnancy. The findings of the current study suggest that women desire additional support in the subsequent pregnancy, as this is a time when they experience intense anxiety and ongoing emotional distress. This finding is consistent with those of other researchers who have suggested that women are likely to benefit from enhanced clinical care due to the high rates of anxiety they experience in the subsequent pregnancy (e.g., Cote-Arsenault, 2002; Hutti, 2004; Saflund, Sjogren, & Wredling, 2004; Wright, 2005). Whilst the health care system has recognised that increased surveillance in the next pregnancy is often warranted because these women may be at increased risk for another pregnancy loss and obstetric complications (Garcia et al., 2002; Simmons & Goldberg, 2011; Wallerstedt, Lilley, & Balwin, 2003), women's reports suggest that this care needs to advance beyond more frequent prenatal visits in order to lessen their anxiety. Several women who had experienced a previous stillbirth noted that although they were now receiving more frequent ultrasound scans (generally on a

fortnightly basis in the later stages of pregnancy), and some even possessed home Doppler devices (to hear the baby's heartbeat), it was not enough to significantly reduce their anxiety. The women felt they would have benefited from additional support services (such as counseling) that were designed to target their anxiety, and that having someone to talk to about this anxiety would have made the subsequent pregnancy experience easier to endure. Indeed, other researchers have also suggested that offering women the opportunity to discuss their feelings and concerns during the subsequent pregnancy would be of benefit (Wallerstedt et al., 2003; Wheeler, 2000).

Considering pregnancy anxiety was not restricted to women who experienced stillbirth but also affected women who experienced a previous miscarriage, it is recommended that support be extended to both gestational groups. Consistent with other research on women's experiences of miscarriage, the first trimester was particularly anxiety provoking for women but anxiety decreased as the pregnancy progressed. In particular, women reported notable feelings of insecurity concerning the viable outcome of their pregnancy, and they experienced substantial anxiety. Therefore, a short-term intervention that targets elevated anxiety in the subsequent pregnancy may be useful, and warrants further exploration.

Among women who experienced a stillbirth, fear and anxiety over the possibility of another loss persisted throughout the subsequent pregnancy. In order to cope with the sense of uncertainty and vulnerability they felt in these pregnancies, these women tried to protect themselves psychologically against another loss by holding back their emotions. They engaged in a process of 'emotional cushioning', whereby they tried to remain hopeful and optimistic about their pregnancy, while inwardly expecting the worst to happen (Cote-Arsenault & Donato, 2011). In addition, these women continued to grieve for their previous

loss and sometimes had difficulty separating their previous baby from their current pregnancy. This was further complicated by an underlying sense of guilt the women felt for their previous loss, and the women actively engaged in specific over-compensatory behaviours in an attempt to avoid another loss. Clearly, these were emotionally challenging and stressful pregnancies, fraught with anxiety and fear.

In order to assist women with the overwhelming anxiety they experience in the subsequent pregnancy, the research findings indicate that interventions designed to reduce anxiety whilst assisting the reintegration of grief, may be of benefit. In the first instance, programs of interconceptual counseling and support should be developed and implemented, to provide psychoeducation on anticipatory anxiety and assist women with the complex array of emotions they are experiencing as they prepare to conceive again. Concerns over the timing of the subsequent pregnancy should be addressed, and the concept of 'emotional readiness' explored. Likewise, women need to be informed about the complex interplay of grief and anxiety in the subsequent pregnancy, to ensure they feel better prepared for the journey that lies ahead.

During the subsequent pregnancy, women's strong need for control and reassurance has implications for clinical care that may challenge current caregiver practices. As mentioned previously, increased frequency of ultrasound scans early on in pregnancy and with greater frequency, may assist to reduce women's anxiety by confirming the current wellbeing of the unborn baby. Likewise, additional testing to rule out pre-existing medical complications may also alleviate distress. However, the findings of the current study have established that increased medical care alone is not sufficient. A more comprehensive model of care is required that considers both physical and psychological aspects of the pregnancy-after-loss experience. In particular, women need assistance to balance their hope

and fear, accept vulnerability and uncertainty, and process their continuing grief. The difficulty in being able to invest emotionally in the pregnancy due to fear of reoccurrence, and the possible consequences of 'emotional cushioning' will also need to be addressed. Hence, a major therapeutic goal may be to encourage emotional bonding with the unborn baby, whilst acknowledging and conveying empathy to the mother that there may be a strong desire to engage in self-protective behaviour that restricts attachment. Research has indicated that cognitive processing such as mindfulness based cognitive therapy (MCBT) may be an effective treatment modality (Goodman et al., 2014), to assist the mother to focus on the present moment and reinterpret anxiety. However, further research is required to determine the best course of psychotherapeutic intervention, as research is limited.

The development and accessibility of a specific pregnancy-after-loss (PAL) support group may also be of benefit. Research pertaining to the use of these support groups has demonstrated promising results (Cote-Arsenault & Freije, 2004). For example, Caelli, Downie, and Knox (1999) developed and evaluated a support program for couples in Western Australia, which preliminary findings indicated was very helpful to participants (Caelli et al., 2002). This midwife-managed intervention, entitled the 'Special Delivery Service', was developed as an adjunct to routine care to support and educate women and their partners in the subsequent pregnancy. The researchers documented that a major strength of this intervention was its holistic approach, which resulted in improved psychological well-being and satisfaction for women and their partners (Caelli et al., 2002). In other parts of the world, such as in the United Kingdom, it has been demonstrated that social support improved the physiological and psychological outcomes of pregnancies after loss compared to routine care (Rajan & Oakley, 1993). In the United States of America, pregnancy-after-loss support groups provided an environment where grief and loss was

acknowledged, where women developed caring and supportive relationships, and where new skills were acquired which helped the women cope with the pervasive anxiety they were feeling (Cote-Arsenault & Freije, 2004).

The positive impact of these groups in helping women to deal with the trials and tribulations of their subsequent pregnancy suggests that perhaps a similar group could be established. Although a specific program would need to be developed, it is suggested that the major focus of any pregnancy-after-loss support group should be on targeting women's anxiety, fear, and sense of fragility in the subsequent pregnancy. Women should be encouraged to engage in activities and practices which are known to reduce anxiety, such as positive self-talk, meditation, physical activity, relaxation, and controlled-breathing (Peterson, 1994; Wallerstedt et al., 2003). Comparable to the suggestions for individual therapeutic intervention, facilitators could use emotional regulation strategies such as exposure therapy, mindfulness, and cognitive-behavioural techniques to facilitate coping.

When referring to women's grief experiences, facilitators should be careful to avoid terms such as 'resolution of grief', and instead utilise terms such as 'reintegration' or 'adjustment' (Wallerstedt et al., 2003). As the current study revealed, women felt that their grief was a lifelong process and resisted the notion that their grief would one day be resolved. In a similar vein, facilitators should not rely on statistical data depicting the unlikelihood of a subsequent loss. Although society generally equates pregnancy with a new baby, this simplistic equation is incongruent with these women's experiences.

One final recommendation for inclusion in any support group is to facilitate the development of a birth plan. Birth plans are intended to support women in their preparations for childbirth and have been shown to increase women's satisfaction by providing them with more control over the birth process and reducing maternal anxiety (Anderson & Kilpatrick, 2012; Kuo et al., 2010). Although no literature currently exists on the efficacy of birth plans for women following pregnancy loss, encouraging women to create a birth plan in the subsequent pregnancy could potentially increase satisfaction and reduce anxiety among this population. For example, women who have endured a stillbirth may currently opt to be induced early (around 38 weeks). This option was reported helpful by women in the current study who had experienced a previous stillbirth, as it helped to alleviate some of the distress they were feeling in the final stages of pregnancy. However, the medical tendency to deliver a subsequent baby early should be interpreted with caution, as there is evidence to suggest that this is not necessarily the safest option. Early induction has been associated with higher rates of infant mortality than those at full-term, and increased medical complications (Kriebs, 2015).

Regardless, establishing a birth plan could be pivotal to facilitate informed decision-making regarding the processes of labour and birth during the subsequent pregnancy and to assist women to prepare for the reality of their impending birth. This is important because it is not yet known how the decrease in prenatal attachment that occurs in the subsequent pregnancy affects maternal attachment to the subsequent child (Lamb, 2002). Further research is required to determine the value of birth plans in helping to reduce women's anxiety in the subsequent pregnancy, and to establish how they could be utilised to facilitate coping.

## **Implications for Future Research**

Although the knowledge gained through this thesis has provided a deeper understanding of the bereavement experience for women who experience pregnancy loss, further research is required to better determine how theory-based professional care can best assist bereaved women. This thesis has demonstrated that effective professional support

after pregnancy loss requires a comprehensive understanding of the grief experience, but further analysis is necessary to isolate how specific components of grief affect individual bereavement response. For example, further quantitative research is needed to determine exactly *what* factors contribute to maternal anxiety and post-loss grief reactions, and further qualitative research is required to ascertain *how* exactly these factors affect these responses. Understanding the how is undeniably important as "evidence based practice must be rooted in evidence based theories" (Wright & Hogan, 2008, p. 350). Thus, the development of an empirically derived theory of maternal perinatal bereavement is needed, before any model of care specific to perinatal loss can be developed (Wright, 2011). Likewise, both maternal attachment and grief theory require further refinements that incorporate broader theoretical bases – including biological, psychological and social understandings, if they are to form a basis for effective interventions.

In addition, further research is required to differentiate between women's experiences of early pregnancy loss (miscarriage) versus late-term pregnancy loss (stillbirth), to isolate if and how women's grief responses differ according to gestational age. Whilst similarities and differences among these groups were evident, women's accounts revealed that gestational age alone is not a sole predictor of grief response. Furthermore, the current study did not utilise psychometric instruments to determine the precise intensity and duration of emotional responses encountered by the women. Such information may assist in distinguishing how perinatal grief differs from pathological conceptualisations of bereavement (e.g., complicated/prolonged grief), as well as other distinct mental illnesses (e.g., depression, PTSD). In addition, the relationship of gestational age of loss to the concept of 'replacement' or 'vulnerable' child requires further

271

clarification, as the appropriateness of this concept for a perinatal population seems controversial.

Finally, although the current study only dealt with women's experiences of pregnancy loss, grief did not occur in a vacuum. Many women described how the experience not only affected them but was also difficult for their partners and immediate family. In particular, the women voiced concern that the grief of fathers is often ignored, even more so than their own. Fathers were also acknowledged as having the difficult role of trying to stay strong and support their grieving spouse, whilst also grieving himself. There were also notable gender differences in grieving between women and their partners, which ultimately affected their bereavement experience. Therefore, further research on the grieving experience and emotional needs of men following the loss of a baby, and on measures to facilitate the grieving experience of couples, is recommended.

## **Study Limitations**

In the current study, the use of qualitative research methodology facilitated the isolation of rich and descriptive data, which enabled a detailed examination of women's bereavement experiences. Furthermore, the choice of a longitudinal design, in which the participants were interviewed periodically, enabled a detailed account of women's bereavement experiences over a specified time frame. As the focus of the research was on identifying the experience of pregnancy loss, this type of in-depth research design facilitated an accurate representation of women's experiences. In addition, the use of phenomenological enquiry meant that interpretations were able to be derived from the real-world lived experiences of the women themselves, rather than restricted to pre-determined categorical indicators of bereavement. However, whilst the choice of research method

facilitated an accurate analysis of the phenomena in question, there are some limitations of the study that should be addressed.

First, as documented by other researchers, bereavement research presents unique challenges in sampling and recruitment of participants due to the vulnerability of this population (Caserta, Utz, Lund, & de Vries., 2010; Stroebe et al., 2008). Some women may not have been willing to participate in the study because their grief may have been too intense, or they might have feared that participation would have increased their grief (Stroebe et al., 2003). Thus, it is possible that the participant's accessed may not have been representative of the bereaved population, and that a selection bias may have ensued. Researchers also face further challenges in retaining those who have been recruited for the duration of the study (Cook, 1995; Grant & DePew, 1999; Lyons et al., 2004; Stroebe et al., 2003), as was the case with four women in the current study that chose to discontinue. One woman relocated overseas, another acknowledged that she was trying to move forward with her life and didn't want to look back, and two women were unable to be contacted at follow-up. Taking into account selection biases and attrition rates is especially critical in bereavement research, because participation decisions and grief reactions are likely to be closely related, and it is precisely these grief responses that are being examined (Stroebe et al., 2003).

A second issue that deserves consideration is the possibility of response bias as a result of demand characteristics (Stroebe et al., 2003). Although social desirability response bias can be a problem with self-report research in general (van de Mortel, 2008), the data gathered through qualitative interviews has the potential to be distorted because participants may feel they are expected to respond in a certain way (Rosenblatt, 1995). For example, some women may have exaggerated their grief intensity because admitting to

minimal grieving may be misinterpreted as them having 'recovered' from their loss, or that their baby was forgotten. Indeed, in the current study women overtly rejected the notion that their grief would ever be 'resolved', and they also refuted any false assumptions that construed their subsequent pregnancy as a 'replacement child'. However, the replacement child phenomenon clearly angered the women, as it was undoubtedly not how the women perceived their deceased baby. Furthermore, the consistency in women's descriptions of reintegration and acceptance of their loss as opposed to resolution or recovery from it. suggests that it is unlikely that any of the women's responses during the interviews were anything other than sincere representations of their unique and painful bereavement experiences.

A third issue is the notion that women's responses were also susceptible to researcher effects. Although the researcher was careful not to engage in the dual role of interviewer and 'therapist', it is possible that the interviews resulted in a therapeutic effect for some women in the study. Indeed, some women acknowledged that participating in the research and sharing their feelings of loss had facilitated their emotional journey in coming to terms with their loss experience. Whilst this implied therapeutic effect is not entirely negative, it may have inadvertently affected women's grieving experiences, therefore biasing the very process that it set out to study (Stroebe et al., 2003).

Despite the inherent limitations discussed above, all attempts were made to ensure the research process was as rigorous as possible. Credibility of the current study was demonstrated through the maintenance of professional boundaries, prolonged engagement with the data, participant verification of data interpretations, supervisory debriefing, and an audit trail to ensure transparency of the research findings (Lincoln, 1995). This resulted in a rich, transparent and contextualised analysis of the women's bereavement experiences,

whereby the interpretations of the findings are visibly derived from the data (Tobin & Begley, 2004).

## Personal Reflections on the Research

In contrast to what many people might assume, my motivation for conducting this research was not based on a personal experience of loss. This reality has indeed resulted in some quizzical looks and interesting comments from others who have questioned my choice in research topic, such as "So why would you choose such a depressing topic?" and "Isn't making a big deal about this only going to make it worse?" But perhaps the most insensitive comment came from a member on one of the ethical review committees who stated, "Well, we know they are grieving but why do we really need to know how?" Such simplistic acuities reinforce how the day-to-day sadness of expectant mothers who have lost a baby is largely ignored by society. Personally speaking, it was only when a close friend of mine lost her unborn baby that I myself realised the full extent of this loss.

