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# CONTINUING BONDS: PARENTS' EXPERIENCE OF AN ONGOING RELATIONSHIP WITH THEIR STILLBORN BABY

**EMMA ELIZABETH JONES**

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## Abstract

Continuing bonds theory suggests that bereaved parents can adapt to the loss of their child by sharing and transforming mental representations of the child, allowing them to be integrated into parents' everyday lives and support systems. Few studies examine continuing bonds following stillbirth, and little is known about the potential mental health benefits of expressing continuing bonds. Most studies focus on parent-baby contact and memory-making activities in the immediate aftermath of the loss. Findings are inconclusive although there is evidence that sharing memories of the baby is related to better maternal mental health. Therefore, this project explored how parents continued bonds with their stillborn baby longer term, and investigated any association between key aspects of the relationship, parents' perceptions of social support for the relationship, and bereavement adaptation.

A mixed methods design was employed. In Study 1, 12 parents were interviewed. Data analysis was informed by grounded theory and the constant comparative method applied. In Study 2, parents (*N* = 170) completed an online questionnaire examining engagement in continuing bonds expressions over time; characteristics of the relationship and parents' experience of sharing it; social support, and meaning-making. Measures of anxiety, depression, posttraumatic stress, and posttraumatic growth were also included to quantify bereavement adaptation. Results showed the creative strategies employed by parents to maintain connections with their baby; the affective depth and potentially interactive nature of bonds; and the enduring, pervading influence of the relationship on parents' ongoing lives. How the relationship was expressed changed over time. Parents appreciated sharing their relationship with their baby with compassionate others. Generally, partners, family members and friends understood and supported parents' relationship with their baby. However, over half of parents stated that some family members and friends did not support the relationship. Few parents believed the relationship was expected or widely understood in society, and social support for it tended to fade over time. Most parents thought the relationship aided coping. Regression analyses showed that time since death, meaning-making, engaging with nature and legacy building are positively linked to parents'

bereavement adaptation. Risk factors included inadequate social support for the relationship, a greater desire to share it more freely, an increased sense of integration with baby, and societal pressure to move on. For the first time this project shows that key aspects of parents' ongoing relationship with their stillborn baby, and parents' perceptions of the social context in which they experience the relationship are related to bereavement adaptation. A social context that fails to fully accommodate parents' relationship with their baby may be contributing to poorer outcomes. Moreover, results indicate the therapeutic potential of nature following stillbirth. Recommendations for care and the development of a nature-based intervention are proposed.

# Chapter 1 Introduction

## 1.1 Thesis overview

The focus of this thesis is on parents who continue bonds, that is, engage in an ongoing relationship with their stillborn baby. It is not the aim of this project to make comparisons or identify differences between those parents who do continue bonds with their baby, and those who do not. Rather, the intention is to explore in detail the experience of those parents who continue a relationship with their baby, and to examine which aspects or expressions of this relationship may be helpful to parents. Chapter 1 provides an overview of the literature within the main subject areas of bereavement, grief, continuing bonds and stillbirth, and outlines the primary aims of the current research. Chapter 2 presents Study 1 (Continuing bonds following stillbirth) and details the first phase of the project. Chapter 3 reports Study 2 (Continuing bonds and bereavement adaptation) and the second phase of the project. Chapter 4 provides a synthesised summary of both studies' findings, outlines a number of recommendations relating to stillbirth management in light of these findings, and presents methodological reflections.

## 1.2 Chapter overview

This chapter contextualises the current research by providing an historical overview of theoretical perspectives on coping with bereavement. Moreover, it explores current themes pertinent to stillbirth and perinatal loss, and the short and long-term psychosocial effects on families. The project's research rationale and primary aims will be outlined and the methodological approach introduced and discussed.

## 1.3 Background

*The world of Dead Babies is a silent and shuttered place.*

(Jolly, 2015, p. 45)

Stillbirth is defined in the UK as a baby delivered at or after 24 weeks' gestation showing no signs of life, irrespective of when the death occurred (MBRRACE-UK, 2018). This differs to the definition in other parts of the world, for example, North America where the gestational age is set earlier at ≥ 20 weeks, and to the World Health Organisation's (WHO) recommended definition that sets gestational age at ≥ 28 weeks, primarily to allow for international comparison (WHO, 2016). A live born baby born ≥ 20 weeks' gestation who died prior to seven completed days after birth is defined in the UK as an early neonatal death, whilst perinatal death encompasses both stillbirths and early neonatal deaths (MBRRACE-UK, 2018). The causes of stillbirth range from placental and cord related issues to congenital abnormality and infection, although 41.8% of stillbirths in the UK remain unexplained; whilst risk factors include advanced maternal age, smoking, obesity and poverty (Flenady et al., 2017; MBRRACE-UK, 2018). The terms miscarriage (i.e. foetal death at < 24 weeks' gestation), stillbirth, perinatal and neonatal loss will appear during the course of the thesis, however, this project's studies solely focus on stillbirth. Perinatal loss is a commonly used term within the literature to denote loss by miscarriage, stillbirth or neonatal death.

In 2011 the Lancet published a series of papers highlighting stillbirth as one of the "most shamefully neglected" areas of public health, with an estimated 2.6 million babies stillborn every year worldwide; approximately half of which are thought to be preventable (Darmstadt, 2011; De Bernis et al., 2016; Froen et al., 2016). These figures are mere estimates owing to pluralistic cross-cultural definitions of stillbirth and a widespread lack of reporting; a more accurate quantification of this tragic occurrence could be even more startling. Yet, despite this prevalence, stillbirth lacks visibility, and has rarely been central to wider social debate. Moreover, prior to the turn of the 21st century few academic studies addressed the subject. Despite reports in the updated Lancet series (2016) that stillbirth rates have remained largely static since

publication of the first series, generating such attention has undoubtedly identified stillbirth as a key area of interest within the global health agenda, with ongoing calls for improvements to advocacy, policy formulation, monitoring, and research (Froen et al., 2016). Furthermore, this increased level of exposure of stillbirth to a global audience has engendered positive interest from within the research community. As a result, there is an emerging body of literature exploring the often enduring and complicated effects of this unique and poignant, paradoxical fusion of birth and death (Cacciatore, 2011).

## 1.4 Literature review

In order to gain insight into the research area and identify any gaps in the extant body of work, an extensive review of general bereavement and perinatal loss literature was conducted. This review helped to define the direction of the current research programme, and to develop and refine the research questions. Moreover, relevant theoretical frameworks identified during the review are drawn upon throughout the thesis to aid explanation and interpretation of the findings. The results of the literature review are synthesised below under the subject headings: Bereavement and grief; Continuing bonds, and Stillbirth and perinatal loss.

### 1.4.1 Bereavement and grief

Bereavement has been defined as the objective situation of an individual who has lost a significant other (Stroebe, Stroebe & Hansson, 1993). Grief commonly refers to the emotional response to the loss but can also encompass psychological, behavioural, physiological and spiritual reactions (Gross, 2018; Stroebe, Hansson, Stroebe & Schut, 2001a; Worden, 2009). Mourning is generally defined as the social expression of grief and is culturally moulded (Stroebe et al., 2001a). Historically, grief has been characterised and framed in a number of different ways. In the 19th century, Romanticism in the Western world influenced the cultural response to death. Accordingly, the loss of a loved one precipitated grief which signified the critical importance of the deceased to the survivor, the intense bond between the two, and the depth of the bereaved's own spirit. The act of maintaining bonds with a deceased loved

one was privileged, perceived as valiant and courageous, and believed to contribute to living a spiritually profound and meaningful life (Stroebe, Gergen, Gergen & Stroebe, 1992). Life, it was thought, may be inescapably ephemeral but love was undying (Walter, 2018).

In contrast, the evolution of Modernism in the 20th century promoted rationality and functionality, as a consequence, grief was subjected to close examination through a scientific and medicalised lens. Freud's influential work *Mourning and Melancholia* (1917/1957) reflected the age of efficacy and goal orientation, and engendered the psychodynamic relinquishing bonds paradigm that encouraged emotional disengagement from the deceased. This detachment was deemed necessary in order to adjust to life without the lost loved one and achieve grief resolution or recovery. The use of the term "mourning" in this context relates to the bereaved individual's efforts to redefine their relationship with the deceased, together with their own self-concept and sense of the external world (Gross, 2018), and is largely interchangeable with "grief". Freud (1917/1957) proposed that the function of mourning was to allow the bereaved to become psychologically "free and uninhibited again" (p. 245), and released from their affective attachment (*cathexis*) to the deceased. In essence, the cathexis binds libidinal energy to mental representations (i.e. thoughts and memories) of the object (i.e. the deceased). This energy was considered to be a finite resource, therefore, if indefinitely assigned to mental representations of the deceased it would exhaust and preclude investment of energy into new relationships with the living. Detachment from the deceased was thought to be accomplished gradually through a process known as *hypercathexis,* which resulted in an intensification of the bond as the bereaved tested the reality of the loss and sought to maintain the deceased's presence in his or her life. Typically, hypercathexis involved evocation of mental representations of the deceased and a review of the lost relationship, tasks which are commonly termed *grief work*. It was suggested that this often painful process led to an acceptance of the reality of the loss and an eventual *decathexis*, or severance of emotional ties. Failure to fully decathect or to remain emotionally connected to the deceased was associated with pathological grief (Klass & Steffen, 2018a).