While grief is never an easy topic to explore, being able to share in women's stories of grief has been a really inspirational journey. Since I began this research in 2009, many people have enlightened me about their own personal experiences of pregnancy loss. Upon hearing about my research, a work colleague confided in me about her stillbirth several years earlier. Still childless, it moved me immensely to hear her story of grief and loss, and how she continued to reflect on and integrate her daughter into her life. Another acquaintance shared with me her distress at experiencing two successive miscarriages, and subsequent difficulties with infertility. It is through these women's experiences that I realised not only how remarkably resilient women are, but that pregnancy loss is something that is just not spoken about or acknowledged in mainstream society. Women tend to suffer in silence. Clearly, this needs to change if we are to provide effective bereavement support

to this vulnerable population of women. There is still much work to be done if we are to develop the knowledge and competencies to do so, and I hope this research sets the stage for that to occur.

## References

- Abboud, L. N., & Liamputtong, P. (2003). Pregnancy loss: What it means to women who miscarry and their partners. *Social Work in Health Care*, *36*(3), 37-62.
- Abboud, L., & Liamputtong, P. (2005). When pregnancy fails: Coping strategies, support networks and experiences with health care of ethnic women and their partners. *Journal of Reproductive and Infant Psychology*, 23, 3-18.
- Abraham, K. (1927). A short study of the development of the libido, viewed in the light of mental disorders. In K. Bryan & A. Strachey (Eds.), *Selected papers of Karl Abraham MD* (pp. 435-442). London: Hogarth Press.
- Adeyemi, A., Mosaku, K., Ajenifuja, O., Fatoye, F., Makinde, N., & Ola, B. (2008). Depressive symptoms in a sample of women following perinatal loss. *Journal of the National Medical Association*, 100(12), 1463-1468.
- Adolfsson, A., Larsson, P. G., Wijma, B., & Bertero, C. (2004). Guilt and emptiness: Women's experiences of miscarriage. *Health Care for Women International*, 25, 543-560.
- Ahluwalia, I. B., Grummer-Strawn, L., & Scanlon, K. S. (1997). Exposure to environmental tobacco smoke and birth outcome: Increased effects of pregnant women aged 30 years or older. *American Journal of Epidemiology*, 146, 42-47.
- Alhusen, J. L. (2008). A literature update on maternal-foetal attachment. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, *37*, 315-328.
- Allan, A. (2010). The principles that underlie the 2007 code. In A. Allan & A. Love (Eds.), *Ethical practice in psychology: Reflections from the creators of the APS Code*. West Sussex, UK: Wiley-Blackwell.
- Alty, A., & Rodham, K. (1998). The Ouch! Factor: Problems in conducting sensitive research. *Qualitative Health Research*, 8, 275-282.
- Amato, H. C. (2008). A qualitative investigation of the psychological experiences of recurrent miscarriage among women. Doctor of Philosophy Dissertation, Fordham University, New York.
- American Psychiatric Association. (2013). *Diagnsotic and Statistical Manual of Mental Disorders: DSM-5.* (5<sup>th</sup> ed). Arlington, VA: American Psychiatric Association.
- Andersen, A. N., Wohlfahrt, J., Christens, P., Olsen, J., & Melbye, M. (2000). Maternal age and foetal loss: Population based register linkage study. *British Medical Journal*, 320(1708-1712).
- Anderson, C. J., & Kilpatrick, C. (2012). Patients' birth plans: theories, strategies and implications for nurses. *Nursing for Women's Health*, 16(3), 210-218.
- Andersson, G., & Cuijpers, P. (2009). Internet-based and other computerized psychological treatments for adult depression: A meta-analysis. *Cognitive Behaviour Therapy*, 38(4), 196-205.
- Andersson, I., Nilsson, S., & Adolfsson, A. (2012). How women who have experienced one or more miscarriages manage their feelings and emotions when they become pregnant again: A qualitative interview study. *Scandinavian Journal of Caring Services*, 26(2), 262-270.
- Anisfeld, L., & Richards, A. D. (2000). The replacement child: Variations on a theme in history and psychoanalysis. *Psychoanalytic Study of the Child*, *55*, 301-318.
- Archer, J. (1999). *The nature of grief: The evolution and psychology of reaction to loss*. Florence, KY: Routledge.

- Archer, J. (2001). Grief from an evolutionary perspective. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 263-284). Washington, DC: American Psychological Association.
- Armstrong, D. S. (2006). Impact of prior perinatal loss on subsequent pregnancies. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 33(6), 765-773.
- Armstrong, D., & Hutti, M. (1998). Pregnancy after perinatal loss: the relationship between anxiety and prenatal attachment. *Journal of Obstetrics, Gynecology & Neonatal Nursing*, 27(2), 183-189.
- Athey, J., & Spielvogal, A. M. (2000). Risk factors and interventions for psychological sequelae in women after miscarriage. *Primary Care Update for Obstetrics and Gynecology*, 7(2), 64-69.
- Australian Institute of Health and Welfare (2012). *National Health Data Dictionary*. *Version 16*. Cat. no. HWI 119. Canberra: AIHW.
- Australian Psychological Society. (2007). *Code of Ethics*. Melbourne, Victoria: Australian Psychological Society.
- Balk, D. E. (1999). Bereavement and spiritual change. Death Studies, 23(6), 485-493.
- Bangal, V. B., Sachdev, S. Y., & Suryawansh, M. (2013). Grief following pregnancy loss Literature Review. *International Journal of Biomedical Research*, 4(4), 167-172.
- Banner, D. J., & Albarran, J. W. (2009). Computer-assisted qualitative data analysis software: A review. *Canadian Journal of Cardiovascular Nursing*, 19(3), 24-27.
- Barnacle, R. (2001). Phenomenolgy. Melbourne: RMIT University Press.
- Barr, P. (2004). Guilt and shame-proneness and the grief of perinatal bereavement. *Psychology and Psychotherapy*, 77(4), 493-510.
- Bennett, S. M., Ehrenreich-May, J., Litz, B. T., Boisseau, C. L., & Barlow, D. H. (2012). Development and preliminary evaluation of a cognitive-behavioral intervention for perinatal grief. *Cognitive and Behavioral Practice*, *19*, 161-173.
- Bennett, S. M., Lee, B. S., Litz, B. T., & Maguen, S. (2005). The scope and impact of perinatal loss: Current status and future directions. *Professional Psychology: Research and Practice*, *36*(2), 180-187.
- Berg, B. J., Wilson, J. F., & Wingarter, P. J. (1991). Psychological sequelae of infertility treatment: The role of gender and sex role identification. *Social Science and Medicine*, *33*, 1071-1080.
- Berg, B. L. (2001). *Qualitative research methods for the social scientists*. Needham Heights, MA: Allyn & Bacon.
- Bergner, A., Beyer, R., Klapp, B. F., & Rauchfuss, M. (2008). Pregnancy after early pregnancy loss: A prospective study of anxiety, depressive symptomatology and coping. *Journal of Psychosomatic Obstetrics and Gynecology*, 29, 105-113.
- Beutel, M., Deckardt, R., von Rad, M., & Weiner, H. (1995). Grief and depression after miscarriage: Their separation, antecedents, and course. *Psychosomatic Medicine*, 57, 517-526.
- Birch, M., & Miller, T. (2000). Inviting intimacy: The interview as therapeutic opportunity. International *Journal of Social Research Methodology*, *3*(3), 189–202.
- Black, R. B. (1992). Seeing the baby: The impact of ultrasound technology. *Journal of Genetic Counseling*, 1, 45-54.
- Blackmore, E. R., Côté-Arsenault, D., Tang W, Glover V, Evans J, Golding J, O'Connor, T. G. (2011). Previous prenatal as a predictor of perinatal depression and anxiety. *British Journal of Psychiatry*, 14, 373-378.

- Boerner, K. & Heckhausen, J. (2003). To have and have not: Adaptive bereavement by transforming mental ties to the deceased. *Death Studies*, 27, 199–226.
- Bogensperger, J., & Lueger-Schuster, B. (2014). Losing a child: Finding meaning in bereavement. *European Journal of Psychotraumatology*, 5, 1-9.
- Bohannon, J. R. (1991). Religiosity related to grief levels of bereaved mothers and fathers. *Omega: Journal of Death and Dying, 23,* 153-159.
- Bonanno, G. A. (2009). The other side of sadness: What the new science of bereavment tells us about life after loss. New York: Basic Books.
- Boss, P. (2004). Ambiguous loss. In F. Walsh & M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (2nd ed., pp. 237-246). New York: Norton.
- Bowlby, J. (1961). Process of mourning. *International Journal of Psychoanalysis*, 42, 317-340.
- Bowlby, J. (1969). Attachment, separation and loss. New York: Basic Books.
- Bowlby, J. (1980). Attachment and Loss, Vol. 3. Loss: Saddness and depression New York: Basic Books.
- Bowles, S. V., Bernard, R. S., Epperly, T., Woodward, S., Ginzburg, K., Folen, R., Perez, T., Koopman, C. (2006). Traumatic stress disorders following first-trimester spontaneous abortion. The Journal of Family Practice, 55(11), 969-973.
- Boyce, P. M., Condon, J. T., & Ellwood, D. A. (2002). Pregnancy loss: A major life event affecting emotional health and well-being. *Medical Journal of Australia*, 176(6), 250-251.
- Braun, M. J., & Berg, D. H. (1994). Meaning reconstructio in the experience of parental bereavement. *Death Studies*, 18, 105-129.
- Bray, P. (2013). Bereavement and Transformation: A psycho-spiritual and post-traumatic growth perspective. *Journal of Religion & Health*, *52*(3), 890-903.
- Brewster, H. H. (1950). Grief: A disrupted human relationship. *Human Organization*, *9*, 19-22.
- Brier, N. (2004). Anxiety after miscarriage: A review of the empirical literature and implications for clinical practice. *Birth: Issues in Perinatal Care, 31*, 138-142.
- Brier, N. (2008). Grief following miscarriage: A comprehensive review of the literature. *Journal of Women's Health*, 17(3), 451-464.
- Brkovich, A. M., & Fisher, W. A. (1998). Psychological distress and infertility: Forty years of research. *Journal of Psychosomatic Obstetrics and Gynecology, 19*(4), 218-228.
- Brocki, J. J.M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87 108.
- Brownlee, K., & Oikonen, J. (2004). Toward a theoretical framework for perinatal bereavement. The British Journal of Social Work, 34(4), 517-529.
- Bryant, R. A. (2013). Is pathological grief lasting more than 12 months grief or depression? *Current Opinion in Psychiatry*, 26(1), 41-46.
- Buchi, S., Morgeli, H., Schnyder, U., Jenewein, J., Glaser, A., Fauchere, J., Ulrich Bucher, H., & Sensky, T. (2009). Shared or discordant grief in couples 2-6 years after the death of their premature baby: Effects on suffering and posttraumatic growth. *Psychosomatics*, *50*(2), 123-130.
- Buckle, J. L., Dwyer, S. C., & Jackson, M. (2010). Qualitative bereavement research: Incongruity between the perspectives of participants and research ethics boards. *International Journal of Social Research Methodology*, 13(2), 111-125.

- Bugen, L. A. (1977). Human grief: A model for prediction and prevention. *American Journal of Orthopsychiatry*, 47, 196-206.
- Bui, E., Simon, N. M., Robinaugh, D. J., LeBlanc, N. J., Wang, Y., Skritskaya, N., et al. (2013). Periloss dissociation, symptom severity, and treatment in complicated grief. *Depression and Anxiety*, 30(2), 123-128.
- Burns, L. H., & Covington, S. N. (2006). *Infertility treatment: A comprehensive handbook for clinicians* (2 ed.). New York: Cambridge University Press.
- Burns, N., & Grove, S. K. (2005). The practice of nursing research: Conduct, critique and utilization (5th ed.). St. Louis, MO: Elsevier Saunders.
- Burton, R. (1938). *The anatomy of melancholy* (6th ed.). New York: Tudor Publishing Corporation.
- Byrne, M. (2001). The concept of informed consent in qualitative research. *AORN Journal*, 74(3), 401-403.
- Cacciatore, J. (2010). Stillbirth: Patient-centered psychosocial care. *Clinical Obstetrics & Gynecology*, 53(3), 691-9.
- Cacciatore, J., DeFrain, J., & Jones, K. (2008). When a baby dies: Ambiguity and stillbirth. *Marriage and Family Review*, 44(4), 439-454.
- Cacciatore, J., DeFrain, J., Jones, K., & Jones, H. (2008). Stillbirth and the couple: A gender-based exploration. *Journal of Family Social Work, 11*(4), 351-372.
- Cacciatore, J., Radestad, I., & Froen, F. (2008). Effects of contact with stillborn babies on maternal anxiety and depression. *Birth: Issues in Perinatal Care, 35*, 313-320.
- Cacciatore, J., Schnebly, S., & Froen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health & Social Care in the Community, 17*, 167-176.
- Caelli, K., Downie, J., & Knox, M. (1999). Through grief to healthy parenthood: Facilitating the journey through a family pregnancy support programme. *Birth Issues*, 8(3), 85-90.
- Caelli, K., Downie, J., & Letendre, A. (2002). Parents' experiences of midwife managed care following the loss of a baby in a previous pregnancy. *Journal of Advanced Nursing*, 39(2), 127-136.
- Cain, A. C., & Cain, B. S. (1964). On replacing a child. *Journal of the American Academy of Child Psychiatry*, 3, 443-455.
- Calhoun, L. G., & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 157-172). Washington, DC: American Psychological Association.
- Callander, G., Brown, G. P., Tata, P., & Regan, L. (2007). Counterfactual thinking and psychological distress following recurrent miscarriage. *Journal of Reproductive and Infant Psychology*, 25(1), 51-65.
- Callister, L. C. (2006). Perinatal loss: A family perspective. *The Journal of the Perinatal and Neonatal Nursing*, 20(3), 227-234.
- Campbell-Jackson L., & Horsch, A. (2014). The psychological impact of stillbirth on women: a systematic review. *Illness, Crisis and Loss* 22(3), pp. 237-256.
- Capitulo, K. L. (2005). Evidence for healing interventions with perinatal bereavement. *American Journal of Maternal Child Nursing*, 30(6), 389-396.
- Carroll, P., Sweeny, K., & Sheppherd, J. A. (2006). Foresaking optimism. *Review of general psychology*, 10, 56-73.

- Caserta, M. S., Utz, R., Lund, D. A., & De Vries, B. (2010). Sampling, recruitment, and retention in a bereavement intervention study: Experiences from the living after loss project. *Omega*, 61(3), 181-203.
- Chan, M. F., & Arthur, D. G. (2009). Nurses' attitudes towards perinatal bereavement care. *Journal of Advanced Nursing*, 65(12), 2532-2541.
- Chapleau, M. A., Paquin, K., Hofmann, S. G. (2013). Mindfulness-based therapy: A comprehensive meta-analysis. *Clinical Psychology Review*, *33*, 763–771.
- Chichester M. (2005). Multicultural issues in perinatal loss. *AWHONN Lifelines*. 9, 312–320.
- Chojenta, C., Harris, S., Reilly, N., Forder, P., Austin, M., & Loxton, D. (2014). History of pregnancy loss increases the risk of mental health problems in subsequent pregnancies but not in the postpartum. *PLOS One*, *9*(4), e95038.
- Clarke, K. A. (2009). Uses of a research diary: Learning reflectively, developing understanding and establishing transparency. *Nurse Researcher*, 17(1), 68-76.
- Clayton, A., & Thorne, T. (2000). Diary data enhancing rigour: Analysis framework and verification tool. *Journal of Advanced Nursing*, 32(6), 1514–21.
- Condon, J. T. (1993). The assessment of antenatal emotional attachment: Development of a questionairre instrument. *British Journal of Medical Psychology, 66*, 167-183.
- Conway, P., & Valentine, D. (1988). Reproductive losses and grieving. *Journal of Social Work and Human Sexuality* 6,43-64.
- Cook, A. S. (1995). Ethical issues in bereavement research: An overview. *Death Studies*, 14, 55-70.
- Cook, A. S. (2001). The dynamics of ethical decision making in bereavement research. In M. Stroebe, R. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: consequences, coping, and care.* Washington, DC: American Psychological Association.
- Corbet-Owen, C., & Kruger, L. (2001). The health system and emotional care: Validating the many meanings of spontaneous pregnancy loss. *Families, Systems, & Health,* 19(4), 411-427.
- Corr, C. A. (1993). Coping with dying: Lessons we should and should not learn from the work of Elizabeth Kubler-Ross. *Death Studies*, *17*, 69-83.
- Cote-Arsenault, D. (2002). The influence of perinatal loss on anxiety in multigravidas. Journal of Obstetric, Gynecologic and Neonatal Nursing, 32, 623-629.
- Cote-Arsenault, D. (2003). Weaving babies lost in pregnancy into the fabric of the family. *Journal of Family Nursing*, *9*(1), 23-37.
- Cote-Arsenault, D., & Dombeck, M. (2001). Maternal assignment of foetal personhood to a previous pregnancy loss: Relationship to anxiety in the current pregnancy. *Health Care for Women International*, 22(3), 649-665.
- Cote-Arsenault, D., & Donato, K. (2007). Restrained expectations in late pregnancy following loss. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, *36*, 550-557.
- Cote-Arsenault, D., & Donato, K. (2011). Emotional cushioning in pregnancy after pregnancy loss. *Journal of Reproductive and Infant Psychology*, 29(1), 81-92.
- Cote-Arsenault, D., Donato, K. L., Earl, S. S. (2006). Watching and worrying: Early pregnancy after loss experiences. *The American Journal of Maternal/Child Nursing*, 31(6), 356-363.
- Cote-Arsenault, D., & Freije, M. M. (2004). Support groups helping women through pregnancies after loss. *Western Journal of Nursing Research*, 26(6), 650-670.

- Cote-Arsenault, D., & Mahlangu, N. (1999). Impact of perinatal loss on the subsequent pregnancy and the self: Women's experience. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 28(3), 271-282.
- Cote-Arsenault, D., & Marshall, R. (2000). One foot in one foot out: Weathering the storm of pregnancy after perinatal loss. *Research in Nursing and Health*, 23, 473-485.
- Côté-Arsenault, D., Schwartz, K., Krowchuk, H., McCoy, T. Evidence-based Intervention with Women Pregnant after Perinatal Loss. *The American Journal of Maternal/Child Nursing*, *39*(3), 177–186.
- Craig, M., Tata, P., & Regan, L. (2002). Psychiatric morbidity among patients with recurrent miscarriage. *Journal of Psychosomatic Obstetrics and Gynecology*, 23, 157-164.
- Cranley, M. (1981). Development of a tool for the measurement of maternal attachment during pregnancy. *Nursing Research*, *30*, 281-284.
- Crawley, R., Lomax, S., & Ayers, S. (2013). Recovering from stillbirth: The effects of making and sharing memories on maternal mental health. *Journal of Reproductive and Infant Psychology*, 31(2), 195-207.
- Creswell, J. (2003). *Research design. Qualitative, quantitative and mixed methods approaches* (2<sup>nd</sup> Ed.). Thousand Oaks, CA: Sage
- Creswell, J. W. (2009). Research design: Qualitative, quantitative, and mixed methods approaches. Los Angeles: Sage.
- Crotty, M. (1996). *Phenomenology and nursing research*. South Melbourne, Australia: Churchill Livingstone.
- Cuisinier, M., Janssen, H., De Graauw, C., Bakker, S., & Ogduin, C. (1996). Pregnancy following miscarriage: Course of grief and some determining factors. *Journal of Psychosomatic, Obstetric and Gynaecology, 17*, 168-174.
- Cuisinier, M. C., Kuijpers, J. C., Hoogduin, C. A., deGrauuw, C. P., & Janssen, H. J. (1993). Miscarriage and stillbirth: time since the loss, grief intensity and satisfaction with care. *European Journal of Obstetrics, Gynecology and Reproductive Biology*, 52, 163-168.
- Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2006). Sense-making, grief, and the experience of violent loss: Toward a mediational model. *Death Studies*, *30*, 403-428.
- Currier, J. M., Neimeyer, R. A., & Berman, J. S. (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: A comprehensive quantitative review. *Psychological Bulletin*, *134*, 648-661.
- Dahlke, J. D., Mendez-Figueroa, H., & Wenstrom, K. (2014). Counseling women about the risks of caesarean delivery in future pregnancies. The Obstetrician & Gynaecologist, 16(4), 239-244.
- Dalgleish, T. (2004). What might not have been: An investigation of the nature of counterfactual thinking in survivors of trauma. *Psychological Medicine*, *34*, 1215-1225.
- Darwin, C., & Ekman, P. (1872/1972/1998). *The expression of the emotions in man and animals* (3rd ed.). New York: Oxford University Press.
- Daugirdaite, V., van den Akker, O., & Purewal, S. (2015). Postraumatic stress and posttraumatic stress disorder after termination of pregnacy and reproductive loss: A systematic review. *Journal of Pregnancy*, 1-14.

- Davis, C. G., & Nolen-Hoeksema, S. (2001). Loss and meaning: How do people make sense of loss. *American Behavioral Scientist*, 44, 726-741.
- Davis, C. G., Wortman, C. B., Lehman, D. R., & Silver, C. (2000). Searching for meaning making in loss: Are clinical assumptions correct? *Death Studies*, *24*, 497-540.
- DeBackere, K. J., Hill, P. D., & Kavanaugh, K. (2008). The parental experience of pregnancy after perinatal loss. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 37(5), 525-537.
- DeFrain, J. (1991). Learning about grief from normal families: SIDS, stillbirth, and miscarriage. *Journal of Marital and Family Therapy*, 17, 215-232.
- DeFrain, J., Martens, L., Stork, J., & Stork, W. (1991). The psychological effects of stillbirth on surviving family members. *OMEGA: Journal of Death and Dying*, 22(2), 81-108.
- DeFrain, J., Millspaugh, E., & Xie, X. (1996). The psychosocial effects of miscarriage: Implications for health professionals. *Families, Systems, & Health, 14*(3), 331-347.
- den Hartog, P. (2014). Supporting parents following perinatal death. *Grief Matters: The Australian Journal of Grief and Bereavement, 17*(2), 58-61.
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks, CA: Sage.
- DeRoberts, E. M. (1996). *Phenomenological Psychology*. Maryland, U.S.A: University Press of America.
- Deutsch, H. (1937). Absence of grief. Psychoanalytic Quarterly, 6, 12-22.
- Deutsch, H. (1945). *The psychology of women: Vol. 2. Motherhood.* New York: Grune & Stratton.
- de Wet, J., & Erasmus, Z. (2005). Towards rigour in qualitative analysis. *Qualitative Research Journal*, 5(1), 27-40.
- de Witt, L., & Ploeg, J. (2006). Critical appraisal of rigour in interpretative phenomenological nursing research. *Methodological Issues in Nursing Research*, 215-229.
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2006). Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research*, 16(6), 853-871.
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2008). Risk to researchers in qualitative research on sensitive topics: Issues and strategies. *Qualitative Health Research*, 18(1), 133-144.
- Dimond, M. F., Lund, D. A., & Caserta, M. S. (1987). The role of social support in the first two years of bereavement in an elderly sample. *Gerontologist*, 27, 599-604.
- DiPietro, J. A., Novak, M. F., Costigan, K. A., Atella, L. D., & Reusing, S. P. (2006). Maternal psychological distress during pregnancy in relation to child development at age two. *Child Development*, 77(3), 573-587.
- Doka, K. H. (1989). *Disenfranchised grief: Recognizing hidden sorrow*. Lexington, MA: Lexington Books.
- Doka, K. J. (2002). Disenfranchised grief: New directions, challenges and strategies for practice. Illinois: Research Press.
- Dowling, M. (2007). From Husserl to van Manen: A review of different phenomenological approaches. International Journal of Nursing Studies, 44(1), 131–142.

- Downe, S., Schmidt, E., Kingdon, C., Heazell, A. Bereaved parents' experiences of stillbirth in UK hospitals; A qualitative interview study. British Medical Journal Open, 13(2), e002237.
- Dubose, J. T. (1997). The Phenomenology of Bereavement, Grief, and Mourning. *Journal of Religion and Health*, 36(4), 367-374. doi: 10.1023/a:1027489327202
- Dunn, L. (1991). Research alert! Qualitative research may be hazardous to your health! *Qualitative Health Research*, *1*(3), 388-392.
- Dyregrov, K. (2004). Bereaved parents' experience of research participation.
- Social Science and Medicine, 58, 391–400.
- Dyregrov, K., & Dyregrov, A. (2008). Effective grief and bereavement support: The role of family, friends, colleagues, schools and support professionals. London: Jessica Kingsley Publishers.
- Dyson, L., & While, A. (1998). The long shadow of perinatal bereavement. *Journal of Community Nursing*, *3*, 432-439.
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179–194). London: Sage.
- Egan, K. A., & Arnold, R. L. (2003). Grief and bereavement care. *The American Journal of Nursing*, 103(9), 42-53.
- Erlandsson, K., Warland, J., Cacciatore, J., & Radestad, I. (2013). Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth findings from an online questionnaire. *Midwifery*, 29(3), 246-250.
- Evans, R. (2012). Emotional care for women who experience miscarriage. *Nursing Standard*, 26(42), 35-41.
- Evans, L., Lloyd, D., Considine, R., & Hancock, L. (2002). Contrasting views of staff and patients regarding psychosocial care for Australian women who miscarry: A hospital based study. *Australian and New Zealand Journal of Obstetric Gynecology*, 42, 155-160.
- Ewton, D. S. (1993). A perinatal loss follow-up guide for primary care. *Nurse Practitioner*, 18(12), 30-36.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal*, 328, 1116-1170.
- Fehring, H. (2002). Ethical considerations within the constructivist research paradigm. In P. Green (ed.) Slices of Life: *Qualitative Research* Snapshots, RMIT University Press, Melbourne, pp. 18-34.
- Fenstermacher, K., & Hupcey, J. E. (2013). Perinatal bereavement: A principle-based concept analysis. *Journal of Advanced Nursing*, 69(11), 2389-2400.
- Field., N. (2006). Unresolved grief and continuing bonds: An attachment perspective. *Death Studies*, *30*(8), 739-756.
- Field, N. & Filanosky, C. (2009). Continuing bonds, risk factors for complicated grief, and adjustment to berevament. *Death Studies*, 34(1), 1-29.
- Field, N., Packman, W., Ronen, R., Pries, A., Davies, B., & Kramer, R. (2013). Type of continuing bonds expression and its comforting versus distressing nature: Implications for adjustment among bereaved mothers. *Death Studies*, *37*(10), 889-912.
- First, M. (2011). DSM-5 proposals for mood disorders: A cost-benefit analysis. *Current Opinion in Psychiatry*, 24, 1-9.

- Fish, W. (1986). Differences of grief intensity in bereaved parents. In T. A. Rando (Ed.), *Parental loss of a child* (pp. 415-430). Champaign, IL: Research Press.
- Flannery, R. B. (1990). Social support and psychological trauma: A methodological review. *Journal of Traumatic Stress*, *3*, 593-611.
- Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: Developing a Gadamerian-based research method. *Nursing Inquiry*, 10, 113–120.
- Flenady V, King J, Charles A, Gardener G, Ellwood D, Day K, et al. (2009). *PSANZ Clinical Practice Guideline for Perinatal Mortality* (2<sup>nd</sup> Ed.). Perinatal Society of Australia and New Zealand (PSANZ) Perinatal Mortality Group. 2009. Retrieved from http://www.psanzpnmsig.org
- Folkman, S. (2001). Revised coping theory and the process of bereavement. In M. S. Stroebe, R. O. Hansson, W.Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 563-584). Washington, DC: American Psychological Association.
- Forray, A., Mayes, L. C., Magriples, U., & Epperson, C. N. (2009). Prevalence of posttraumatic stress disorder in pregnant women with prior pregnancy complications. *Journal of Maternal-Foetal and Neonatal Medicine*, 22(6), 522-527.
- Fraley, R. C., & Shaver, P. (1999). Loss and bereavment: Attachment theory and recent controversies concerning 'grief work' and the nature of detachment. In J. Cassidy & P. Shaver (Eds.), *Handbook of attachment theory and research*. New York: Guilford Press.
- Frances, A., Pies, R., & Zisook, S. (2010). DSM-5 and the medicalization of grief: two perspectives. *Pschiatric Times*, *27*(5), 46-47.
- Franche, R., & Bulow, C. (1999). The impact of a subsequent pregnancy on grief and emotional adjustment following a perinatal loss. *Infant Mental Health Journal*, 20(2), 175-187.
- Franche, R., & Mikail, S. (1999). The impact of perinatal loss on adjustment to subsequent pregnancy. *Social Science & Medicine*, 48(11), 1613-1623.
- Fretts, R. C., Schmittidiel, J., McLean, F. H., Usher, R. H., & Goldman, M. B. (1995). Increased maternal age and the risk of foetal death. *New England Journal of Medicine*, 333, 953-957.
- Freud, S. (1909/1990). Five lectures on psychoanalysis. New York: Norton.
- Freud, S. (1917/1957). Mourning and melancholia. London: Hogarth Press.
- Friedman, T., & Gath, D. (1989). The psychiatric consequences of spontaneous abortion. *British Journal of Psychiatry*, *155*, 810-813.
- Frost, J., Bradley, H., Levitas, R., Smith, L., & Garcia, J. (2007). The loss of possibility: Scientisation of death and the special case of early miscarriage. *Sociology of Health and Illness*, 29(7), 1003-1022.
- Frost, M., & Condon, J. T. (1996). The psychological sequelae of miscarriage: A critical review. *Australian and New Zealand Journal of Psychiatry*, 30(1), 54-62.
- Fuller, A. R. (1990). *Insight into value*. Albany: State University of New York Press.
- Gadamer, H. G. (1976). *Philosophical Hermeneutics*. Berkley, California: University of California Press.
- Gadamer, H. G. (1990). The hermeneutical problem. In Gayle Ormiston & Alan Schrift (Eds.), The hermeneutic tradition: From Ast to Ricouer (pp.273-297). New York: State University of New York Press.