It should be noted that whilst Freud's academic writings advocated emotional disengagement from the deceased over time, in his personal communications based on his own experience of loss he admitted the inherent difficulties in achieving this:

> Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually, this is how it should be, it is the only way of perpetuating that love which we do not want to relinquish. (Freud, 1960, p. 386)

Nevertheless, Freud's seminal theoretical ideas relating to grief work and recovery through emotional detachment from the deceased influenced a number of prominent theorists whose work has permeated Western culture (e.g. Bowlby, 1980; Parkes, 1972; Raphael, 1984; Worden, 1991). As Berzoff (2003) has suggested, it is perhaps to be expected that an individualist culture which privileges autonomy and independence would tend to frame bereavement and grief in this way, as an inescapable succession of partings. Following on from Freud, *phasal* or *stage theories* became particularly prevalent. The notion of grief work was inherent in many of these theoretical conceptualisations and was broadly defined as a "cognitive process of confronting a loss, of going over the events before and at the time of death, of focussing on memories and working toward detachment from the deceased" (Stroebe, 1992-1993, p. 33). These concepts began to underpin much of the conventional wisdom of bereavement counselling and therapeutic practice (Walter, 1996).

One "stage theory" that has attained considerable mainstream popularity is Elisabeth Kubler-Ross's (1970) pioneering descriptive observation of the experience of dying. Whilst the five stages discussed in her work: denial, anger, bargaining, depression and acceptance, have commonly been applied to post-mortem grief and bereavement these were actually some of the emotional responses of terminally-ill individuals when discussing their experience of dying, of which anticipatory or preparatory grief was a part

(Kellehear, 2009). In a posthumously published work the author herself extrapolated the five stages of dying, suggesting the framework could help the bereaved find meaning in their grief following the loss of a loved one (Kubler-Ross & Kessler, 2005). Perhaps in part due to its simplicity and accessibility, the model remains globally ubiquitous and influential (Corr, 2019).

Bowlby's (1980) attachment based theory of loss outlined how individuals respond to the loss of a loved one "over the course of weeks and months /…/ by moving through a succession of phases" (p. 85). These phases or stages were: Numbing, distress and/or anger; Yearning and searching; Disorganisation and despair; and Reorganisation. Whilst Bowlby's model is often cited as aligning with the relinquishing bonds paradigm (Balk, 1996; Silverman & Klass, 1996; Stroebe et al., 1992; Vickio, 1999) there has been some debate as to whether this is indeed the case. It has been suggested that his final phase of bereavement "reorganisation" has been erroneously interpreted as, or confused with "detachment", a term used to describe a defensive posture assumed by children on the return of a parent following a short absence (Shaver & Tancready, 2001). However, in *The Making and Breaking of Affectional Bonds* first published in 1979, Bowlby did posit that "there is, indeed, good reason to believe that the sequence of responses described [following a child's period of separation from the mother] - protest, despair, and detachment - is a sequence that, in one variant or another, is characteristic of all forms of mourning" (Bowlby, 1989, p. 49).

Whilst Bowlby (1980) did make reference to the potential benefits of the deceased's enduring sense of presence "During the months and years that follow he will probably be able to organize his life afresh, fortified perhaps by an abiding sense of the lost person's continuing and benevolent presence" (p. 243), these ideas did not appear to gain prominence (Klass & Walter, 2001; Silverman & Klass, 1996). Furthermore, Silverman and Klass (1996) point to the omission from some of his works, and subsequent pathologisation in others, of certain expressions of continuing bonds, namely, internalisation, which involves the bereaved integrating aspects of their lost loved one into their own thoughts and behaviours (Russac, Steighner & Canto, 2002), as evidence of Bowlby's tendency toward privileging emotional detachment from

the deceased. Subsequently, Stroebe and Schut (2005) have concluded that "Bowlby recognised the adaptive functions of retained bonds, but relinquishing bonds was also fundamental to his theory of the impact of separation: Relinquishment was also considered integral to successful adaptation" (p. 483).

Influenced by both Bowlby's and Freud's approach to coping with bereavement, Worden (1983) developed a task based model. This framework largely underpinned the planning of counselling and therapeutic interventions for those struggling to cope with loss (Stroebe & Schut, 2010). Its main premise suggested that the bereaved individual would need to accomplish four basic tasks in order to successfully complete mourning. In its initial inception these tasks were: 1. To accept the reality of the loss, 2. To work through the pain of grief, 3. To adjust to an environment in which the deceased in missing, 4. Withdrawing emotional energy from the deceased and reinvesting it in another relationship. Worden re-worded the final task in the second edition of his work to "emotionally relocate the deceased and move on with life" (Worden, 1991, p. 16) as he believed it sounded too mechanical. Nevertheless, at this stage the final task still emphasised emotional withdrawal, or distancing from the deceased, to enable the bereaved to move on with his or her life. However, a further modification was made to the final task in the most recent edition which now states that the aim is "To find an enduring connection with the deceased in the midst of embarking on a new life" (Worden, 2009, p. 50). As with the aforementioned ambiguity surrounding Bowlby's conceptualisation of continuing bonds with the deceased, so Worden appears to have gradually acknowledged that the bereaved do maintain meaningful connections with the deceased and that these enduring attachments are not solely indicative of pathology but can be beneficial to the bereaved in their efforts to adapt to loss.

Recently, the seemingly rigid, reductionist models of grief outlined above have received criticism for framing grief as an illness to be treated, for being too prescriptive and for "representing grief as a measurable, predictable, controllable condition" (Valentine, 2008). It should be noted that a number of these models' authors did advise that grief was not a strictly linear process and that the suggested stages/tasks were more complex than presented, were

not clear cut, may overlap, were not time restrictive and that there may be a passing back and forth through and between them (e.g. Bowlby, 1980; Kubler-Ross, 1970; Raphael 1984; Worden, 1991). Nevertheless, for some these models have come to represent a limited, functional approach to bereavement and have been challenged for implying an orderly, sequential, linear progression through grief (Silver & Wortman, 2007) with an endpoint of recovery to be achieved within implicit timescales (Wortman & Silver, 2001), thus oversimplifying complex experiences and creating inappropriate expectations for grievers (Attig, 2004). The inclusion of sequential numbering, as is the case in Worden's (1983) task based model, certainly contributes to the representation of grief as an ordered and predictable process. Moreover, it has been suggested that the models fail to account for individual difference and cultural variance, or acknowledge the degree to which grief is socially shaped (Valentine, 2008; Weiner, 2007). Recently, Stroebe, Schut and Boerner (2017) have posited that the ongoing popularity and influential reach of simplistic models of grief that have been subjected to little empirical testing, such as Kubler-Ross's stage theory, might even be harmful to grievers as they can impose restrictive, formulaic and unrealistic expectations on bereaved individuals' coping efforts.

Bowlby applied the core principles of his developmental attachment theory to explain mourning as separation from a loved one. In a similar way, general coping theories have been used to explore bereavement as a stressful life event. In this context, coping is defined as cognitive and behavioural efforts to reduce or tolerate the external and internal demands of stressful situations, with two general types of coping being posited: problem-focussed coping, aimed at problem-solving or actively attempting to alter the person-environment relationship and source of the stress, and emotion-focussed coping which aims to regulate the emotional distress associated with the situation (Folkman, 2001; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). In response to the perceived limitations of general coping theories and the suggested linearity and rigidity of the aforementioned phasal/task models of coping with bereavement (e.g. Bowlby, 1980; Worden, 1991), Stroebe and

Schut (1999) argued that the existing frameworks did not adequately address the specific stressors of bereavement, and failed to fully identify when, for whom, and how working through grief contributed to coping and delivered positive outcomes (Stroebe & Schut, 2010). By adapting, integrating and developing elements of earlier theoretical formulations of grief, and stress and coping theory, Stroebe & Schut (1999) proposed a more fluid, non-phasal Dual Process Model (DPM) of coping with loss.

In this model, coping is defined as a process during which an individual responds to (i.e. confronts or avoids) stressors associated with loss. Coping is argued to have an integral impact on an individual's adjustment to bereavement, therefore, when coping is efficacious it may be expected that the negative physical and psychological problems associated with bereavement would dissipate, and adaptive outcomes would prevail (Stroebe & Schut, 2010). The DPM identifies two types of stressors associated with bereavement: loss-orientated and restoration-orientated which can be both problem focussed and/or emotion focussed in terms of cognitive stress theory, thus providing a more flexible and dynamic framework. *Loss-orientation* refers to the bereaved individual's focus upon, and appraisal and processing of, some aspect of the loss experience itself, particularly with respect to the deceased person. Essentially, it incorporates elements of grief work such as confronting the reality of the loss, and ruminating and reliving memories, and includes a painful dwelling upon or yearning for the lost loved one. Denial, or avoidance of restoration type changes may also be demonstrated. Moreover, loss-orientation encapsulates relinquishing, continuing and relocating bonds with the deceased. *Restoration-orientation* refers to dealing with the secondary sources of stress that accompany bereavement, incorporating redefining and reorienting oneself in a changed world, and planning for a future without the deceased; additionally, it can include distraction from, or denial and avoidance of grief (Stroebe & Schut, 2010).

Oscillation between the two types of orientations is thought to be central to adaptive coping, as is respite from grief. Oscillation sees the bereaved at times attending to, or avoiding the loss-oriented or restoration-oriented stressors, hence serving as a complex regulatory process (Stroebe, Stroebe & Schut,

2001). Furthermore, oscillation between positive and negative affect is understood to be an important mechanism in the coping process. It is suggested that persistent negative affect can intensify and prolong grief, yet working through grief, which encompasses rumination, is deemed necessary in coming to terms with loss (Stroebe & Schut, 2010). Similarly, positive reappraisals enhance coping efforts, however, grieving may be neglected if positive states continue indefinitely, with adaptive resolution of grief becoming more elusive (Stroebe & Schut, 2001; Stroebe & Schut 2010). These processes of confrontation-avoidance are considered key mechanisms in adjustment to bereavement as they enable the bereaved to adjust to a new life without the deceased, relocate the deceased emotionally and move on. (Stroebe & Schut, 2010).

Whilst the DPM is a more dynamic model than the aforementioned traditional grief paradigms, and can accommodate individual differences in coping with loss, for example, gender differences or attachment style (Stroebe, Schut & Boerner, 2010; Wijngaards-de Meij et al., 2008), it does not appear to fully accommodate or explain cultural differences. As outlined above, oscillation between loss and restoration orientations is thought to be key for adaptive coping, with extreme confrontation, or avoidance of one of the orientations deemed indicative, or predictive of pathology. However, as the authors themselves state, certain communities have cultural customs and expectations regarding responses to loss that appear inherently extreme by Western norms. For example, it has been reported that Muslims living on Bali are expected to show no overt expression of grief or distress following bereavement (Stroebe, Gergen, Gergen & Stroebe, 1996; Stroebe & Schut, 2010; Wikan, 1988). It is unclear whether oscillation in these circumstances would be (mal)adaptive. Nevertheless, the DPM provides a detailed and dynamic framework with which to explore the bereaved's experiences of coping with loss.

To this point, prominent 20th century theories of bereavement and grief have been outlined, including psychodynamic, phasal/stage, task and cognitive conceptualisations. These frameworks incorporate aspects of the grief work hypothesis and some allude to a continuing attachment to the deceased, to a

greater or lesser degree, and have varied perspectives on its (mal)adaptiveness. The following section focuses on the evolution of the continuing bonds framework for understanding bereavement and grief.

### 1.4.2 Continuing bonds

*Your body is away from me, but there is a window open from my heart to yours. From this window, like the moon, I keep sending news secretly.*
(Rumi, Melancholy Heart, 2012)

It has been argued that for nearly a century "the grief work model has constituted 'normal science' in the field of thanatology, focusing our attention on hyper-cathexis/decathexis at the expense of other important aspects of mourning" (Russac et al., 2002, p. 465). However, the evolution of the continuing bonds framework began to address this somewhat narrow focus and contested traditional perspectives on what constitutes "normal grieving". Within bereavement literature, the last two decades has seen a challenge to the dominant, Western, modernist view of adaptive emotional disengagement from the deceased over time, with a paradigmatic shift toward continuing bonds with those lost, which, it is suggested, can facilitate loss adjustment (Klass, Silverman & Nickman, 1996; Stroebe et al., 1992). Historically, the strengthening of bonds with the deceased had largely been viewed as a prelude to detachment and re-investment of energy in new relationships, an introjection of the deceased in the survivor's psyche, or futile searching behaviour which would exhaust over time (see Klass & Walter, 2001). As a consequence of this understanding of grief, maintaining an ongoing attachment to the deceased was thought to hinder recovery and deemed potentially indicative of pathology. In Klass et al.'s (1996) pivotal work *Continuing Bonds: New Understandings of Grief* the contributors summoned those within the field of bereavement and beyond to:

> …consider bereavement as a cognitive as well as an emotional process that takes place in a social context of which the deceased is a part. The process does not end, but in different ways bereavement affects the mourner for the rest of his or her life. People are changed by the

> experience; they do not get over it, and part of the change is a transformed but continuing relationship with the deceased. (p. 19)

In contrast to former conceptualisations of ongoing dependence as symptomatic of pathology, Klass et al. (1996) posited that the bereaved actively construct an inner representation of the deceased which is dynamic and changeable, thus constructing and reconstructing new connections to their lost loved one, processes considered to be part of normative grieving (Silverman & Klass, 1996). In the same year, Walter (1996) published a model of grief based on the idea of integrating the memory of the dead into the survivor's life through construction of a durable biography of the deceased, created in conversation with others who knew the deceased. Similarly, Walter emphasised a need for Western society to acknowledge the presence of the dead and to permit the bereaved to retain the deceased in their ongoing life. Within many cultures the bereaved continue to honour and remain closely connected with the dead, with continuing bonds being a cultural norm (Klass, 2001; Klass, 2014-2015; Klass & Walter, 2001; Stroebe et al., 1996). For example, in Japan, where Buddhism largely influences understanding of death and bereavement rituals (Klass, 1996a; Klass, 2001), home altars and daily observances are commonplace, the living provide the dead with food, company and the family's news, and the dead can be consulted for advice at times of uncertainty (Arnason, 2012). There is an acceptance of interdependence between the living and the dead, with Klass (2014-2015) suggesting the bond between the two can be mutually beneficial.

Klass's (1996b) ethnographic study of bereaved parents attending self-help groups in North America made a significant contribution to the emerging continuing bonds thesis. This study demonstrated how parents forged connections with their deceased child over time through symbolic linking objects and rituals, by sensing their child's presence and honouring their child with altruistic acts. Significantly, Klass (1996b) reported a general lack of cultural understanding of continuing bonds; sharing with other members of the group provided social support to parents whilst consolidating and validating their bonds with their child. Following his observations over several years, Klass proposed that bereavement adaptation involved the transformation of

parents' inner representations of their deceased child in both their internal and social worlds. Inner or mental representations were defined in line with Fairbairn (1952) and Kernberg (1976) as "the part of the self actualized in the bond with the person, characterizations, and thematic memories of the person, and the emotional states connected with the characterizations and memories" (Klass, 1996b, p. 200). It is thought that these representations can play an active and healthy role in bereavement (Marmit & Klass, 1996). Typically, traditional theoretical conceptualisations of bereavement had focussed predominantly on the individual and their internal, intrapsychic responses. Klass (1996b) maintained that these inner representations could be influenced, validated and adaptively transformed through social bonds. In essence, it was argued that sharing mental representations with others can facilitate successful integration of the child, in a different way from when the child was alive, into the parent's life and wider social support systems, a process which may contribute to bereavement adaptation. Critically, it has been further suggested that a social context that does not encourage a person's attempt to share mental representations of the deceased, or even family members holding divergent mental representations of the deceased, can have a negative impact upon the adaptive transformation of inner mental representations, and subsequent integration of the deceased into the individual's personal and public narrative (Boerner & Heckhausen, 2003).

The work of Klass et al. (1996) has received some criticism for overlooking "signs of pathology" and suggesting that "all continuing bonds and unresolved elements of grief are beneficial" (Shaver & Tancready, 2001, p. 82). However, it should be noted that Klass (2006) has stressed that continuing bonds are not universally adaptive and that the theoretical ideas initially presented were not intended to represent a new, hegemonic model to replace former theories of bereavement and grief, some of which pathologised lasting emotional ties with the deceased, but rather were to illustrate how continuing bonds are a part of many people's bereavement experience and are a normal facet of grief (Klass & Steffen, 2018a).

Empirical research has failed to provide consistent evidence to support the adaptiveness of either relinquishing affective ties, or continuing bonds

(Stroebe, Abakoumkin, Stroebe & Schut, 2012). In a study of family members who had lost a child to cancer, over half referred to the comforting effects of continuing bonds with the child, however, 10% of family members described discomforting effects (Foster et al., 2011). Links between certain dimensions of continuing bonds and bereavement adjustment have been proposed. Notably, bereaved individuals who tend toward maintaining more concrete connections with their lost loved one through prolonged physical proximity (e.g. use of the deceased's possessions to derive comfort) have been shown to suffer more severe and lasting grief reactions, whereas maintaining more internalised, symbolic connections (e.g. evoking memories of the deceased) was not predictive of increased distress (Field, Gao & Paderna, 2005; Field, Nichols, Holen & Horowitz, 1999). Similarly, Scholtes and Browne (2015) reported that externalised expressions of continuing bonds were associated with poorer grief outcomes and less posttraumatic growth, whereas internalised expressions predicted a better grief outcome and more posttraumatic growth for bereaved parents. However, as stated in the previous paragraph, social bonds are thought to be integral to adaptive transformation of mental representations and integration of the deceased into the bereaved's ongoing life. Moreover, grief is not only a psychological response but also a constructed cultural product (Prior, 1989, as cited by Riches & Dawson, 1997), as such, it has been argued that studies of grief and continuing bonds need to consider the social and cultural contexts in which these processes occur (Klass, 2006).

This approach was taken by Valentine (2008), who interviewed 25 bereaved individuals to explore continuing bonds in modern British society. The findings demonstrated that the bereaved tried to manage the painful paradox of the deceased's absence/presence through materialisation of the loss which encompassed ritualised activities and memorialisation. Integral to their narratives was an ongoing concern to sustain the deceased's personhood and maintain relatedness. Moreover, interviewees continued to care for and be protective of their lost loved ones, for example, by honouring and preserving their memory. Significantly, the process of locating and sustaining bonds occurred both inwardly via psychological, affective and imaginative activity,

and existing beliefs about life and death, and outwardly by means of social and cultural interaction, including conversational sharing and memory-making during which the bereaved could also discover new information about the deceased. Thus, bonds are influenced by and constructed within an individual's social and cultural environments. This notion of the intersubjectivity of continuing bonds is central to recent discussions within the field. Enduring relationships with the dead are viewed as interpersonal and embedded within complex matrices of social and cultural bonds, and as such they contribute to the bereaved's personal and social identities (Klass & Steffen, 2018a).