- Gaffney, K. F. (1988). Prenatal maternal attachment. *IMAGE: Journal of nursing scholarship*, 20, 106-109.
- Gaizauskiene, A., Padaiga, Z., Basys, V., Grigorjev, G., & Mizeriene, R. (2003). Risk factors of perinatal mortality in Lithuania, 1997-1998. *Scandinavian Journal of Public Health*, 31, 137-142.
- Gamino, L. A., & Sewell, K. W. (2004). Meaning constructs as predictors of bereavement adjustment: A report from the Scott & White grief study. *Death Studies*, 28, 397-421.
- Garcia, J., Bricker, L., Henderson, J., Martin, M. A., Mugford, M., Nielson, J., et al. (2002). Women's views of pregnancy ultrasound: A systematic review. *Birth*, *29*, 225-250.
- Gaudet, C., Sejourne, N., Camborieux, L., Rogers, R., & Chabrol, H. (2010). Pregnancy after perinatal loss: Association of grief, anxiety and attachment. Journal of Reproductive and Infant Psychology, 28(3), 240-251.
- Gee, V. (2013). *Perinatal, infant and maternal mortality in Western Australia, 2006-2010* (D. o. Health, Trans.). Perth, Western Australia.
- Geller, P. A., Kerns, D., Klier, C. M. (2004). Anxiety following miscarriage and the subsequent pregnancy: A review of the literature and future directions. *Journal of Psychosomatic Research*. *56*, 35–45
- Geller, P. A., Klier, C. M., & Neugebauer, R. (2002). Anxiety disorders following miscarriage. *Journal of Clinical Psychiatry*, 62, 432-438.
- Geller, P. A., Psaros, C., & Kornfield, S. L. (2010). Satisfaction with pregnancy loss aftercare: are women getting what they want? *Archives of Womens Mental Health*, 13(2), 111-124.
- Gerrish, N., Dyck, M. J., & Marsh, A. (2009). Post-traumatic growth and bereavement. Mortality: Promoting the interdisciplinary study of death and dying, 14(3), 226-244.
- Getz, L. (2012). Complicated grief Does it belong in DSM-5? *Social Work Today, 12*(4), 8.
- Gilbert, K. R. (1989). Interactive grief and coping in the marital dyad. *Death Studies*, 13, 605-626.
- Giorgi, A. (2009). The descriptive phenomenological method in psychology: A modified Husserlian approach. Pittsburgh, PA: Duquesne University Press.
- Gold K. J. (2007). Navigating care after a baby dies: a systematic review of parent experiences with health providers. *Journal of Perinatology*, 27. 230-7.
- Gold, K. J., & Johnson, T. R. (2014). Mothers at risk: Maternal mental health outcomes after perinatal death. *Obstetrics & Gynecology*, 123(Suppl 1):6S.
- Gold, K. J., Sen, A., & Hayward, R. A. (2010). Marriage and cohabitation outcomes after pregnancy loss. *Pediatrics*, 125 (5), e1202 e1207
- Goldbach, K. R. C., Dunn, D. S., Toedter, L., & Lasker, J. N. (1991). The effects of gestational age and gender on grief after pregnancy loss. *American Journal of Orthopsychiatry*, 61(3), 461-467.
- Goodman, J. H., Guarino, A., Chenausky, K., Klein, L., Prager, J., Petersen, R., Forget, A., & Freeman, M. (2014). CALM Pregnancy: results of a pilot study of mindfulness-based cognitive therapy for perinatal anxiety. *Archives of Womens Mental Health*, 17, 373-387.
- Gorer, G. (1967). Death, grief, and mourning. Garden City, NJ: Doubleday.
- Granek, L. (2010). Grief as pathology: The evolution of grief theory in psychology from Freud to the present. *History of Psychology, 13*(1), 46-73.

- Grant, J. S., & DePew, D. D. (1999). Recruiting and retaining research participants for a clinical intervention study. *Journal of Neuroscience Nursing*, *31*(6), 357-362.
- Green, M., & Solnit, A. (1964). Reactions to the threatened loss of a child: A vulnerable child syndrome. *Pediatrics*, *34*, 58-66.
- Greenspan, M. (2004). *Healing through the dark emotions: The wisdom of grief, fear and dispair*. Boston: Shambhala Publications.
- Green, S. M., Haber, E., Frey, B. N., McCabe, R. E. (2015). Cognitive-behavioral group treatment for perinatal anxiety: A pilot study. *Archives of Women's Health*, 05 *February 2015* (1434-1816).
- Grekin R, & O'Hara M. W. (2014). Prevalence and risk factors of postpartum posttraumatic stress disorder: A meta-analysis. *Clinical Psychology Review*, *34*, 389-401.
- Greeson J., Brantley, J. (2009). Mindfulness and anxiety disorders: Developing a wise relationship with the inner experience of fear. In F. Didonna, F (ed), *Clinical handbook of mindfulness*. (pp. 171-187). New York: Springer.
- Grof, C., Grof, S. (1990) The stormy search for the self: A guide to personal growth through transformational crisis. New York: Tarcher/Perigee.
- Grout, L. A., & Romanoff, B. D. (2000). The myth of the replacement child: Parents stories and practices after perinatal death. *Death Studies*, 24(2), 93-113.
- Hadjistavropoulos, T., & Smythe, W. E. (2001). Elements of risk in qualitative research. *Ethics & Behavior*, 11(2), 163-174.
- Hall, C. (2014). Bereavement theory: Recent developments in our understanding of grief and bereavement. *Bereavement Care*, 33(1), 7-12.
- Hamill, C., & Sinclair, H. (2010). Bracketing-practical considerations in Husserlian phenomenological research. *Nurse Researcher*, 17, 16-24.
- Hannah, K. (2013). Antenatal care in pregnancy following a stillbirth. British Journal of *Midwifery*, 21(2), 92-97.
- Heeren, A., Philippot, P. (2011). Changes in ruminative thinking mediate the clinical benefits of mindfulness: Preliminary findings. *Mindfulness*, 2, 8-13.
- Heidegger, M. (1962). Being and time. New York: Harper. (Original work published 1927).
- Heidrich, S. M., & Cranley, M. S. (1989). Effects of foetal movement, ultrasound scans, and amniocentesis on maternal-foetal attachment. *Nursing Research*, *38*(2), 81-84.
- Heller, S., & Zeanah, C. (1999). Attachment disturbances in infants born subsequent to perinatal loss: A pilot study. *Infant Mental Health Journal*, 20(2), 188-199.
- Hennink, M., Hutter, I., & Bailey, A. (2011). Qualitative Research Methods. London: Sage.
- Herbert, L., & Dahlquist, L. (2008). Perceived history of anaphylaxis and parental overprotection, autonomy, anxiety, and depression in food allergic young adults. *Journal of Clinical Psychology in Medical Settings*, 15, 261-269.
- Herbert, D., Lucke, J. C., & Dobson, A. (2009). Pregnancy losses in young Australian women: Findings from the Australian longitudinal study on women's health. *Women's Health Issues*, 19, 21–29.
- Hogan, N. S., Morse, J. M., & Tason, M. C. (1996). Towards an experiential theory of bereavement. *Omega: The Journal of Death and Dying, 33*, 43-65.
- Holland, J. M., Neimeyer, R. A., Boelean, P. A., & Prigerson, H. G. (2009). The underlying structure of grief: A taxometric investigation of prolonged and normal reactions to loss. *Journal of Psychopathology and Behavioural Assessment*, 31, 190-201.
- Holloway, I., & Wheeler, S. (1995). Ethical issues in qualitative nursing research. *Nursing Ethics*, 2(3), 223-232.

- Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing* (2nd ed.). Oxford: Blackwell Science.
- Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., et al. (2002). Observed and perceived parental protection in relation to psychosocial adjustment in preadolsecents with a physical disability: The mediational role of behavioural autonomy. *Journal of Consulting and Clinical Psychology*, 70(1), 96-110.
- Honemever, U., & Kurjak, A. (2014). Pregnancy and Loneliness: The Therapeutic Value of 3D/4D Ultrasound. *Psychology*, *5*, 744-752.
- Horowitz, M. J. (2005). Meditating on complicated grief disorder as a diagnosis. *Omega*, 52(1), 87-89.
- Horowitz, M. J., Siegel, B., Holen, A., Bonanno, G. A., Milbrath, C., & Stinson, C. H. (1997). Diagnostic criteria for complicated grief disorder. *American Journal of Psychiatry*, 154, 904-910.
- Horsburgh, D. (2003). Evolution of qualitative research. *Journal of Clinical Nursing*, 12(2), 307-312.
- Hsu, M., Tseng, Y., Banks, J., & Kuo, L. (2004). Interpretations of stillbirth. *Journal of Advanced Nursing*, 47(4), 408-416.
- Hubbard, G., Backett-Milburn, K., & Kemmer, D. (2001). Working with emotions: Issues for the researcher in fieldwork and teamwork. *International Journal of Social Research Methodology*, 4(2), 119-137.
- Hughes, P., & Riches, S. (2003). Psychological aspects of perinatal loss. *Current Opinion in Obstetrics & Gynecology*, 15(2), 107–111.
- Hughes, P. M., Turton, P., & Evans, C. D. H. (1999). Stillbirth as a risk factor for depression and anxiety in the subsequent pregnancy: Cohort study. *British Medical Journal*, *318*, 1721-1724.
- Hughes, P. M., Turton, P., Hopper, E., & Evans, C. D. H. (2002). Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: A cohort study. *Lancet*, *360*, 114-118.
- Hughes, P. M, Turton, P., Hopper, E., McGauley, G. A., & Fonagy, P. (2001). Disorganised attachment behaviour among infants born subsequent to stillbirth. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 42*(6), 791-801.
- Hughes, V. (2011). Shades of grief. Scientific Americam, 304(6), 34-35.
- Hunfield, J. A. M., Wladimiroff, J. W., Verhage, F., & Passchier, J. (1995). Previous stress and acute psychological defense as predictors of perinatal grief An exploratory study. *Social Science and Medicine*, 40, 829-835.
- Hunt, S., & Greeff, A. P. (2011). Parental bereavement: A panoramic view. *Omega: Journal of Death and Dying, 64*(1), 41-63.
- Husserl, E. (1970). *Ideas: General Introduction to pure phenomenology, volume I.* New York: Collier Books.
- Hutti, M. H. (1986). An exploratory study of the miscarriage experience. *Health Care for Women International*, 7, 371-389.
- Hutti, M. H. (2004). Social and professional support needs of families after perinatal loss. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 34(5), 630-638.
- Hutti, M. H. (2005). Social and professional support needs of families after perinatal loss *Journal of Obstetric, Gynecologic and Neonatal Nursing 34*(5), 630-638.
- Hynson, J. L., Aroni, R., Bauld, C., & Sawyer, S. M. (2006). Research with bereaved parents: a question of how not why. *Palliative Medicine*, 20, 805-811.

- Jackman, C., McGee, H. M., & Turner, M. (1991). The experience and psychological impact of early miscarriage. *Irish Journal of Psychology*, 12, 108-120.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: Maxwell Macmillan International.
- Janssen, H. J., Cuisinier, M. C., DeGrauuw, K. P., & Hoogduin, K. A. (1997). A prospective study of risk factors predicting grief intensity following pregnancy loss. *Archives of General Psychiatry*, *54*(1), 56-61.
- Janssen, H.J., Cuisinier, M.C., Hoogduin, C. A. L., De Graauw, C., & Kees, P. H. M. (1996). Controlled prospective study of the mental health of women following pregnancy loss. *Obstetrical & Gynecological Survey*, *51*(9), 512-514.
- Jasper, M. A. (1994). Issues in phenomenology for researchers of nursing. *Journal of Advanced Nursing*, 19, 309-314.
- Jensen, D. (2008). The SAGE *Encyclopaedia of Qualitative Research Methods*, Volume 2. Thousand Oaks, CA: Sage Publications
- Johnson, S., Burrows, A., & Williamson, I. (2004). Does my bump look big in this? The meaning of bodily changes for first time mothers-to-be. *Journal of Health Psychology*, *9*, 361–374.
- Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, 23(23), 42-46.
- Joyce, A., & Tran, B. N. (2009). Western Australia's mothers and babies, 2009: Twenty-seventh annual report of the Western Australian midwives' notification system (D. o. Health, Trans.). Perth, Western Australia: Department of Health.
- Karlsson, G. (1993). *Psychological qualitative research from a phenomenological perspective*. Stockholm, Sweden: Almqvist & Wiksell International.
- Kavanagh, K., & Ayres, L. (1998). Not as bad as it could have been: Assessing and mitigating harm during research interviews on sensitive topics. *Research in Nursing and Health*, 21, 91-97.
- Kavanaugh, K., & Paton, J. B. (2001). Communicating with parents who experience a perinatal loss. *Illness, Crisis, & Loss, 9*, 369-380.
- Kavanaugh, K., Trier, D., & Korzec, M. (2004). Social support following perinatal loss. *Journal of Family Nursing*, 10(1), 70-92.
- Kelley, M. C., & Trinidad, S. B. (2012). Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth: A qualitative analysis. BMC Pregnancy and Childbirth, 12(1), 137-151.
- Keng, S., Smoski, M. J., Robins, C. J. (2011). Effects of mindfulness on psychological health: A review of empirical studies. *Clinical Psychology Review*, *31*, 1041-1056.
- Kennell J, Slyter, H.,, Klaus, M. (1970). The mourning response of parents to the death of a newborn infant. *New England Journal of Medicine*, 283, 344-349.
- Kenny, L. C., Lavender, T., McNamee, R., O'Neill, S. M., & Tracey, A. S. (2013). Advanced maternal age and adverse pregnancy outcome: Evidence from a large contemporary cohort. *Plos One*, 8(2), e56583.
- Kersting, A., Dolemeyer, R., Steinig, J., Walter, F., Kroker, K., Baust, K., & Wagner, B. (2013). Brief internet-based intervention reduces posttraumatic stress and prolonged grief in parents after the loss of a child during pregnancy: A randomized controlled trial. *Psychotherapy & Psychosomatics*, 82, 372-381.
- Kersting, A., Kroker, K., Schlicht, S., Baust, K., & Wagner, B. (2011). Efficacy of cognitive behavioural internet-based therapy in parents after the loss of a child