**Meaning**

It has been posited that the key aspect that links all of the theoretical conceptualisations presented thus far is the bereaved's determination to find, construct or reconstruct meaning in both their internal and external worlds following loss (Gillies & Neimeyer, 2006). Integral to a number of theories of trauma and grief is the suggestion that successful adaptation to distressing life events is largely dependent upon a person's capacity to make sense of their experience in existential terms (see Gillies & Neimeyer, 2006; Park, 2010). Negative and traumatic life events, such as bereavement, can present existential challenges by threatening or violating a person's assumptive world, that is, their pre-existing core beliefs that underpin their conceptual framework for understanding themselves, the world and others (Janoff-Bulman, 1989, 1992; Park, 2010). Park's (2010) integrated theoretical framework of meaning-making suggests that an individual draws upon global meanings, which include personal beliefs, life goals and purposes, to facilitate interpretation of distressing life events, that these events or situations are appraised for meaning, and that any cognitive dissonance arises from a divergence between global and situational meanings. Thus, the ensuing search for meaning serves to reconcile or reduce this discrepancy. Drawing upon previous models of meaning-making, including those of Gillies and Neimeyer (2006) and Park (2010), Kunkel, Dennis and Garner (2014) have more recently outlined four main tenets of meaning reconstruction: sense-making; acceptance or

resignation without understanding; realisation of benefits, and realignment of roles and relationships.

The process of meaning reconstruction is thought to re-establish a sense of control, purpose, order and predictability in how life events unfold (Davis, Nolen-Hoeksema & Larson, 1998; Gillies & Neimeyer, 2006; Janoff-Bulman & Frantz, 1997; Neimeyer, 2000). In contrast to stage/phasal theories of grief which emphasised the universality of certain aspects of grief, the constructionist approach suggests that each bereaved individual will experience grief in a unique way (Neimeyer, 1999). Moreover, meaning-reconstruction is not solely a private intrapersonal process but also takes place in conjunction with others in social and cultural contexts (Neimeyer, Klass & Dennis, 2014). This aligns with the aforementioned view of grief and continuing bonds as intersubjective phenomena. Neimeyer et al.'s (2014) social constructionist framework for understanding bereavement and grief emphasises the interactional aspect of meaning reconstruction through interpersonal communication, both spoken and written, and its potential to aid coping with grief following loss. This communication, or narrative activity involves processing the "event story" of the loss itself and accessing the "back story" of the survivor's relationship with the deceased. It is thought that this process can restore an element of coherence to the survivor's ongoing narrative whilst also strengthening bonds with the deceased. In essence, meaning-reconstruction can reinforce the bereaved's sense of security by reaffirming meaningful attachment to their lost loved one (Neimeyer et al., 2014).

**Sense of presence**

As mentioned previously, Klass (1996b) reported that sensing their child's presence was not uncommon amongst bereaved parents. Indeed, experiences of post-death contact punctuate the bereavement and continuing bonds literature. Sense of presence experiences can involve sensory perceptions of the deceased including visual, auditory, tactile and olfactory modalities (Longman, Lindstrom & Clark, 1988), and an awareness or feeling of the deceased individual's proximity to the perceiver (Rees, 2001).

Explanations addressing the underlining purpose of sense of presence experiences are multi-fold, ranging from attachment theories which suggest the phenomena are searching behaviours triggered by the goal of restoring proximity to the deceased (Bowlby, 1980), to a more psycho-social paradigm which views these events as affirmation of a continuing spiritual bond, that can be successfully integrated into bereaved individuals' ongoing lives (Klass, 1996b; Steffen & Coyle, 2011). There is little consensus in the bereavement literature as to whether sense of presence experiences are indicative of adaptive or maladaptive bereavement outcomes, with some studies reporting negative effects including increased anxiety, feelings of worry and worthlessness, memory disturbances and complicated grief (Field & Filanosky, 2010; Grimby, 1998; Simon-Buller, Christopherson & Jones, 1988-1989), whilst others suggest a positive influence on grief and coping outcomes, and the potential for posttraumatic growth (Parker, 2005; Steffen & Coyle, 2010). Sormanti and August (1997) reported that for the majority of bereaved parents, spiritual connections, for example, experiencing a sense of presence or dreams, brought reassurance and peace to help sustain them through their grief. It is possible that factors such as existing worldview and spiritual beliefs (Klass, 1999), type and quality of relationship prior to death, and emotional connectivity within the relationship might influence the bereaved's response to sense of presence occurrences and could in part account for the mixed findings.

### 1.4.3 Stillbirth and perinatal loss

*Then we went home and oh, to leave the hospital and not have the baby with us, I went home with wilted flowers and a backpack.*

(Mother, as cited by Lindgren, Malm & Radestad, 2013-2014, p. 340)

One of the most acutely poignant images of stillbirth projected by perinatally bereaved parents is that of leaving hospital without their baby, essentially empty-handed (Lindgren et al., 2013-2014). Historically, perinatal loss has been enshrouded in silence (Hazen, 2006; Layne, 1997), but the hushed, cavernous void that their baby's physical absence leaves in parents' lives is, for them, piercingly deafening and deeply felt.

## Impact on families

In the UK around 3065 stillbirths each year (MBRRACE-UK, 2018) leave bereaved parents desperately struggling to cope with this profound and devastating loss. A confounding convergence of life and death (Cacciatore, 2011), the traumatic experience of stillbirth can have considerable, pervasive intrapersonal and interpersonal consequences: physical, social, psychological, cognitive, spiritual, emotional and physiological (Barr & Cacciatore, 2007-2008; Burden et al., 2016; Cacciatore, 2013; Dyregrov & Matthiesen, 1991; Erlandsson, Saflund, Wredling & Radestad, 2011). The death of a child has generally been found to provoke more intense, enduring and complicated grief reactions than other types of bereavement (Zeanah, Danis, Hirshberg & Dietz, 1995). The psychological effects of stillbirth include an increased risk of depression, anxiety and posttraumatic stress disorder (PTSD) (Cacciatore, 2013; Campbell-Jackson & Horsch, 2014). Furthermore, stillbirth can negatively affect self-esteem and identity, with many women perceiving themselves to have failed in their familial roles, whilst fathers feel a sense of failure in their role as provider and protector (Burden et al., 2016). To further compound this unanticipated tragedy, many parents face these consequences largely in silence and isolation owing to persistent societal misperceptions (Cacciatore, Froen & Killian, 2013), stigma (Brierley-Jones, Crawley, Lomax & Ayers, 2014-2015), and non-validation of loss and parental grief (Cacciatore, DeFrain & Jones, 2008).

Evidently, the impact of stillbirth can threaten intrapersonal stability and psychological well-being (Cacciatore et al., 2013), but can also disturb interpersonal relations, as parents' internal struggles inform behaviour and interactions within relationships. One study found that women who experienced miscarriage or stillbirth have greater odds of divorce than women who have not experienced a loss, the chances of marital dissolution being especially high for women who have suffered stillbirth, indicating that stillbirth is particularly distressing and can have an immensely destabilising effect on relationships (Shreffler, Wonch Hill & Cacciatore, 2012). Gender differences in response to loss have been reported, with mothers expressing a greater intensity of grief than fathers, following both perinatal and post-perinatal loss

(Michon, Balkou, Hivon & Cyr, 2003), whilst fathers are inclined to attend to external demands (e.g. hospital protocol and funeral arrangements), and tend to preoccupy themselves with stoically supporting their partner, or trying to find solutions for recovery (Kelley & Trinidad, 2012; McCreight, 2004). Critically, partners' incongruent grief and divergent coping strategies may have a detrimental effect on communication within the relationship, which could potentially lead to disharmony if parents struggle to understand and respect their individual differences (Avelin, Radestad, Saflund, Wredling & Erlandsson, 2013). The consequences of stillbirth also extend beyond the parents, with reports of adverse effects upon other family members including siblings and grandparents (Burden et al., 2016).

**Bonds and memory-making**

Until the latter part of the 20th century, the medicalised relinquishing bonds model for understanding bereavement and grief, prevalent in UK society following the advent of Modernism, was reflected in the clinical management of stillbirth. As a result, stillborn babies were treated as medical anomalies or failures, hurriedly removed from parents, hidden out of sight, secretly disposed of and essentially unacknowledged by health professionals and society at large (Lovell, 1983). It was thought that this practice protected the parents from distress and the assumed psychological consequences that contact with their baby or mention of the experience would induce (Hughes, Turton, Hopper & Evans, 2002; Lasker & Toedter, 1994). The prevailing attitude encouraged parents to put the loss behind them and focus on their future (Hughes & Riches, 2003). In 1976, Dr Emanuel Lewis, a consultant psychiatrist challenged this detached, invalidating approach; feeling it impeded mourning he suggested that:

> …there is an added sense of unreality with stillbirth as there are no experiences with the baby to remember. Looking at and holding the dead baby, giving the baby a name, arranging the certification, attending the funeral, and knowing its grave help make stillbirth a reality for the family. (Lewis, 1976, p. 620)

Alice Lovell's (1983) seminal work providing insight into the management of perinatal loss at four London hospitals and mothers' perceptions of their loss experience, further supported this call for change. She uncovered a *hierarchy of sadness* with professionals viewing miscarriages and stillbirths as *lesser losses* than deaths of children who had lived. As such they were not considered "real" bereavements, and subsequently, mothers' loss experience was rarely acknowledged. Lovell (1983) suggested that such belittling and dismissive attitudes contributed to the detrimental deconstruction of baby's and mother's identity. Moreover, mothers were given little opportunity or choice regarding contact with their baby. Those mothers that had contact with their baby described it as an emotional but positive experience that had acknowledged and legitimated their baby's existence. It was thought that this opportunity to process memories, thoughts and feelings about their dead baby may have led them to a sense of acceptance of their loss which facilitated their grieving.

In recent years, the evolution of the continuing bonds paradigm within the field of bereavement has extended into the medical arena, and has further influenced transformation in stillbirth management. The Royal College of Obstetricians and Gynaecologists' (RCOG, 2010) guidelines for Late Intrauterine Death and Stillbirth state that carers should support parents' desires to have contact with and retain artefacts of remembrance of their stillborn baby but not persuade them to do so. Similarly, current National Institute for Clinical Excellence (NICE) guidelines on antenatal and postnatal mental health, published in 2014, advise clinicians to "discuss with a woman whose baby is stillborn /…/ and her partner, and family, the option of 1 or more of the following: seeing a photograph of the baby, having mementos of the baby, seeing the baby, holding the baby" (NICE, 2014a, p. 39). Sands, the Stillbirth and Neonatal Death charity, also advocates staff offering families culturally appropriate ways to create memories in their guidelines for professionals (Schott, Henley, Kohner & Hunter, 2016). As a result, participation in such rituals following their baby's death has become common practice for many bereaved parents in UK hospitals. Ritual can be broadly defined as "Any activity /…/ that includes the symbolic expression of a

combination of emotions, thoughts, and/or spiritual beliefs of the participant(s) and that has special meaning for the participant" (Castle & Phillips, 2003, p. 43). Rituals can mediate transitions and connections, enable expression of emotions and help validate, transform and give meaning to relationships with the dead (Romanoff & Terenzio, 1998). Moreover, they have been shown to aid bereaved parents, some of whom had experienced stillbirth, to re-assume a sense of control, to help them to continue bonds with their child, and to potentially facilitate positive transformative growth through memorialisation of their child (Cacciatore & Flint, 2012a). In essence, rituals can offer parents the opportunity to make precious memories and build valuable connections with their stillborn baby, whose physical presence is so tragically brief and so profoundly missed.

The majority of empirical studies relating to parents' bonds with their stillborn baby focus on parents' (predominantly mothers') participation in rituals or memory-making activities which take place in hospital in the immediate aftermath of the loss, and their subsequent mental health outcomes. To date, the results have been largely inconclusive (Hennegan, Henderson & Redshaw, 2015; Koopmans, Wilson, Cacciatore & Flenady, 2013). A number of studies have reported potential detrimental effects on parents of interventions such as seeing and holding their stillborn baby (Hughes et al., 2002; Hennegan, Henderson & Redshaw, 2018; Redshaw, Hennegan & Henderson, 2016; Turton, Evans & Hughes, 2009). In 2002, Hughes et al. reported that women who did not see or hold their baby had better psychological outcomes, both during and one year after a subsequent pregnancy, than those mothers who did see and hold their baby. Results from a recent study showed that holding their stillborn baby was associated with poorer mental health outcomes and greater relationship difficulties for mothers (Redshaw et al., 2016). Similarly, Turton et al. (2009) found that holding their stillborn baby was associated with subsequent partnership breakdown and higher scores on the re-experiencing and arousal symptom clusters for PTSD. Partners' short-term mental health outcomes and well-being may also be negatively impacted by holding the baby following stillbirth (Hennegan et al., 2018).

In contrast, numerous studies have evinced the positive effects of contact between parent and stillborn baby (see Kingdon, Givens, O'Donnell & Turner, 2015a). Seeing and holding their stillborn baby has been associated with fewer anxiety and depression symptoms for non-pregnant mothers (Cacciatore, Radestad & Froen, 2008), whereas not seeing baby for as long as wished and a lack of physical mementos increases mothers' risk of anxiety and depression related symptoms (Radestad, Steineck, Nordin & Sjogren, 1996). Moreover, having held the baby may be a protective factor for posttraumatic stress for mothers following stillbirth (Gravensteen et al., 2013). An online questionnaire study suggested that mothers responded better and felt more comfortable if the care provider engaged in *assumptive bonding*, as is the case with a live birth, by presenting the stillborn baby naturally to the mother without requiring her to choose whether or not to have contact with her baby (Erlandsson, Warland, Cacciatore & Radestad, 2013). Interestingly, Crawley, Lomax and Ayers (2013) highlighted the potential importance of opportunities afforded to parents to share memories of their baby with others. Whilst no association was found between memory-making and maternal mental health, regression analyses showed a relationship between memory-sharing and psychological outcomes, with more opportunities to share memories predicting better maternal mental health.

A Cochrane review (2013) concluded that due to a dearth of rigorous randomised trials in this area, the literature around the potential beneficial or adverse effects of interventions such as seeing and holding a deceased baby following perinatal loss, is inconclusive. However, a number of descriptive studies included in the review found that with the appropriate care and support, parents often perceived their experiences of contact with their baby as positive (Koopmans et al., 2013). A recent systematic review of parents' contact with their baby following stillbirth and subsequent mental health outcomes, also reported a mixed body of work, and again concluded that evidence of the potential impact of interaction with their baby on parents' mental health and wellbeing, was sparse, low-quality and inconclusive (Hennegan et al., 2015). Similarly, owing to contradictory findings and methodological weaknesses in the extant literature, a systematic review of a wider range of standard care

practices and interventions intended to improve parents' adjustment following stillbirth advised that the current evidence base is inadequate for the provision of definitive, reliable recommendations relating to care practices and interventions for bereaved parents (Crispus Jones, McKenzie-McHarg & Horsch, 2015).

Multiple explanations have been suggested to account for the variation in findings across the studies including: pregnancy status at the time of assessment, differences in gestational age, time between baby's death and delivery and subsequent appearance of the baby, and memory-sharing opportunities (Cacciatore et al., 2008b; Crawley et al., 2013; Crispus Jones et al., 2015; Radestad & Christoffersen, 2008; Ryninks, Roberts-Collins, McKenzie-McHarg & Horsch, 2014). It is possible that variations in measures used to assess mental health outcomes across studies, parents' emotional connectivity to their baby during pregnancy, parents' proclivity toward continuing bonds or attachment style could also be impacting upon results. Irrespective of the inconsistencies surrounding the impact of contact with their baby, typically, parents are satisfied with their decision to interact with them and engage in memory-making activities, with feelings of regret often surfacing for those who chose not to interact with their baby, or who had limited opportunity to engage in memory-making activities (Brierley-Jones et al., 2014-2015; Hennegan et al., 2015; Ryninks et al., 2014). Many parents have reported that the transient moments they share with their baby are important and helpful, as this time enables creation of memories and mementos of remembrance that sustain them through their grief, and create an enduring connection between parent and baby (Kingdon, O'Donnell, Givens & Turner, 2015b; Ryninks et al., 2014; Schott & Henley, 2009; Trulsson & Radestad, 2004).

**Perinatal loss and continuing bonds**

From the amalgamated findings of four qualitative studies exploring pregnancy following perinatal loss, Cote-Arsenault (2003) identified multiple ways in which parents remembered and actively incorporated their deceased babies into their post-loss lives. Parents remembered their babies by means of rituals

(e.g. saying prayers), symbols (e.g. a lit candle) and by creating a visible and tangible presence for them through associated artefacts (e.g. lock of hair). These mechanisms of memorialisation and remembrance enabled the baby to maintain a position within the family. Acts of remembrance could be experienced privately but sharing memories with others was considered an important factor for parents in integrating their deceased baby into their family life. However, some parents noted that there were not many places where they felt able to openly discuss their baby.

One study that has specifically considered the continuing bonds paradigm in relation to stillbirth is Murphy and Thomas's (2013) qualitative exploration of the strategies used by parents to retain bonds with their baby. The authors adopted a sociological approach to the subject that primarily considered family practices after stillbirth that facilitated parents' reinforcement of their relationship with their baby in the years following loss. Parents experienced bonds privately and domestically, and to a lesser extent within the public sphere. Privatised bonds were established through construction of an alternate biography for their baby had they lived, and via sense of presence experiences. Bonds extended into the family domain, and more tentatively beyond into the public domain, by means of sharing the baby's biography with others, through the display of artefacts of remembrance (e.g. photographs and ornaments), and attending memorial services. Barriers to display were also reported, including opposition from partners to exhibiting artefacts within the family domain, and social stifling of discussion relating to parents' experience of stillbirth. The authors concluded that continuing bonds through narrative display, and use of physical reminders or symbolic representations can be valuable strategies as they can reinforce parental roles, establish the baby's identity and place within the family, whilst also helping to raise awareness of the experience of baby loss more widely.

**Coping with stillbirth**

A number of other potentially influential factors appear in the literature relating to parents' ability to cope following stillbirth. Time since death has been reported as a predictor of mental health status, with more recent losses linked

to poorer outcomes (Cacciatore et al., 2008b; Crawley et al., 2013; Turton, Hughes, Evans & Fainman 2001). The importance of professional support for parents after their baby's death has also been highlighted (Cacciatore, Schnebly & Froen, 2009; Crawley et al., 2013; Murray & Callan, 1988). Crawley et al. (2013) found that mothers who reported a greater satisfaction with professional support had lower PTSD and depression scores. In addition to perceived professional support, social support could prove to be influential in coping with stillbirth. Positive social support and support satisfaction have been linked with lower levels of anxiety and depression (Cacciatore et al., 2009) and fewer reported PTSD symptoms (Christiansen, Elklit & Olff, 2013; Horsch, Jacobs & McKenzie-McHarg, 2015). Moreover, women who attended a support group after their stillbirth experience recorded fewer symptoms of PTSD, suggesting that sharing their experience may help mothers to better cope with their loss (Cacciatore, 2007).