- during pregnancy: pilot data from a randomized controlled trial. *Archives of Womens Mental Health*, 14, 465-477.
- Kersting, A. & Wagner, B. (2012). Complicated grief after perinatal loss. *Dialogues in Clinical Neuroscience*, 14(2), 187-194.
- Kesmodel, U., Wisborg, K., Olsen, S. F., Henrikson, T. B., & Secher, N. J. (2002). Moderate alcohol intake during pregnancy and the risk of stillbirth and death in the first year of life. *American Journal of Epidemiology*, *155*, 305-312.
- Khoury, B., Lecomte, T., Fortin, G., Masse, M., Therien, P., Bouchard, V., Chapleau, K., Paquin, K., & Hofmann, S. G. (2013). Mindfulness-based therapy: A comprehensive meta-analysis. *Clinical Psychology Review*, *33*(6), 763-771.
- Kirkley-Best, E., Kellner, K. (1982). The forgotten grief: A review of the psychology of stillbirth. *American Journal of Orthopsychiatry*, *52*, 420-429.
- Klass, D., Silverman, P.R., & Nickman, S.L. (1996). *Continuing bonds: New understandings of grief.* Washington: Taylor and Francis.
- Klaus, M. H., & Kennell, J. H. (1976). *Maternal-infant bonding*. Saint Louis, MO: C.V: Mosby Company.
- Kleinman, A. (2007). Psychiatry without context: turning sadness into a disease. *The Lancet*, *370*(9590), 819-820.
- Klier, C. M., Geller, P. A., & Neugebauer, R. (2000). Minor depressive disorder in the context of miscarriage. *Journal of Affective Disorders*, *59*, 13-21.
- Koch, T. (1999). An interpretive research process: Revisiting phenomenological and hermeneutical approaches. *Nurse Researcher*, *6*(3), 20-34.
- Kohn, I., & Moffitt, P. (2005). Perinatal loss: Helping families grieve and heal. *International Journal of Childbirth Education*, 20(3), 4-7.
- Kohn, I., Moffitt, P., & Wilkins, I. A. (2013). A silent sorrow: Pregnancy loss guidance and support for you and your family (2nd ed.). New York: Routledge.
- Kohner, N. (2001). When a baby dies: Parents stories. MIDIRS 11, 243-246.
- Komaromy, C., Layne, L., & Earle, S. (2013). *Understanding reproductive loss:*Perspectives on life, death & fertility. Burlington, USA: Ashgate Publishing.
- Kong, G. W. S.. Lok, I. H., Lam, P. M., Yip, A. S. K., & Chung, T. K. H. (2010). Conflicting perceptions between health care professionals and patients on the psychological morbidity following miscarriage. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 50(6), 562-567.
- Koopmans, L., Wilson, T., Cacciatore, J., & Flenady, V. (2013). Support for mothers, fathers and families after perinatal death. The Cochrane database of systematic reviews, Issue 6. DOI: 10.1002/14651858.CD000452.pub3.
- Kriebs, J. M. (2015). Patient safety during induction of labor. *The Journal of Perinatal & Neonatal Nursing*, 29(2), 130-137.
- Kubler-Ross, E. (1969). On death and dying. New York: Tavistock.
- Kuo, S., Lin, K., Lin, L., Hsu, C., Yang, C., & Chang, M. (2010). Evaluation of the effects of a birth plan on Taiwanese women's childbirth experiences, control and expectations fulfilment: A randomised controlled trial. *International Journal of Nursing Studies*, 47(7), 806-814.
- Kuyken, W., Watkins, E., Holden, E., White, K., Taylor, R. S., Byford, S., Evans, A., Radford, S., Teasdale, J. D., Dalgleish, T. (2010). How does mindfulness-based cognitive therapy work? *Behaviour Research Therapy*, 48, 1105-1112.
- Kvale, S. (1996). *An Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: SAGE.

- Lake, M.F., Johnson, T.M., Murphy, J., & Knuppel, N. (1987). Evaluation of a perinatal grief support team. *American Journal of Obstetrics and Gynecology*, 157, 1203–1206.
- Lamb, E. H. (2002). The impact of previous perinatal loss on subsequent pregnancy and parenting. *The Journal of Perinatal Education*, 11(2), 33-40.
- Lang, A., Edwards, N., & Benzies, K. (2005). A false sense of security in caring for bereaved parents. *Birth*, *32*(2), 158-159.
- Lang, A., Fleiszer, A., Duhamel, F., Sword, W., Gilbert, K., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *Omega: Journal of Death and Dying, 63*(2), 183-196.
- Lang, A., & Gottlieb, L. (1993). Parental grief reactions and marital intimacy following infant death. *Death Studies*, 17, 233-255.
- Lang, A., Goulet, C., & Amsel, R. (2004). Explanatory model of health in bereaved parents post-foetal/infant death. *International Journal of Nursing Studies*, 41(8), 869-880.
- Lang, A., & MacLean, L. M. (2007). Hardiness in Bereaved Parents Following Foetal or Infant Death. In P. T. P. Wong, L. C. J. Wong, M. J. McDonald, & D. W. Klaassen (Eds.), *The Positive Psychology of Meaning and Spirituality*. Selected pares from Meaning Conferences. Abbotsford, BC: INPM Press.
- Langridge, D. (2007) *Phenomenological psychology: theory, research and method.* Harlow, Pearson Prentice Hall.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*, 102-120.
- Lasker, J. N., & Toedter, J. (1994). Satisfaction with hospital care and interventions after pregnancy loss. *Death Studies*, *18*, 41-64.
- Lasker, J. N., & Toedter, L. J. (1991). Acute versus chronic grief: The case of pregnancy loss. *American Journal of Orthopsychiatry*, 61, 510-522.
- Lasker, J. N., & Toedter, L. J. (2000). Predicting outcomes after pregnancy loss: Results from studies using the Perinatal Grief Scale. *Illness, Crisis, and Loss, 8,* 350-372.
- Laws, P., Abeywardana, S., Walker, J., & Sullivan, E. A. (2007). Australia's mothers and babies 2005 *Perinatal Statistics Series no. 20* (Vol. 20). Sydney: Australian Institiue of Health and Welfare.
- Laxton-Kane, M., & Slade, P (2002). The role of maternal prenatal attachment in a woman's experience of pregnancy and implications for the process of care. *Journal of Reproductive and Infant Psychology*, 20(4), 253-266.
- Lazare, A. (1979). Unresolved grief. In A. Lazare (Ed.), *Outpatient psychiatry: Diagnosis and treatment* (pp. 498-512). Baltimore, MD: Williams & Wilkins.
- Leahy, J. M. (1992). A comparison of depression in women bereaved of a spouse, child, or a parent. *Omega: The Journal of Death and Dying, 26*, 207-218.
- Leavitt, J. (1986). *Brought to bed: Child-bearing in America*, 1750-1950. New York: Oxford University Press.
- Lee, L., McKenzie-McHarg, K. & Horsch, A. (2013). Women's decision making and experience of subsequent pregnancy following stillbirth. *Journal of Midwifery and Women's Health*, 58, 431-439
- Lee, C., Slade, P., & Lygo, V. (1996). The influence of psychological debriefing on emotional adaptation in women following early miscarriage: A preliminary study. *British Journal of Medical Psychology*, 69, 47-58.
- Leech, N. L., & Onwuegbzie, A. J. (2011). Beyond constant comparison qualitative data analysis: Using NVivo. *School Psychology Quarterly*, 26(1), 70-84.

- Leifer, M. (1977). Psychological changes accompanying pregnancy and motherhood. *General Psychiatry Monographs*, 95(1), 55-96.
- Leininger, M. (1994). Evaluating criteria and critique of qualitative research studies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods*. Newbury Park, CA: Sage.
- Leon, I. G. (1992). The psychoanalytic conceptualization of perinatal loss: A multidimensional model. *American Journal of Psychiatry*, 149, 1464-1472.
- Leon, I. G. (1996). Revising psychoanalytic understandings of perinatal loss. *Psychoanalytic Psychology*, *13*(2), 161-176.
- Lerum, C. W., & LoBiondo-Wood, G. (1989). The relationship of maternal age, quickening, and physical symptoms of pregnancy to the development of maternal-foetal attachment. *Birth*, *16*, 13-17.
- Letherby, G. (1993). The meanings of miscarriage. *Women's Studies International Forum,* 16(2), 165-180.
- Leyland, A. (2013). The midwife's role in caring for the needs of bereaved parents following a stillbirth. *The practising midwife*, 16(2), 20-22.
- Li, J., Precht, D. H., Mortensen, P. B., & Olsen, J. (2003). Mortality in parents after the death of a child in Denmark: A nationwide follow-up study. *Lancet*, 361, 363-367.
- Li, Z., Zeki, R., Hilder, L. & Sullivan, E. A. (2013). *Australia's mothers and babies, 2011. Perinatal statistics series* no. 28. Cat. no. PER 59. Canberra: AIHW National Perinatal Epidemiology and Statistics Unit.
- Lin, S. X., & Lasker, J. N. (1996). Patterns of grief reaction after pregnancy loss. American *Journal of Orthopsychiatry*, 66, 262–271.
- Liamputtong, P., & Ezzy, D. (2005). *Qualitative research methods* (2nd ed.). New York: Oxford University Press.
- Lichtenthal, W. G., Cruess, D. G., & Prigerson, H. G. (2004). A case for establishing complicated grief as a distinct mental disorder in DSM-V. *Clinical Psychology Review*, 24(6), 637-662.
- Lincoln, Y. S. (1995). Emerging criteria for qualitative interpretative research. *Qualitative Inquiry*, *3*, 275-289.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverley Hills, CA: Sage.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
- Lindemann, H. (2014). Holding and letting go: The social practice of personal identities. New York: Oxford University Press.
- Lindgren, H. M., & Malm, M. C., & Radestad, I. (2014). You don't leave your baby: Mother's experiences after a stillbirth. *OMEGA Journal of Death and Dying*, 68(4), 337-346.
- Lindsey, B., & Driskill, C. (2013). The psychology of infertility. *International Journal of Childbirth Education*, 28(3), 41-47.
- Lok, I. H., & Neugebauer, R. (2007). Psychological morbidity following miscarriage. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 21(2), 229-247.
- Lovell, A. (1983). Some questions of identity: Late miscarriage, stillbirth and perinatal loss. *Social Science & Medicine*, *17*(11), 755-761.
- Lumley, J. M. (1972). The development of maternal-foetal bonding in first pregnancy. Third International Congress. *Psychosomatic Medicine in Obsetrics and Gynaecology*, *4*(4), 271-284.

- Lumley, J. M. (1980). Through a glass darkly: Ultrasound and prenatal bonding. *Birth*, *17*, 214–217.
- Lumley, J. (1982). Attitudes to the foetus among primigravidae. *Australian Paediatric Journal*, 18, 106-109.
- Lyons, K. S., Carter, J. H., Carter, E. H., Rush, K. N., Stewart, B. J., & Archbold, P. G. (2004). Locating and retaining research participants for follow-up studies. *Research in Nursing and Health*, 27(1), 63-68.
- Maciejewski, P. K., Zhang, B., Block, S. D., & Prigerson, H. (2007). An empirical examination of the stage theory of grief. *JAMA*, 297(7), 716-723.
- Madden, M. E. (1994). The variety of emotional reactions to miscarriage. *Women and Health*, 21, 85-103.
- Malacrida, C. (1997). Perinatal death: Helping parents find their way. *Journal of Family Nursing*, 3(2), 130-148.
- Malacrida, C. (1999). Complicated mourning: The social economy of perinatal death. *Qualitative Health Research*, *9*(4), 504-519.
- Malkinson, R., Rubin, S., & Witztum, E. (2000). *Traumatic and nontraumatic loss and bereavement: Clinical theory and practice*. Madison, CT: Psychosocial Press.
- Malm, M. C., Radestad, I., Erlandsson, K., & Lindgren, H. (2011). Waiting in no-mansland Mothers experiences before the induction of labour after their baby has died in utero. *Sexual and Reproductive Healthcare*, *2*, 51-55.
- Marris, P. (1958). Widows and their families. London: Routledge.
- Marsh, M., & Ronner, W. *The empty cradle: Infertility in america from colonial Times to the Present* (Baltimore & London: Johns Hopkins University Press, 1996)
- Martin, T. L., & Doka, K. J. (2000). *Men don't cry, women do: Transcending gender stereotypes of grief.* Philadelphia: Brunner/Mazel.
- McCreight, B. S. (2004). A grief ignored: Narratives of pregnancy loss from a male perspective. *Sociology of Health and Illness*, 26(3), 326-350.
- McHaffie, H. E. (2000). Ethical issues in research. In D. Cormack (Ed.), *The research process in nursing* (4 ed., pp. 51-61). Oxford: Blackwell Science.
- Mennin, D. S., Heimberg, R. G., Turk, C. L, Fresco, D. M. (2005). Preliminary evidence for an emotion dysregulation model of generalized anxiety disorder. *Behaviour Research and Therapy*, *43*, 1281-1310.
- Mevorach-Zussman, N., Bolotin, A., Shalev, H., Bilenko, N., Mazor, M., & Bashiri, A. (2012). Anxiety and deterioration of quality of life factors associated with recurrent miscarriage in an observational study. *Journal of Perinatal Medicine*, 40(5), 495-501.
- Mills, T. A., Ricklesford, C., Cooke, A., Heazell, A. E. P., Whitworth, M., Lavender, T. (2014). Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal death: A metasynthesis. *British Journal Of Gynaecology, 121*, 943-950.
- Misri, S., & Kendrick, B. (2007). Treatment of Perinatal Mood and Anxiety Disorders: A Review. *Canadian Journal of Psychiatry*, 52(8), 489-498.
- Momartin, S. (2012). Is 'complicated grief' a viable new diagnosis in the DSM-5? *Psychotherapy in Australia, 18*(4), 53-54.
- Moran, D. (2000). Heidegger's critique of Husserl's and Brentano's accounts of intentionality. *Inquiry*, 31(1), 39-66.
- Morrissey, M. (2007). Our first child was incompatible with life: Understanding miscarriage as a lived experience. *International Journal of Psychiatric Nursing Research*, 12, 1415-1428.

- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2), 13-22.
- Moscarello, R. (1989). Perinatal bereavement support service: Three year review. *Journal of Palliative Care*, *5*(4), 12-18.
- Moulder, C. (1994). Towards a framework for understandin pregnancy loss. *Journal of Reproductive and Infant Psychology, 12*, 65-67.
- Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks, California: SAGE.
- Muller, M. E. (1992). A critical review of prenatal attachment research. *Scholarly inquiry for nursing practice: An international journal*, *6*, 5-21.
- Muller, M. E. (1993). The development of the prenatal attachment inventory. *Western Journal of Nursing Research*, 15, 199-215.
- Munhall, P. L. (2007). *Nursing research: A qualitative perspective*. Sudbury, MA: Jones and Bartlett Publishers.
- Murphy, F.A. (1998) The experience of early miscarriage from a male perspective, Journal of Clinical Nursing, 7(4), 325–32.
- Murphy, S., Shevlin, M., & Elklit, A. (2014). Psychological conseuques of pregnancy loss and infant death in a sample of bereaved parents. *Journal of Loss & Trauma*, 19(1), 56-69
- Nansel, T. R., Frederick, M., Doyle, F., Zhang, J.(2005). Quality of life in women undergoing medical treatment for early pregnancy failure. *Journal of Obstetric, Gynecological, and Neonatal Nursing*, 34(4), 473-481.
- Neimeyer, R. A., & Currier, J. M. (2009). Grief therapy: Evidence of efficacy and emerging directions. *Current directions in psychological science*, 18, 352-356.
- Neimeyer, R. A., & Hogan, N. S. (2001). Quantitative or qualitative? Measurement issues in the study of grief. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping and care* (pp. 89-118). Washington, DC: American Psychological Association.
- Neugebauer, R., Kline, J., Shrout, P., Skodol, A., O'Connor, P., Geller, P. A., et al. (1997). Major depressive disorder in the 6 months after miscarriage. *Journal of the American Medical Association*, 277, 383-388.
- Neugebauer, R., Kline, J., Bleiberg, K., Baxi, L., Markowitz, J. C., Rosing, M., et al. (2007). *Depression and Anxiety*, 24(3), 219-222.
- Nikcevic, A. V., Kuczmierczyk, A., & Nicolaides, K. H. (2007). The influence of medical and psychological interventions on women's distress after miscarriage. *Journal of Psychosomatic Research*, 63, 283-290.
- Noelen-Hoeksema, S., & Larson, J. (1999). Coping with loss. Mahwah, NJ: Erlbaum.
- Ockhuijsen, H. D. L., van den Hoogen, A., Boivin, J., Macklon, N. S., & de Boer, F. (2014). Pregnancy after miscarriage: Balancing between loss of control and searching for control. *Research in Nursing & Health*, 37(4), 267-275.
- O'Leary, C. M., Bower, C., Knuiman, M., & Stanley, F. J. (2007). Changing risks of stillbirth and neonatal mortality associated with maternal age in Western Australia 1984-2003. *Paediatric and Perinatal Epidemiology*, 21(6), 541-549.
- O'Leary, J. (2003). Grief and its impact on prenatal attachment in the subsequent pregnancy. *Archives of Womens Mental Health*, 7(1), 7-18.
- O'Leary, J., Gaziano, C., & Thorwick, C. (2006). Born after loss: The invisible child in adulthood. *Journal of Prenatal and Perinatal Psychology and Health*, 21(1), 3-23.

- O'Leary, J., & Thorwick, C. (2005). Fathers' perspectives during pregnancy, postperinatal loss. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 35(1), 78-86.
- O'Leary, J., & Thorwick, C. (2008). Attachment to the unborn child and parental mental representations of pregnancy following perinatal loss. *New Directions in Psychotherapy and Relational Psychoanalysis*, 2(3), 292–320.
- O'Leary, J., & Warland, J. (2013). Parents' untold stories of infant loss: The importance of contact with the baby for bereaved parents. *Journal of Family Nursing*, 19(3), 324-347.
- O'Neill, B. (1998). Fathers' grief dealing with stillbirth, Nursing Forum, 33(4), 33–7.
- Oliver, L. (1999). Effects of a child's death on the marital relationship: A review. *Omega: The Journal of Death and Dying, 39*(3), 197-227.
- Ozer, E. J., Best, S. R., Lipsey, T. L., & Weiss, D. S. (2003). Predictors of posttraumatic stress disorder and symptoms in adults: A meta-analysis. *Psychological Bulletin*, 129(1), 52-73.
- Parkes, C. M. (1965a). Bereavement and mental illness: Part 1. A clinical study of the grief of bereaved psychiatric patients. *British Journal of Medical Psychology*, 38(1-12).
- Parkes, C. M. (1965b). Bereavement and mental illness: Part 2. A classification of bereavment reactions. *British Journal of Medical Psychology, 38*(13-26).
- Parkes, C. M. (1971). Determination of outcome of bereavement. *Proceedings of the royal society of medicine*, 64, 279.
- Parkes, C. M. (1995). Guidelines for conducting ethical bereavment research. *Death Studies*, 19, 171-181.
- Parkes, C. M., & Weiss, R. S. (1983). *Recovery from bereavement*. New York: Basic Books.
- Parry, D. C. (2004). Understanding women's lived experiences with infertility: Five short stories. *Qualitative Inquiry*, 10(6), 909-922.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Peppers, L. G., & Knapp, R. J. (1980). *Motherhood and mourning: Perinatal death*. New York: Praeger.
- Peters, M., Riitano, D., Lisy, K., Jordan, Z., Pearson, A., & Aromataris, E. (2014). Provision of effective, meaningful and appropriate care for families who have experienced stillbirth: A comprehensive systematic review protocol. *The JBI Database of Systematic Reviews and Implementation Reports*, 12(11), 141 156.
- Peterson, G. (1994). Chains of grief: Impact of perinatal loss on subsequent pregnancy. Journal of Prenatal and Perinatal Psychology and Health, 9, 149-158.
- Phipps, S. (1985). The subsequent pregnancy after stillbirth: Anticipatory parenthood in the face of uncertainty. *International Journal of Psychiatry in Medicine*, 15, 243-267.
- Polatinsky, S., & Esprey, Y. (2000). An assessment of gender differences in the perception of benefit resulting from the loss of a child. *Journal of Traumatic Stress*, 13, 709-718.
- Polkinghorne, D. (1983). *Methodology for the human sciences: Systems of inquiry*. Albany: State University of New York Press.
- Popay J., Rogers A. & Williams G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8(3), 341–351.

- Prettyman, R. J., Cordle, C. J., & Cook, G. D. (1993). A three month follow-up of psychological morbidity after early miscarriage. *British Journal of Medical Psychology*, 66(4), 363-372.
- Prigerson, H. G., Horowitz, M. J., Jacobs, S. C., Parkes, C. M., Aslan, M., Goodkin, C., et al. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *Plos Medicine*, *6*(8), e1000121.
- Prigerson, H. G., & Jacobs, S. C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 613-637). Washington, DC: American Psychological Association.
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*, 18(3), 20-24.
- Pullen, S., Golden, M. A., Cacciatore, J. (2012). I'll never forget those cold words as long as I live: Parent perceptions of death notification for stillbirth. *Journal of Social Work in End-of-Life & Palliative Care*, 8(4), 339-355.
- Racher, F. E., & Robinson, S. (2003). Are phenomenology and positivism strange bedfellows? *Western Journal of Nursing Research*, *25*, 464-481.
- Radestad, I. (2001). Stilbirth: Care and long-term psychological effects. *British Journal of Midwifery*, *9*, 474-479.
- Radestad, I., & Christoffersen, L. (2008). Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery*, 16(9), 588-591.
- Radestad, I., Nordin, C., Steinbeck, G., & Sjogren, B. (1996). Psychological complications after stillbirth influence of memories and immediate management: Population based study. *British Medical Journal*, *312*, 1505-1507.
- Radestad, I., Nordin, C., Steinbeck, G., & Sjogren, B. (1998). A comparison of women's memories of care during pregnancy, labour and delivery after stillbirth or live birth. *Midwifery*, 14(2), 111-117.
- Radestad, I., Surkan, P. J., Steineck, G., Cnattinggius, S., Onelov, E., & Dickman, P. W. (2009). Long-term outcomes for mothers who have or who have not held their stilborn baby. *Midwifery*, 25(4), 422-429.
- Rajan, L. (1994). Social isolation and support in pregnancy loss. *Health Visitor*, 67(3), 97-101.
- Rajan, L., & Oakley, A. (1993). No pills for heartache: The importance of social support for women who suffer pregnancy loss. *Journal of Reproductive and Infant Psychology*, 11, 75-87.
- Rando, T. A. (1984). *Grief, dying, and death: Clinical interventions for caregivers*. Champaign, IL: Research Press.
- Rando, T. A. (1985). Bereaved parents: Particular difficulties, unique factors, and treatment issues. *Social Work, 30*, 19-23.
- Rando, T. A. (1986). A comprehensive analysis of anticipatory grief: Perspectives, processes, promises, and problems. In T. A. Rando (Ed.). *Loss and anticipatory grief.* Lexington, MA: Lexington Books.
- Rando, T. A. (1993). Treatment of complicated mourning. Champaign, IL: Research Press.
- Reagan, L. (2003). From hazard to blessing to tragedy: Representations of miscarriage in twentieth-Century America, *Feminist Studies*, 29, 356-378.

- Reagan, L., & Rai, R. (2000). Epidemiology and the medical causes of miscarriage. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 14(5), 839-854.
- Reck, C., Zimmer, K., Dubber, S., Zipser, B., Schlehe, B., & Gawlik, S. (2013). The influence of general anxiety and chilbirth-specific anxiety on birth outcome. *Archives of Women's Health*, *16*(5), 363-369.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18, 20-23.
- Richards, L. (2005). Handling qualitative data: A practical guide. London: Sage.
- Righetti, P. L., Dell'Avanzo, M., Grigio, M., & Nicolini, U. (2005). Maternal/paternal antenatal attachment and fourth-dimensional ultrasound technique: A preliminary report. *British Journal of Psychology*, *96*, 129-137.
- Robins, L. N., Helzer, J. E., Croughan, J., & Ratcliff, K. (1981). National Institute of Mental Health Diagnostic Interview Schedule: Its history, characteristics and validity. *Archives of General Psychiatry*, 38, 381-389.
- Robinson, G. E. (2011). Dilemmas related to pregnancy loss. *Journal of Nervous & Mental Disease*, 199(8), 571-574.
- Robinson, M., Baker, L., & Nackerud, L. (1999). The relationship of attachment theory and perinatal loss. *Death Studies*, 23, 257-270.
- Roemer, L, & Orsillo, S. M. (2002). Expanding our conceptualization of and treatment for generalized anxiety disorder: integrating mindfulness/ acceptance-based approaches with existing cognitive-behavioral models. *Clinical Psychology: Science and Practice*, *9*, 54-68.
- Romm, J. (2002). Breaking bad news in obstetrics and gynecology: Educational conference for resident physicians. *Archives of Women's Mental Health*, *5*, 177-179.
- Ronen, R., Packman, W., Field, N., Davies, B., Kramer, R., & Long, J. K. (2010). The relationship between grief and adjustment and continuing bonds for parents who have lost a child. *Journal of Death and Dying*, 60(1), 1-31.
- Rosenblatt, P. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies*, 19, 139-155.
- Rosenblatt, P. (2000). *Parent grief: Narratives of loss and relationship*. Philadelphia, PA: Brunner/Mazel.
- Rosenfeld, J. A. (1991). Bereavement and grieving after spontaneous abortion. *American Family Physician*, 43(5), 1679-1684.
- Rubin, R. (1975). Maternal tasks in pregnancy. *Maternal-Child Nursing Journal*, 4(3), 143-153.
- Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Rubin, R. (1984). Maternal identity and the maternal experience. New York: Springer.
- Rubin, S. S. (1999). The two-track model of bereavement: Overview, retrospect, and prospect. *Death Studies*, *23*, 681-714.
- Rubin, S. S., & Malkinson, R. (2001). Parental response to child loss across the life cycle: Clinical and research perspectives. In M. S. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping and care* (pp. 219-240). Washington, DC: American Psychological Association.
- Rush, B. (1812/1947). Medical inquiries and observation upon the diseases of the mind. *Occupational Therapy*, *26*, 177-180.
- Ryan-Nicholls, K. D., & Will, C. I. (2009). Rigour in qualitative research: Mechansims for control. *Nurse Researcher*, 16(3), 70-83.

- Ryninks, K., Roberts-Collins, C., McKenzie-McHarg, K., Horsch, A. (2014). Mothers experience of their contact with their stillborn infant: An interpretative phenomenological analysis. *BMC Pregnancy and Childbirth*, 14, 203-212.
- Saflund, K., Avelin, P., Erlandsson, K., Wredling, R., & Radestad, I. (2013). Parental grief and relationships after the loss of a stillborn baby. *Midwifery*, 29(6), 668-673.
- Saflund, K., Sjogren, B., & Wredling, R. (2004). The role of caregivers after a stillbirth: Views and experiences of parents. *Birth: Issues in Perinatal Care, 31*(2), 132-137.
- Sanders, C. (1980). A comparison of adult bereavement in the death of a spouse, child, and a parent. *Omega: Journal of Death and Dying, 10,* 303-322.
- Schaefer, J. A., & Moos, R. H. (2001). Bereavement experiences and personal growth. In M. S.Stroebe, R. O.Hansson, W.Stroebe & H.Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 145-167). Washington, DC: American Psychological Association.
- Schott, J., Henley, A., & Kohner, N. (2007). *Pregnancy loss and the death of a baby: Guidelines for professionals.* SANDS, London.
- Schwandt, T. A. (2001). Dictionary of qualitative inquiry. Thousand Oaks, CA: Sage.
- Sejourne, N., Callahan, S., & Chabrol, H. (2010). Support following miscarriage: What women want. *Journal of Reproductive and Infant Psychology*, 28(4), 403-411.
- Shand, A. F. (1914/1920). The foundations of character (2nd ed.). London: Macmillan.
- Shapiro, G. D., Fraser, W. D., Frasch, M. G., & Seguin, J. R. (2013). Psychosocial stress in pregnancy and preterm birth: Associations and mechanisms. *Journal of Perinatal Medicine*, 41(6), 631.
- Shaw, R. L. (2001). Why use interpretative phenomenological analysis in Health Psychology? *Health Psychology Update*, 10(4), 48-52.
- Shaw, A., Joseph, S., & Linley, P. A. (2005). Religion, spirituality, and posttraumatic growth: A systematic review. *Mental Health, Religion, & Culture, 8*(1), 1-11.
- Shear, K., Frank, E., Houck, P. R., & Reynolds, C. (2005). Treatment of complicated grief: A randomized controlled trial. *Journal of the American Medical Association*, 293(21), 2601-2608.
- Shear, M. K., Simon, N., Wall, M., Zisook, S., Neimeyer, R. A., Duan, N., et al. (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 28(2), 103-117.
- Shepperd, J, A., Findley-Klein, C., Kwavnick, K. D., Walker, D., & Perez, S. (2000). Bracing for loss. *Journal of Personality & Social Psychology*, 78, 620-634.
- Sherkat, D. W., & Reed, M., D. (1992). The effects of religion and social support on self-esteem and depression among the suddenly bereaved. *Social Indicators Research*, 26, 259-275.
- Shiverick, K. T., & Salafia, C. (1999). Cigarette smoking and pregnancy: Ovarian, uterine, and placental effects. *Placenta*, 20, 265-272.
- Shoebridge, P., & Gowers, S. (2000). Parental concern and adolescent onset anorexia nervosa. *British Journal of Psychiatry*, 176, 132-137.
- Shuchter, S. R., & Zisook, S. (1986). Treatment of spousal bereavement: A multidimensional approach. *Psychiatric Annals*, 16(295), 298-305.
- Shuchter, S., & Zisook, S. (1993). The course of normal grief. In M. S. Stroebe, W. Stroebe & R. O. Hansson (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 23-43). New York: Cambridge University Press.