**Approaches to care**

The actions, behaviours and attitudes of healthcare professionals can have a considerable impact on parents' ability to cope with stillbirth, and on the memories they form of their baby (Ellis et al., 2016). A recent review of research, guidelines and arguments surrounding best practice in bereavement care following stillbirth in high-income countries, such as the UK, also concluded that a flexible, individually tailored, patient-centred approach to care should be implemented (Bakhbakhi, Burden, Storey & Siassakos, 2017). Parents consider their interactions with professional caregivers to be vitally important to their experience of care (O'Connell, Meaney & O'Donoghue, 2016) and want staff to validate their emotions, provide clear information and support them through the decision making processes relating to their care (Peters, Lisy, Riitano, Jordan & Aromataris, 2015). Healthcare professionals should assume respectful, sensitive and empathetic communication whilst providing culturally appropriate care (Bakhbakhi et al., 2017). Effective, supportive bereavement care can not only help families adapt to their loss but can also facilitate staff to process their own feelings of distress and sadness (Homer & ten Hoope-Bender, 2016).

Furthermore, given the potentially wide-ranging and complex consequences of stillbirth, psychosocial support and therapeutic care can be central to parents' bereavement adaptation and long-term psychological outcomes (Cacciatore, 2013). Patient-centred psychosocial care has been proposed as a complementary practice to the traditional, more rigid clinical model of care. Humble, compassionate and intuitive communication underpins this approach to care following stillbirth (Cacciatore, 2010; Cacciatore & Flint 2012b). Cacciatore and Flint (2012b) argue that fostering a more mindfulness-based sensitive therapeutic environment, through application of this humanistic and empathetic framework, could reduce the symptomatology of complicated grief, and enable bereaved parents to experience positive, personal transformations, thus transcending their shattering losses.

Layne (2003), during her historical account of pregnancy loss in America, observed that for some parents of stillborn babies, nature can represent a redemptive, spiritually healing force. Parents' use of symbolism, analogy and metaphorical representations served to emphasise the transience of life, to find meaning in the wake of their devastating loss and to depict their own transformation through grief. Following a recent systematic review of experimental interventions following stillbirth, Huberty, Matthews, Leiferman, Hermer and Cacciatore (2017) highlighted a pressing need for further development and exploration of effective interventions to improve the mental, physical, emotional and social health of those affected by baby loss (Huberty et al., 2017).

## 1.5 Research rationale and aims

*The question of how humans both hold on and let go of those who have died is a worthwhile, and a grand problem in science. To a great extent, it still lies before us unresolved.*

(Klass, 2006, p. 857)

The literature review, conducted as part of this doctoral research, identified a paucity of studies which specifically examine continuing bonds following stillbirth. Murphy and Thomas's (2013) sociological approach to this subject highlighted issues of identity construction and family display. However, little is

known about the potential benefits of continuing bonds expressions, activities or rituals in relation to coping and mental health outcomes. The majority of studies in this area focus on parent-baby contact and memory-making activities which predominantly take place in the hospital in the immediate aftermath of the loss (e.g. Cacciatore et al., 2008b; Gravensteen et al., 2013; Hughes et al., 2002; Radestad et al., 1996; Redshaw et al., 2016). The findings of these studies are mixed and controvertible. Crawley et al. (2013) highlighted the potential importance of parents sharing memories of their baby with others in relation to mental health outcomes, suggestive of the social and intersubjective nature of adaptive continuing bonds, a topic at the forefront of recent discussion within bereavement literature. Therefore, the intention of this project is to expand upon the existing body of work by exploring in detail the ways in which parents continue bonds, that is, experience an ongoing relationship with their stillborn baby longer term, and consider how these strategies might be related to coping and bereavement adaptation. The social context in which parents conduct their relationship with their baby will also be examined. Parents' engagement in a broad range of continuing bonds expressions, activities and rituals over time will be assessed. Any association between certain expressions or characteristics of parents' relationship with their baby, their perceptions of social support for the relationship, and mental health outcomes will be examined. It is intended that by delivering a more detailed insight into continuing bonds following stillbirth, this project will make a valuable and original contribution to the evidence base.

The experiences of bereaved parents who do not continue bonds with their stillborn baby are not addressed in the current research. As previously stated, the intention of the theorists who presented the continuing bonds paradigm was not to replace one dominant model with another. Rather, it was to demonstrate an alternative and potentially adaptive way of responding to bereavement (Klass, 2006). In a similar vein, whilst the focus of the current thesis is parents who continue bonds with their stillborn baby and how aspects of this relationship might be beneficial to coping, it is in no way intended to marginalise or devalue the experience of bereaved parents who do not maintain ties with their stillborn baby.

## 1.6 Methodological approach

This thesis comprises two studies. Chapter 2 details the first phase of the project, Study 1 “Continuing bonds following stillbirth” which is purely qualitative. The aim of the first phase was to identify key themes in parents’ narratives relating to their ongoing relationship with their baby, and how the relationship might aid coping. The second phase, Study 2 “Continuing bonds and bereavement adaptation” is presented in Chapter 3. Whilst mixed methods were employed in Study 2, it is predominantly quantitative. In phase 2, key aspects of the parent-baby relationship identified in Study 1 were further examined with a larger sample, and operationalised in order to analyse any association between continuing bonds expressions and parents’ mental health outcomes. Taking advantage of a valuable opportunity to collect data for an external study (not reported here), qualitative data relating to parents’ engagement with nature was also collected during the project. Each individual study chapter outlines the specific methodological approach and design chosen, and provides details of ethical considerations, recruitment, data collection, data analysis and interpretation of findings. Moreover, Chapter 4 includes a “Methodological reflection” section where these approaches are evaluated and the role of the researcher in the production of the findings is considered.

Characterised by deductive reasoning, rationality and researcher objectivity, quantitative research’s stringent, systematic methods allow for analysis of causal and correlational relationships between variables and facilitate explanation of data through prediction and control of phenomena. Underpinned by positivist and post-positivist philosophies such methods have dominated psychological inquiry for over 150 years (Ponterotto, 2005). However, it has been noted that prominent figures such as Freud and Piaget effectively used qualitative interviews to further psychological knowledge (Willig & Stainton-Rogers, 2008). Qualitative research, typically associated with interpretive and constructivist epistemologies (Yardley & Bishop, 2008) is exploratory and dynamic, and considers how people make sense of the world and their experiences within their socio-cultural environment, with the researcher an accepted part of the knowledge generating process (Corbin &

Strauss, 2015; Willig, 2013). As such, it is particularly valuable when the subject under investigation is under-researched as is the case for continuing bonds following stillbirth.

Combining quantitative and qualitative methods, as is practised in the current project, in order to take advantage of their varied strengths has become increasingly prevalent and popular in recent years within psychology (Povee & Roberts, 2015). Mixed methods has been defined as a research method which "focuses on collecting, analyzing, and mixing both quantitative and qualitative data in a single study or series of studies" (Creswell & Plano Clark, 2007, p. 5) with a view to achieving "breadth and depth of understanding and corroboration" (Johnson, Onwuegbuzie & Turner, 2007, p. 123). It can provide the most complete analysis and subsequent understanding of human behaviour (Creswell & Plano Clark, 2007; Yardley & Bishop, 2008).

Questions have been raised relating to how best to reconcile the contrasting worldviews of quantitative and qualitative methods (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 1998). It is argued that by adopting a pragmatic approach the ontological and epistemological disparities between interpretivist/constructivist and positivist/post-positivist philosophies can be deconstructed and resolved (Yardley & Bishop, 2008). Essentially, by adopting a pragmatic approach, belief in knowledge and judgement of its value are determined not by its truth or falsehood but by its usefulness and applicability in relation to achieving goals (Charon, 1995). Pragmatists consider the research question to be of primary importance, therefore, if the chosen methodology is useful and works in the given situation/study to successfully answer the research question and bring about positive consequences within the field, then any potential philosophical tension should be resolved (Tashakkori & Teddlie, 1998).

Mixed methodology has been employed widely and to good effect in studies of general bereavement, child bereavement, pregnancy and childbirth, and infant and perinatal loss, across multiple disciplines within academic and health care research (e.g. Cacciatore, 2007; Cacciatore, Blood & Kurker, 2018; Cote-Arsenault & Donato, 2011; Dyregrov & Gjestad, 2011; Favrod,

Holmes, Vial, Morisod Harari & Horsch, 2018; Foster et al., 2011; Keesee, Currier & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer & Keesee, 2010; Nuzum, Meaney & O'Donoghue, 2018; Rubin & Shechory-Stahl, 2012-2013; Vale-Taylor, 2009). Both Neimeyer and Hogan (2001) and Stroebe, Hansson, Stroebe and Schut (2001b) have promoted methodological pluralism in bereavement research, specifically the use of in-depth qualitative investigation prior to quantitative assessment. Moreover, it has been argued that future research into continuing bonds would benefit from integrating qualitative and quantitative methods in order to improve understanding of the topic (Foster et al., 2011) and to examine the frequency and personal experience of diverse continuing bonds expressions (Root & Exline, 2014). Thus, in order to affect a full and rigorous exploration of the characteristics of parents' relationship with their stillborn baby, and the ways in which the relationship might be helping them to cope, the researcher adopted a pragmatic stance and employed mixed methodology during the project. Specifically, a multiphase triangulation mixed methods design was employed (Creswell & Plano Clark, 2007). Data from the qualitative and quantitative phases/studies were collected and analysed separately. The results from both studies were then integrated to enhance understanding of continuing bonds following stillbirth.

An array of terms are used within the bereavement literature in relation to dealing with bereavement and managing grief. Examples include: *coping*, *adaptation*, *adjustment*, *resolution*, *healing*, *recovery* and *equilibrium*. Most are commonly and often interchangeably used in the literature and can incorporate both the process of dealing with a stressful or difficult situation (i.e. bereavement), and the associated outcomes. Some authors are explicit in their definition of the terms used and how they may be quantified, for instance, Stroebe and Schut (2010) specifically refer to coping as the process of managing the loss and adaptation as the outcome. Whereas, many authors are less explicit about the application and quantification of terms, for example, Klass (1996b) describes equilibrium as "difficult to measure, but easy to subjectively sense" (p. 200). As a result, these terms are used flexibly in this way during the current research and thesis. However, *coping* was predominantly used in Study 1 during interviews by both the researcher and

participants as a generic, accessible term that allowed for exploration and identification of a number of aspects of parents' continuing bonds experience which they had found to be helpful. *Bereavement adaptation* was predominantly used in Study 2 to represent parents' outcomes as measured by mental health status (i.e. presence of anxiety, depression and PTSD symptoms) and posttraumatic growth scores.

Klass's (1996b, 2006) psychosocial theory of continuing bonds underpins the project as a whole. This theoretical paradigm covers bereaved parents' construction of mental representations of their child, transformation and consolidation of these mental representations through sharing with others, integration of the child into parents' ongoing life, and the potential for parents' transformative, personal growth. These aspects of continuing bonds are evident in the data collected, as a result, this theoretical framework spans the thesis, and is utilised predominantly as a basis from which to discuss and explore the core emergent themes, and results. To date, Klass has delivered the most comprehensive framework that specifically addresses the journey of bereaved parents over time, and emphasises the importance of social context. In these aspects it aligned well with the aims of the current research and was deemed an appropriate and useful point of reference. As continuing bonds encapsulates a plethora of diverse concepts, various other relevant frameworks are introduced to aid explanation of the data and provide a more in depth exploration of the primary constructs at play, for example, theories of meaning-making (e.g. Kunkel et al., 2014), the Dual Process Model of coping with bereavement (Stroebe & Schut, 1999), and Attention Restoration Theory (Kaplan & Kaplan, 1989).

### 1.7 Summary

The continuing bonds paradigm suggests that bereaved parents can adapt to the loss of their child by sharing and transforming mental representations of the child, allowing them to be integrated into the parent's everyday life and wider support systems. Few studies investigate continuing bonds following stillbirth, and little is known about the potential mental health benefits of expressing continuing bonds. The majority of studies in this area focus on

parent-baby contact and memory-making activities which occur in hospital in the immediate aftermath of the loss. The findings of these studies are inconclusive although there is evidence that sharing memories of the baby is related to better maternal mental health. Therefore, the intention of this project is to explore how parents continue bonds with their stillborn baby longer term, and to examine any association between key aspects of the parent-baby relationship, parents' perceptions of social support for the relationship, and bereavement adaptation. The first phase of the project, Study 1 "Continuing bonds following stillbirth", which explores parents' experience of an ongoing relationship with their stillborn baby using qualitative methods, is presented in the following chapter.

# Chapter 2 Study 1 Continuing bonds following stillbirth

*Through our stories, our children live and we heal.*
(Mother, cited by Cacciatore & Bushfield, 2007, p. 71)

## 2.1 Chapter overview

This chapter reports the first study which explores perinatally bereaved parents' relationship with their stillborn baby. The various ways in which parents continue bonds with their baby over time and the characteristics of the relationship are analysed. Interviews with parents of stillborn babies revealed five main themes which are presented and evidenced by participant quotations. Parents' experience of constructing and maintaining a relationship with their baby, and sharing it with others is examined. Moreover, strategies used by parents to cope, manage their grief and integrate their baby into their ongoing life are explored and discussed. The findings are interpreted in light of relevant available literature and conclusions drawn.

## 2.2 Introduction and rationale

Klass (1996b) suggested that bereavement adaptation could be achieved by parents through transformation of mental representations of the child, which when shared with others, allows successful integration of the child into the parent's ongoing life and wider social support systems. In essence, it is acceptance and integration, as opposed to denial and severing of bonds, which can potentially engender parents' adjustment to loss and transformative, personal growth. As discussed in Chapter 1, continuing bonds was a notable departure from the traditional Western theoretical paradigms promoting emotional disengagement from the deceased. Some have conceptualised continuing bonds predominantly in terms of an intrapsychic relationship with the deceased (Field, Gal-Oz & Bonanno, 2003; Shuchter & Zisook, 1993; Schut, Stroebe, Boelen & Zijerveld, 2006). However, there is a growing body of work which argues that expressions of continuing bonds are not merely mental constructs and are as much an external, social practice as an internal, cognitive process (Klass, 1996b, 2006; Klass & Steffen, 2018b; Valentine,

2008; Walter, 1996). Arnold and Gemma (2008) reported that parents who had experienced the death of a child (age range: birth to 48 years) appreciated communicating with others about their loss, finding it both strengthening and gratifying. Moreover, bereaved mothers have reported continuing a relationship with their deceased child in a number of ways, be it through tending to the grave and the child's remains, linking objects, or integrating a symbolic representation of the child into their daily lives. More socially acceptable symbolic representations of the child were interpreted by the authors as being more adaptive (Harper, O'Connor, Dickson & O'Carroll, 2011).

Informal rituals such as collecting mementos and photographs following stillbirth are now standard practice within UK hospitals, and are thought to be positive ways of forming lasting memories that validate the child's existence and integrate him or her into the family's narrative, define parental roles, construct meaning, and subsequently facilitate parents' bereavement adaptation (Capitulo, 2005; Godel, 2007; Kobler, Limbo & Kavanagh, 2007; Layne, 2003). In addition, creating online memorial websites (De Vries & Rutherford, 2004; Finlay & Krueger, 2011; Mitchell, Stephenson, Cadell & MacDonald, 2012), attending peer support groups (Klass, 1996b; Reeves & Boersma, 1989-1990), research participation (Kobler et al., 2007) and talking about the deceased in general (Lovell, 1983) can be considered informal rituals which allow bereaved individuals to openly express, and maintain, a meaningful connection to their lost loved one.

There is a paucity of studies which specifically examine continuing bonds following stillbirth. Murphy and Thomas's (2013) sociological approach to the subject highlighted issues of identity construction and family display. Parents of stillborn babies were reported to use physical artefacts and symbolic representations in a private setting, and more tentatively, in the public sphere, in order to construct and legitimise their baby's identity, and develop the child's biographical narrative within the family context. The overwhelming majority of studies in this area focus on a specific aspect of the relationship, predominantly parents' interaction with their baby during engagement in

memory-making activities, which take place in hospital in the immediate aftermath of the loss (see Hennegan et al., 2015). Debate continues as to whether this contact between parents and their stillborn baby is helpful or otherwise. In response to gaps and inconsistencies in the literature, this qualitative study provides a broader analysis of the degree to which parents conduct an ongoing relationship with their stillborn baby over time, the strategies used to facilitate this continuity, and parents' perceptions of the value of this relationship as a potential aid to coping, in order to increase understanding of the entire continuing bonds process over time following stillbirth.

### 2.2.1 Aims

The primary objectives of the study were to explore:

1. How parents continue bonds with their baby long term following stillbirth.
2. The characteristics of any ongoing relationship and changes over time.
3. How bonds might be shared with others.
4. Parents' perceptions of the value of continuing bonds, and how their ongoing relationship may be helping them to cope.

## 2.3 Methodology

### 2.3.1 Design

This study employed an exploratory qualitative research design informed by Grounded Theory (Charmaz, 2006, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Parents' experience of continuing bonds with their stillborn baby was investigated during semi-structured interviews.

### 2.3.2 Participants

Participants were aged 18 years or over and were parents of stillborn babies (i.e. ≥ 24 weeks' gestation) who felt they had an ongoing connection to their baby. Two participants were in a marital relationship with each other.

### 2.3.3 Recruitment

Parents were recruited with the help of Sands (Stillbirth and Neonatal Death Charity). An official request for assistance with participant recruitment and advertisement of the study was made to UK Sands' national headquarters prior to commencement of the study. This request was approved and Sands agreed to provide support for the duration of the project. A contact letter (Appendix A) was sent to a number of Sands' support groups to ascertain their willingness to help with recruitment. The researcher liaised with a designated support officer at Sands' headquarters and subsequently built valuable connections with local support group facilitators who promoted the study, both verbally and via social media platforms, and assisted in securing participants.

### 2.3.4 Sample characteristics

Sample characteristics are shown in Table 1. Predominantly, participants were female, British and married or living with a partner. Time since baby's death spanned a broad range from less than one year to over 22 years, and most participants were parenting other children at the time they took part in the study. Seven participants were employed by, or volunteered for Sands.