- Shreffler, K. M., Hill, P. W., & Cacciatore, J. (2012). Exploring the increased odds of divorce following miscarriage or stillbirth. *Journal of Divorce & Remarriage*, 53(2), 91-107...
- Simmons, H. A., & Goldberg, L. S. (2011). 'High-risk' pregnancy after perinatal loss: Understanding the label. *Midwifery*, 27(4), 452-457.
- Simmons, R., Singh, G., Maconochie, N., Doyle, P., & Green, J. (2006). Experience of miscarriage in the UK: Qualitative findings from the national women's health study. *Social Science & Medicine*, 63(7), 1934-1946.
- Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. Smith, R. Harre & L. v. Langenhove (Eds.), *Rethinking methods in psychology* (pp. 9-26). London: Sage.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39-54.
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being*, 2, 3-11.
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9-27.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London: Sage.
- Smith, J. A., Jarman, M., & Osborne, M. (1999). Doing phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods*. London: Sage.
- Smith, L., Kalus, C., Russell, P., & Skinner, T. C. (2009). Exploring current service provision for prolonged grief disorder and suggestions for future advances. *Mortality*, *14*(1), 53-69.
- Snelgrove, S. R. (2014). Conducting qualitative longitudinal research using interpretative phenomenological analysis. *Nurse Researcher*, 22(1), 20-25.
- Sormanti, M., & August, J. (1997). Parental bereavement: Spiritual connections with deceased children. *American Journal of Orthopsychiatry*, 67, 460-469.
- Sorrell, J. M., & Redmond, G. M. (1995). Interviews in qualitative nursing research: differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*, 21(6), 1117-1122.
- Spence, D. (2001). Hermeneutic notions illuminate cross-cultural nursing experience. *Journal of Advanced Nursing*, 35, 624-630.
- St John, A., Cooke, M., & Goopy, S. (2006). Shrouds of silence: Three women's stories of prenatal loss. *The Australian Journal of Advanced Nursing*, 23, 8-12.
- St. John, W., & Johnson, P. (2000). The pros and cons of data analysis software for qualitative research. *Journal of Nursing Scholarship*, 32, 393-397.
- Stern, K., Williams, G. M., & Prados, M. (1951). Grief reactions in later life. *American Journal of Psychiatry*, 108, 289-294.
- Stratton, K., & Lloyd, L. (2008). Hospital-based interventions at and following miscarriage: Literature to inform research-practice initiative. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 48(1), 5-11.
- Stormer, N. (2003). Seeing the foetus: The role of technology and image in the maternal-foetal relationship. *Journal of the American Medical Association*, 289, 1700.
- Stoyles, B. J. (2015). The value of pregnancy and the meaning of pregnancy loss. *Journal of Social Philosophy*, 46(1), 91-105.

- Stringham, J., Riley, J., & Ross, A. (1982). Silent birth: Mourning a stillborn baby. *Social Work*, 27(4), 322-327.
- Stroebe, M. S., Abakoumkin, G., Stroebe, W., & Schut, H. (2012). Continuing bonds in adjustment to be eavement: Impact of abrupt versus gradual separation. *Personal Relationships*, 19(2), 255-266.
- Stroebe, M. S., Boelen, P. A., van den Hout, M., Stroebe, W., Salemink, E., & van den Bout, J. (2007). Ruminative coping as avoidance: A reinterpretation of its function in adjustment to bereavement. *Clinical Neuroscience*, *257*, 462-472.
- Stroebe, M. S., Gergen, M. M., Gergen, K. J., & Stroebe, W. (1992). Broken hearts or broken bonds: Love and death in historical persepective. *American Psychologist*, 47, 1205-1212.
- Stroebe, M. S., Hansson, R. O., Schut, H., & Stroebe, W. (2008). Bereavement research: Contemporary perspectives. In M. S. Stroebe, R. O. Hansson, H. Schut & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 3-25). Washington, DC: American Psychological Association.
- Stroebe, M., Hansson, R., Stroebe, W., & Schut, H. (2001). *Handbook of bereavement research: Consequences, coping and care*. Washington, DC: American Psychological Association.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavment: Rationale and description. *Death Studies*, *23*, 197-224.
- Stroebe, M. S. & Schut, H. A. W. (2005). To continue or relinquish bonds: A Review of consequences for the bereaved. *Death Studies*, *29*, 477-494.
- Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavment: A decade on. *Omega: The Journal of Death and Dying*, 61(4), 273-289.
- Stroebe, M., Schut, H., & Boerner, K. (2010). Continuing bonds in adaptation to bereavement: Toward a theoretical integration. *Clinical Psychology Review*, 30(2), 259-268.
- Stroebe, M., Stroebe, W., & Schut, H. (2003). Bereavement research: Methodological issues and ethical concerns. *Palliative Medicine*, 17, 235-240.
- Stroebe, M., van Son, M., Stroebe, W., Kleber, R., Schut, H., & Van den Bout, J. (2000). On the classification and diagnosis of pathological grief. *Clinical Psychology Review*, 20(1), 57-75.
- Stroebe, M. S., Stroebe, W., & Schut, H. (2003). Bereavement research: Methodological issues and ethical concerns. *Palliative Medicine*, 17, 235-240.
- Stroebe, M. S., Stroebe, W., Schut, H., & van den Bout, J. (1998). Bereavement. In H. Friedman, N. Adler & R. D. Parke (Eds.), *Encyclopedia of mental health*. San Diego, CA: Academic Press.
- Stroebe, M. S., van der Houwen, K., & Schut, H. (2008). Bereavement support, intervention, and research on the Internet: A critical review. In M. S. Stroebe, R. O. Hansson, H. Schut & W. Stroebe (Eds.), *Handbook of bereavement research and practice*. (pp. 551–574). Washington, DC: American Psychological Association.
- Stroebe, W., Abakoumkin, G., & Stroebe, M. (2010). Beyond depression: Yearning for the loss of a loved one. *OMEGA Journal of Death and Dying*, 61, 85-101.
- Stroebe, W., & Schut, H. (2001). Risk factors in bereavement outcome: A methodological and empirical review. In M. Stroebe, R. O. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping and care* (pp. 349-371). Washington, DC: American Psychological Association.

- Stroebe, W., & Stroebe, M. S. (1987). Bereavement and health. New York: Cambridge University Press.
- Stroebe, W., Zech, E., Stroebe, M. S., & Abakoumkin, G. (2005). Does social support help in bereavement? Journal of Social and Clinical Psychology, 24, 1030-1050.
- Sullivan, K. (1998). Managing the 'sensitive' interview: A personal account. Nurse Researcher, 6(2), 72-85.
- Surkan, P. J., Radestad, I., Cnattinggius, S., Steinbeck, G., & Dickman, P. W. (2008). Events after stillbirth in relation to maternal depressive symptoms: A brief report. Birth: Issues in Perinatal Care, 35, 153-157.
- Swanson, K. M. (1999). Effects of caring, measurement, and time on miscarriage impact and women's well-being. Nursing Research, 48, 288-298.
- Swanson, K. M., Chen, H., Graham, J. C., Wojnar, D. M., & Petras, A. (2002). Resolution of depression and grief during the first year after miscarriage: A randomized controlled clinical trial of couples-focused interventions. Journal of Women's Health, 18(8), 1245-1257.
- Thapar, A. K., & Thapar, A. (1992). Psychological sequelae of miscarriage: A controlled study using the General Health Ouestionnaire and the Hospital Anxiety and Depression Scale. British Journal of General Practice, 42, 94-96.
- Theut, S. K., Pederson, F. A., Zaslow, M. J., Cain, R. L., Rabinovich, B. A., & Morishisa, J. M. (1989). Perinatal loss and parental berevament. American Journal of Psychiatry, 146, 635-639.
- Theut, S. K., Zaslow, M. J., Rabinovich, B. A., Bartko, J. J., & Morishisa, J. M. (1990). Resolution of parental bereavement after perinatal loss. Journal of the American Academy of Child and Adolescent Psychiatry, 29(4), 521-525.
- Thomas, V., & Striegel, P. (1994). Stress and grief of perinatal loss: Intergrating qualitative and quantitative methods. OMEGA: Journal of Death and Dying, 30, 299-311.
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. Journal of Advanced Nursing, 48(4), 388-396.
- Toedter, L. J., Lasker, J. N., & Alhadeff, J. M. (1988). The perinatal grief scale: Development and initial validation. American Journal of Orthopsychiatry, 58, 435-
- Toedter, L. J., Lasker, J. N., & Janssen, H. J. (2001). International comparison of studies using the perinatal greif scale: A decade of research on pregnancy loss. Death Studies, 25, 205-228.
- Toller P. W., & Braithwaite, D. O. (2009). Grieving together and apart: Bereaved parents' contradictions of marital interaction. Journal of Applied Communication Research, *37*(3), 257-277.
- Toneatto, T., Nguyen, L. (2007). Does mindfulness meditation improve anxiety and mood symptoms? A review of the controlled research. Canadian Journal of Psychiatry, *52*, 260-266.
- Trulsson, O., & Radestad, I. (2004). The silent child: Mothers experiences before, during and after stillbirth. Birth, 31(3), 189-195.
- Tsartsara, E., & Johnson, M. P. (2006). The impact of miscarriage on women's pregnancyspecific anxiety and feelings of prenatal maternal-foetal attachment during the course of a subsequent pregnancy: An exploratory follow-up study. Journal of Psychosomatic Obstetrics and Gynecology, 27(3), 173-182.

- Turton, P., Evans, C., & Hughes, P. (2009). Long-term psychosocial sequelae of stillbirth: Phase II of a nested case-control cohort study. *Archives of Women's Health*, *12*(1), 35-41.
- Turton, P., Hughes, P. M., Evans, C. D. H., & Fainman, D. (2001). Incidence, correlates, and predictors of post-traumatic stress disorder in the pregnancy after stillbirth. *British Journal of Psychiatry*, 178, 556-560.
- Tull, M. T., Stipelman, B. A., Salters-Pedneault, K., Gratz, K. L. (2009). An examination of recent non-clinical panic attacks, panic disorder, anxiety sensitivity, and emotion regulation difficulties in the prediction of generalized anxiety disorder in an analogue sample. *Journal of Anxiety Disorders*, 23, 275-282.
- Uren, T. H., & Wastell, C. A. (2002). Attachment and meaning-making in perinatal bereavement. *Death Studies*, 26(4), 279-308.
- Valadan, M., Tanha, F. D., & Sepahi, A. (2011). Pregnancy outcomes in women of advanced age. *Journal of Family & Reproductive Health*, 5(2), 69-63.
- Van, P., & Meleis, A. I. (2003). Coping with grief after involuntary pregnancy loss: Perspectives of African American women. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 32, 28-39.
- van de Mortel, T. (2008). Faking it: Social desirability response bias in self-report research. *Australian Journal of Advanced Nursing*, 25(4), 40-48.
- van den Akker, O. (2011). The psychological and social consequences of miscarriage. *Expert Review of Obstetrics & Gynecology*, *6*(3), 295-304.
- Van den Bergh, B.R.H., Mulder, E.J.H., Mennes, M., & Glover, V. (2005). Antenatal maternal anxiety and stress and the neuro-behavioural development of the foetus and child: Links and possible mechanisms. A review. *Neuroscience and Biobehavioral Reviews*, 29, 237-258..
- van Manen, M. (1990). Researching the lived experience. Human science for an action sensitive pedagogy. Albany, NY: State University of New York Press.
- van Manen, M. (2002). Writing in the dark: Phenomenological studies in interpretive inquiry. London: Althouse Press.
- van Manen, M. (2014). *Phenomenology of Practice: Meaning-giving methods in phenomenological research and writing*. Walnut Creek: Left Coast Press.
- Vance, J. C., Najman, J. M., Thearle, M. J., Embelton, G., Foster, W. J., & Boyle, F. M. (1995). Psychological changes in parents eight months after the loss of an infant from stillbirth, neonatal death, or sudden infant death syndrome: A longitudinal study. *Pediatrics*, *96*, 933-938.
- Vaux, A., Reidel, S., & Stewart, D. (1987). Modes of social support: The social support behaviors (SS-B) scale. *American Journal of Community Psychology*, 15(2), 209-231
- Vickio, C. J. (2000). Developing beliefs that are compatible with death: Revising our assumptions about predictability, control, and continuity. *Death Studies*, *24*(8), 739-758.
- Von Eckartsberg, R. (1998). Existential-Phenomenological Research. In R. Valle (Ed.), Phenomenological inquiry in psychology: Existential and Transpersonal dimensions. New York: Plenum Press
- Wagner, B., & Maercker, A. (2010). The diagnosis of complicated grief as a mental disorder: A critical appraisal. *Psychologica Belgica*, 50(1-2), 27-48.
- Wagstaff, C., Williams, B. (2014). Specific design features of an interpretative phenomenological analysis study. *Nurse Researcher*, 21(3), 8-12.

- Wakefield, J. C. (2011). Should uncomplicated bereavement-related depression be reclassified as a disorder in the DSM-5? Response to Kenneth S. Kendler's statement defending the proposal to eliminate bereavement exclusion. *Journal of Nervous and Mental Disorders*, 199, 203-208.
- Walker, W. (2007). Ethical considerations in phenomenological research. *Nurse Researcher*, 14(3), 36-45.
- Wallerstedt, C., Lilley, M., & Balwin, K. (2003). Inter-conceptual counseling after perinatal and infant loss. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 32, 533-542.
- Warland, J., O'Leary, J., McCutcheon, H., & Williamson, V. (2011). Parenting paradox: Parenting after infant loss. *Midwifery*, 27(5), e163-e169.
- Weisman, C. S., Hillemeier, M. M., Chase, G. A., Misra, D. P., Chuang, C. H., Parrott, R., et al. (2008). Women's perceived control of their birth outcomes in the central pennsylvania women's health study: Implications for the use of preconception care. *Women's Health Issues, 18*(1), 17-25.
- Wheeler, S. (2000). A loss of innocence and a gain in vulnerability: Subsequent pregnancy after a loss. *Illness, Crisis and Loss, 8*, 310-326.
- Willig, C. (2008). Introducing qualitative research in psychology. Second Edition. Berkshire, UK: Open University Press.
- Wing, D. G., Clance, P. R., Burge-Callaway, K., & Armistead, L. (2001). Understanding gender differences in bereavement following the death of an infant: Implications for treatment. *Psychotherapy*, 38(1), 60-71.
- Wong, M. K., Crawford, T. J., Gask, L., & Grinyer, A. (2003). A qualitative investigation into women's experiences after miscarriage: Implications for the primary healthcare team. *British Journal of General Practice*, *53*(494), 697-702.
- Woods-Giscombe, C. L., Lobel, M., & Crandell, J. M. (2010). The impact of miscarriage and parity on patterns of maternal distress in pregnancy. *Research in Nursing & Health*, *33*, 316-328.
- Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (4th ed.). New York: Springer.
- Wortman, C. B., & Silver, R. C. (2001). The myths of coping with loss revisited. In M. Strobe, R. Hansson, W. Stroebe & H. Schut (Eds.), *Handbook of bereavment research: Consequences, coping and care* (pp. 405-430). Washinton, DC: American Psychological Association.
- Wright, P. M. (2005). Childbirth education for parents experiencing pregnancy after perinatal loss. *Journal of Perinatal Education*, 14(4), 9–15.
- Wright, P. M. (2011). Barriers to a comprehensive understanding of pregnancy loss. *Journal of Loss and Trauma, 16*, 1-12.
- Wright, P. M., & Hogan, N. S. (2008). Grief theories and models: Applications to hospice nursing practice. *Journal of Hospice and Palliative Nursing*, 10, 350-356.
- Yahav, R. (2006). The relationship between children's and adolescents' perceptions of parenting style and internal and external symptoms. *Child Care Health & Development*, 33, 460-471.
- Yang, C. J., Stone, P., & Stewart, A. W. (2006). The epidemiology of recurrent miscarriage: A descriptive study of 1214 pregnant women with recurrent miscarriage. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 46, 316-322.

## Appendices

A	Information Letter
В	Participant Return Form
C	Participant Consent Form
D	Participant Interview Guide
Е	Participant Record Form
F	Participant Demographic Data
G	Summary of Results for Participants

#### Appendix A



## A Qualitative Exploration of Women's Experiences of Pregnancy Loss

#### Information Letter for Women

Dear potential participant,

My name is Esther Kint and I am a Psychologist and PhD candidate at Edith Cowan University. First of all, I would like to express my deepest sympathy for your loss. Each year, many women experience the loss of their baby, a loss that is rarely spoken about or acknowledged by society. Consequently, little is known about women's experiences of losing a baby, and what we as a society can do to help during this difficult time.

It would appear that as you were recently a patient at King Edward Memorial Hospital, you are a potential participant. We are hoping you have received some information on this study when you were admitted to hospital.

Women who agree to participate will be interviewed at three points in time. At 4-6 weeks, at 6 months and at 13 months post-loss. Interviews will last approximately 45-90 minutes, will be conversational in style, and held at a time and place of mutual convenience. Interviews will be confidential and you will not be identified. Whether or not you decide to participate in this project will not affect the care you receive at KEMH in any way.

You are eligible to help with this study if you are at least 18 years old, speak English, and live in Perth metropolitan area. Pregnancy loss must have occurred spontaneously, either as a miscarriage or stillbirth.

If you would like to participate in this study, or if you would like further information, please tick the appropriate box on the form provided, and return it in the reply paid envelope.

Should you wish to have further information about the study please telephone Esther on 0439 753 336, or email at <a href="mailto:ekint@our.ecu.edu.au">ekint@our.ecu.edu.au</a>. Alternatively, please contact Belinda Jennings (Clinical Midwife Coordinator, Perinatal Loss Service, KEMH) via switchboard at KEMH 08 9340 2222 pager 3430. If you have any concerns or complaints regarding this study, you can contact the director of Medical Services at KEMH (Telephone No: (08)9340 2222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study. The study has been approved by the King Edward Memorial Hospital and Edith Cowan University Ethics Committees.

On behalf of all of us here at KEMH, I wish to extend our deepest condolences for the loss of your baby. Our thoughts are with you during this very difficult time.

Yours sincerely,	
Director, Clinical Care Unit	Esther Kint, PhD Candidate

#### Appendix B

## Participant Return Form

# PLEASE TICK ONE BOX, THEN SIGN, DATE AND RETURN THE SLIP IN THE ENVELOPE PROVIDED.

	Please do not contact me regarding my participation in the study.
OR	
	I would like further information on the study so I can decide whether or not I will participate.
OR	
	I am happy to be contacted for participation in the research project. Please contact on the following number
Name	:
Signa	ture: Date:

#### Appendix C

#### Participant Consent Form

#### FORM OF CONSENT

PLEASE NOTE THAT VOLUNTARY AND SUBJE IMPACT ON CURRENT OR	CTS CAN WITH				IS NO	
I information (Given Names)			have	read	the	
explaining the study entitled:						
	Cradles: A Qualita n's Experiences o	•				
I have read and understood asked have been answered to		given to me.	Any que	estions I h	ave	
I understand that interviews will be audio-recorded, and erased once transcribed.						
I understand I may withdraw from the study at any stage and withdrawal will not interfere with routine care.						
I agree that research data gathered from the results of this study may be published, provided that names are not used.						
I hereby consent to participati	on in this study.					
Dated da	ay of		Year			

\_\_\_\_have explained the above to the

(Investigators signature)

Signature\_\_\_\_\_

(Investigator's full name)

signatory who stated that she understood the same.

#### Appendix D

#### Interview Guide

Thank you for taking the time to talk to me today. As you are aware, I am here to ask you some questions about your experience of pregnancy loss. I understand that this is a sensitive topic, and if you do not feel comfortable answering any particular question, or would like to take a break at any time during the interview, please let me know. I would like to spend our time together talking about your experience and any issues you feel are important to discuss. By listening to your personal experience, and those of other women who have experienced pregnancy loss, I hope to gain valuable information as to how support for women who experience pregnancy loss can be improved.

Firstly, I have some general questions I would like to ask you:

-	Age	
-	Marital Status	
-	Occupation	
-	Time since loss	
-	Gestational age at time of loss	
-	Number of children	
-	Other losses	

Thank you. Now I would like to ask you some more detailed questions about your experiences:

(Note: the following questions are intended as a guide only. The interview will commence with the first question but successive questions will develop according to participant's responses).

Can you tell me a bit about your pregnancy experience?

- How did you discover you were pregnant?
- What was your reaction at this time?
- Had you been trying for a baby, or was it unexpected? A surprise?
- How did you feel? What were your thoughts?
- What bodily changes or states were you aware of at the time?

Can you describe for me your relationship/affections/attachment with your baby?

Can you tell me about the circumstances surrounding the loss of your baby?

- How did it occur? (miscarriage, stillbirth, preterm birth...)
- What was your experience in the hospital?
- Can you tell me what it was like to lose your baby?
- Description of the experience, and the days that followed.
- How did you feel? What were you thinking?

What were your experiences in the weeks that followed?

- Issues/problems you faced
- Thought processes
- Feelings

Can you describe your experience of support during this difficult time?

- Who supported you?
- How?
- What helped? What didn't?

What were the reactions of people around you?

- Spouse, family, friends, community
- What did they say to you?
- What were your reactions to their reactions? How did you feel?

What was your experience of staff?

- Midwives, nurses, doctors, specialists

Can you tell me how you feel looking back on the experience now?

- How are you feeling now?
- Personal growth?
- How do you feel about the future?

Can you tell me if the experience of losing a baby has changed the way you see yourself?

- How, why?
- Do you think this is positive or negative?

We've nearly come to the end of the interview. Is there anything else you would like to tell me about your experience of losing your baby? Have you shared all that is significant with reference to the experience? Are there any other questions you wished I had asked you that you feel are important?

Thank you for your time. How do you feel about what we have talked about? (Engage in debriefing session with participant).

I have some information and pamphlets here which I would like to give to you that may be useful. They also contain contact details of relevant organisations that are able to assist you should you wish to talk further about anything we have discussed.

#### Examples of probes:

- Can you give me some examples?
- Can you tell me a little more about that?
- How did that make you feel?

Appendices 315

## Appendix E

## Participant Record Form

Code Name:
Name:
Age:
Address:
Marital Status:
Occupation:
Date of Loss: Gestational Age at time of Loss:
Gestational Age at time of Loss:
Gestational Period:
Number of Children:
Other losses:
Interview Schedule
First Interview:
Second Interview:
Γhird Interview:

Appendix F Participant Demographic Data

Name	Age	Type of	Marital	Other	Previous	Subsequent	Number of
		Loss	Status	(living)	Losses	Pregnancy	Interviews
				Children	(Spontaneous)		
Paige*	33	Miscarriage	Married	0	0	Y	3
		(7 weeks)					
Maria*	27	Miscarriage	Married	1	0	Y	3
01: : 4	2.5	(8 weeks)			4	**	2
Olivia*	35	Miscarriage	Married	1	1	Y	3
	22	(12 weeks)	D 6 .		(18 weeks)	<b>T</b> 7	2
Audrey*	22	Miscarriage	De facto	1	1	Y	3
	2.	(15 weeks)			(25 weeks)		
Leanne*	36	Miscarriage	Married	0	0	Y	3
a		(18 weeks)		_			•
Susan*	32	Stillbirth	Married	2	0	Y	3
	•	(20 weeks)		•			
Jessica*	26	Stillbirth	Married	3	1	Y	3
T	2.5	(20 weeks)			(5 weeks)	<b>T</b> 7	2
Jenny*	25	Stillbirth	Married	1	1	Y	3
<b>5</b> 1 10		(21 weeks)			(8 weeks)		
Rachael*	31	Stillbirth	Married	0	0	Unknown	2
		(21 weeks)				1	
Eveline*	35	Stillbirth	Married	0	0	Unknown	1
		(21 weeks)					
Mary*	25	Stillbirth	Married	1	0	Y	3
		(24 weeks)	- 0				
Amanda	32	Stillbirth	De facto	0	0	Unknown	1
	• •	(26 weeks)					
Ruth*	20	Stillbirth	Married	0	0	Y	3
		(31 weeks)				4	
Alyssa*	34	Stillbirth	Married	1	0	Unknown	1
		(38 weeks)					
Stephanie*	33	Stillbirth	De facto	1	0	Y	3
G1.1 .		(39 weeks)	a: 1				
Chloe*	23	Stillbirth	Single	0	0	Unknown	1
		(39 weeks)	5 0				
Emily*	31	Stillbirth	De facto	0	0	Y	3
		(40 weeks)	D 6	_			_
Phoebe*	26	Stillbirth	De facto	0	0	Y	3
		(40 weeks)					
Grace*	35	Stillbirth	Married	0	0	Y	3
		(41 weeks)					

<sup>\*</sup> Participants are listed by their pseudonyms.

#### Appendix G

#### Summary of Results for Participants

[Date]

Dear [Name],

Firstly, I would like to apologise for the delay in providing you with a summary of findings of the research you took part in. The analysis and write up of the research findings took longer than expected. Hopefully, the extra time taken has resulted in a better thesis, as I wanted to ensure your experiences were accurately portrayed.

In all, I interviewed nineteen women who experienced the loss of a child during pregnancy. Of these, fourteen women completed all three interviews. Please find enclosed a summary of my findings. I have only provided a summary as the actual thesis is over 100,000 words in length. Should you wish to obtain a copy of the thesis in its entirety, please contact me using the details provided below.

I would like to thank you once again for your participation in this valuable research. It was a privilege to meet all of you and listen to your stories.

Kind Regards,

Esther Kint
PhD Candidate
Edith Cowan University

Tel: 0439 753 336

Email: ekint@our.ecu.edu.au

### Women's Experiences of Pregnancy Loss: A Phenomenological Interpretative Analysis **Esther Kint**

#### **Summary of Findings**

The thesis findings were divided into three chapters. Consequently, I have provided a brief summary of each of these chapters, as well as a short discussion of the overall implications of the findings for research and practice.

#### Women's Experiences of Bereavement Following Pregnancy Loss

Historically, grief has been portrayed as a temporary process, that one eventually 'recovers' from over time. Consisting of a series of stages that must be 'worked through', grief is predominantly conceptualised as short-term, stage-based and resolvable, through eventual detachment from the deceased.

Despite these assumptions, all the women I interviewed did not talk about their grief experience in this way. On the contrary, women described their grief as unique, longlasting, and characterised by a range of oscillating emotions. Grief feelings were varied and complex - women not only grieved for the loss of their baby, but also grieved for the loss of motherhood and all that the child had come to represent. In addition to feelings of sadness and despair, feelings of guilt, anger, shame, and self-blame were prominent and experienced with fluctuating intensity. The women also referred to an acquired sense of vulnerability following their loss, resulting from a perceived loss of control. In essence, the women spoke about their grief as a process of acceptance and adjustment, rather than resolution or recovery from grief. Ensuring continued attachment to their deceased baby was important, and the women described in detail their efforts to maintain these connections over time.

#### Women's Experiences of Support Following Pregnancy Loss

This chapter explored women's experiences of support following pregnancy loss. The findings highlighted experiences of both positive and negative support, on both a social and professional level. Women reported feeling isolated and unsupported in their grieving, when others failed to acknowledge or empathise with their grief. For example, women felt unsupported when friends and family ignored them following their loss, or offered unwarranted advice. Unhelpful comments such as "don't worry, you can always have another one", were all too common, and left the women feeling hurt and misunderstood. In contrast, women reported that behaviours such as listening, empathising, and showing genuine concern were most helpful, especially when they were able to share their experiences with friends and family who had endured a similar experience.

In terms of professional support, grief experiences were intensified when health care providers failed to respond with appropriate sensitivity. Inappropriate and insensitive comments experienced by some women greatly affected their perceptions of care, as did systemic inadequacies where the women experienced care that did not meet their expectations. Caregivers who listened, conveyed sensitivity, and who understood the emotional significance of the loss were deemed the most helpful. Overall, the midwives

who assisted in labour and birth were able to provide this relationship, and women were satisfied with the services they received as a result.

Lack of follow-up care and support was a major theme identified from the research, and suggests that women require extended support.

#### The Subsequent Pregnancy: Continued Grief and Heightened Anxiety

This chapter focused on women's experiences of pregnancy after loss. Findings highlighted the complex interaction of grief and anxiety in the subsequent pregnancy, whereby women faced the difficult task of balancing hope and fear as they endured a pregnancy journey fraught with uncertainty. Specifically, the subsequent pregnancy was characterised by intense anxiety, together with ongoing grief. The anxiety experienced was directly related to an overarching fear of another loss. As a result, the women were extremely hypervigilent during their pregnancy and sought constant reassurance that all was well with their unborn child. Furthermore, they engaged in 'emotional cushioning' behaviour, whereby they inadvertently restricted their emotional attachment with their baby.

#### **Discussion and Implications**

Despite its high prevalence, the psychosocial burden pregnancy loss entails remains appreciably unrecognised and misunderstood. The research findings illuminate how current theoretical constructions of grief do not sufficiently embody the bereavement experience following pregnancy loss. Without a thorough appreciation of the course and impact of this diverse grief experience, the current trend towards classifying 'abnormal' representations of grief as 'pathological' has the potential to pathologise a grief response which should be considered a normal response to be reavement. Consequently, service providers and the community at large are likely to hold unrealistic expectations about perinatal bereavement, and the social and professional support needs of women following pregnancy loss are unlikely to be met. The discussion highlights the need to improve and extend service provision for women affected by pregnancy loss, and addresses the urgency in deriving a theory specific to pregnancy-related bereavement upon which to inform evidence-based practice.