Table 1. Sample characteristics (*N* = 12)

| | | No. | % |
|---|---|---|---|
| Gender | Female | 9 | 75 |
| | Male | 3 | 25 |
| Education | Postgraduate or professional qualification | 6 | 50 |
| | University or college degree | 3 | 25 |
| | Further education, upper/lower secondary | 2 | 16.5 |
| | None of the above | 1 | 8.5 |
| Marital status | Married or living with partner | 12 | 100 |
| Ethnic origin | White British | 12 | 100 |

| | | No. | % |
|---|---|---|---|
| Religion | Christian | 8 | 67 |
| | No Formal | 4 | 33 |
| No. of children before stillbirth | 0 | 8 | 67 |
| | 1 or more | 4 | 33 |
| No. of children since stillbirth | 0 | 2 | 16.5 |
| | 1 or more | 10 | 83.5 |
| Baby died | Before labour | 8 | 67 |
| | During labour | 2 | 16.5 |
| | Undetermined | 2 | 16.5 |
| Age of parent (years) | 25-34 | 1 | 8.5 |
| | 35-44 | 9 | 75 |
| | 45-54 | 2 | 16.5 |
| Gestational age of baby (weeks) | Range | 33-44 | |
| | Mean (*SD*) | 39 (2.98) | |
| Time since baby's death (years:months) | Range | 0:08-22:01 | |
| | Mean (*SD*) | 7:05 (5.77) | |

### 2.3.5 Ethical considerations

Stillbirth is a highly personal and acutely sensitive research area. As such, the welfare and well-being of participants during the course of recruitment and data collection, and following participation was of primary concern and importance to the researcher. Support and advice from Sands' employees and an independent parent representative who had experience of neonatal death was sought to help guide and inform interactions with parents. Electronic data was stored securely on the researcher's password protected PC, with hard copies of data being stored in a locked filing cabinet solely accessible by the researcher. Ethics approval for the study was granted by the University Research Ethics Committee (UREC) on 05/01/15 (see Appendix B).

### 2.3.6 Procedure

Potential participants instigated initial contact with the researcher via email or text message to register their interest in taking part in the study. The study information sheet (Appendix C) providing additional details/contacts, and outlining what would be required of parents should they choose to participate, was sent at this stage. Once confirmation of their desire to take part was received, the researcher liaised with parents to formalise arrangements for discussions. This initial interaction helped to build familiarity and rapport between the researcher and parents. If parents did not follow up on their initial contact, following receipt of the information sheet, one further attempt at contact was made and if no subsequent response was received, parents were not approached again. Prior to participation, all parents were required to complete and return a consent form (Appendix D) and provide personal details (Appendix E). The consent form offered parents the choice of whether to participate in a focus group with other parents of stillborn babies, or an interview with the researcher. No parent specifically requested participation in a focus group, so all data was collected via one-to-one interviews. Parents were given the opportunity to ask any questions during this initial interaction. All participants met the inclusion criteria, that is, they were 18+ years old and had a stillborn baby at 24 weeks or later, and were willing to discuss any ongoing relationship with their baby.

### 2.3.7 Interviews

Data collected via one-to-one, semi-structured interviews was used to identify general themes pertaining to continuing bonds following stillbirth. The researcher interviewed 12 parents over a 6 month period. Seven interviews took place in person (five in participants' homes, one at participant's place of work, one at university) and five conducted over the telephone. The location of the interview, and mode of discussion (i.e. whether it was face-to-face or by telephone), was determined by the participant. The two participants who were in a marital relationship with each other were interviewed separately some weeks apart. It is not thought that their relationship had an undue effect on the

study's findings as their overall experience of continuing bonds with their baby differed considerably.

Interviews were relatively informal and conversational in style to create a relaxed, safe, supportive and enabling environment in which parents could share their highly emotive experiences. Before each interview, participants were advised that they could stop at any time, and were reassured that everything they talked about was relevant, valuable and confidential. Although a number of specific subject areas and discussion prompts had been noted by the researcher prior to interview, the primary intention was to allow parents to dictate the flow of conversation by focusing on the personally significant aspects of their ongoing relationship with their baby. Parents were initially invited to talk about any relationship they had with their stillborn baby and how they felt and expressed it. Further questions were drawn upon from the interview schedule (Appendix F) where appropriate to the content of parents' responses, whilst impromptu questions were used to probe topics significant to parents and to help conversation maintain a more natural flow. Thus, the interview schedule was utilised flexibly to facilitate the organic emergence, identification and development of areas of interest and importance to parents (Charmaz, 2006). Identification of these salient topics during interviews led to a more detailed exploration of the full scope of these themes as discussions developed. As the interview schedule was used flexibly, and the researcher often reacted to parents' comments with naturalistic and impromptu questions there was no requirement to make significant amendments to the content of questions in the schedule after each interview.

In light of Layne's (2003) observations about the prominence of nature references within the perinatal loss community, as mentioned in Chapter 1, the interview schedule also included a question relating to parents' engagement with nature with a view to exploring this subject further if it was mentioned by parents. This question was only asked if parents made reference to nature spontaneously during the course of discussions. Interviews lasted between 38 and 70 minutes and were audio-recorded. All interviews were transcribed verbatim by the researcher. A debrief sheet (Appendix G) was sent to each

participant following their interview to thank them for their valuable contribution and to reiterate contact details for relevant support organisations.

### 2.3.8 Data analysis

#### 2.3.8.1 Approach

Qualitative research excels at revealing the processes and contexts which influence people's experience of everyday life (Barbour, 2014), therefore, it was deemed the most appropriate research method for the first study to enable primary, fluid, data driven exploration of parents' experience of continuing bonds with their stillborn baby. Data analysis was informed by Grounded Theory (Charmaz, 2006, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1990). By employing systematic analysis techniques in order to explore how people construct actions, intentions and associated meanings, its application in psychology can provide a useful conduit between positivist and interpretive methods, and deliver insight into the development, maintenance or transformation of individual and interpersonal processes (Charmaz, 2008). The constant comparative method of analysis used in Grounded Theory involves comparing data with data at every level of the analytical process thus allowing theorists to "reveal the properties and range of the emergent categories and to raise the level of abstraction of their developing analyses" (Charmaz, 2014, p. 342). Completed analyses should then be compared with relevant theoretical conceptualisations within the extant literature (Charmaz, 2012). Grounded Theory methodology can be especially useful where directly relevant literature is limited (Lancaster & Palframan, 2009). This approach was deemed to be particularly appropriate due to a dearth of existing literature specifically addressing continuing bonds and stillbirth; essentially it allows for theoretical concepts to be built inductively from the data.

Traditionally, Grounded Theory (Glaser & Strauss, 1967) was solely inductive and advised starting with *tabula rasa* or a clean slate to ensure the researcher's analytical and conceptual ideas were not biased by preconceived notions gained from the existing literature base (Flick, 2018). Evidently, it was not possible to approach the current study with *tabula rasa* as it is not workable

for doctoral research. A thorough review of the literature must be executed before starting the PhD programme to allow for the development of a sound research proposal and to ensure the research undertaken will deliver an original contribution to knowledge. Later variants of grounded theory, for example, Strauss and Corbin's (1990) version and Charmaz's (2006; 2014) constructivist grounded theory are more flexible approaches and incorporate both inductive and deductive strategies (Flick, 2018). As a result, the current study was predominantly informed by these later variants. Furthermore, constructivist grounded theory acknowledges subjectivity and the role of the researcher in the construction and interpretation of data which is congruent with the researcher's own views on the subject (see Chapter 4, Methodological reflections). It is largely underpinned by a social constructivist perspective which views the acquisition and understanding of knowledge as being inextricably linked to one's social existence (Charmaz, 2014).

Interpretative Phenomenological Analysis (IPA) was also considered during the design stage as a potentially useful approach to the current research. However, it was felt that IPA is more focussed on the lived experience of the individual, whereas constructivist grounded theory predominantly focusses on social processes. Constructivist grounded theory's emphasis on social context and interaction in the production of knowledge better aligns with the intersubjective nature of the continuing bonds paradigm.

#### 2.3.8.2 Levels of analysis

During first level analysis the researcher conducted open, line by line coding on each transcript thus generating hundreds of preliminary codes; this was followed by more focused coding, and repetitive re-analysis and iterative comparison of transcripts as new codes were generated. Second level analysis involved a detailed review of all codes which enabled numerous codes to be subsumed into broader concepts. All codes/concepts were then arranged into provisional themes and sub-themes, and transcripts analysed a further time, being particularly mindful of exceptions or atypical data that would allow comprehensive development of the dimensions and properties of each theme. A third level of analysis consisted of axial coding, during which the

main themes and sub-themes were further considered to determine how they were connected relationally, and to develop an extensive, detailed representation of the full continuing bonds experience. Members of the supervision team performed credibility checks on a sample of transcripts. Moreover, developing themes were discussed at length by the researcher and supervision team over the course of the analytical process; this ensured rigour and comprehensiveness of interpretation. As a result of this systematic process, five overarching themes emerged: *Constructing and maintaining a relationship, Negotiating the social landscape, Journeying with grief, Developing coping strategies* and *Establishing a "new normal"*.

#### 2.3.8.3 Participant quotations

Participant quotations are used in this chapter to evince themes identified during Study 1. All personal and place names were removed from quotations to ensure anonymity. A unique signifier appears in brackets after each quotation to confirm its source. Appendix H (Table H1) provides details of age, gender and time since baby's death for all participants. A number of linguistic notations have been used in the presentation of quotations. Ellipsis points /…/ within quotations denote omitted material. Any additional information deemed necessary to clarify a participant's remarks has been added by the researcher and appears in square brackets [ ].

## 2.4 Findings and discussion

All five themes and associated sub-themes are presented and discussed, supported by participant quotations, in the following section. Table 2 provides an overview of main themes and sub-themes.

Theme 1 *Constructing and maintaining a relationship* examines the ways in which parents try to build upon prenatal bonds, as they seek to nurture and define the parent-baby relationship in the aftermath of loss. Moreover, it depicts how parents experience the relationship and identifies some of its core characteristics. Theme 2 *Negotiating the social landscape* explores how parents share their continuing bonds with their baby more broadly with others and examines social responses to the relationship. Theme 3 *Journeying with*

*grief* addresses parents' various experiences of grief and their efforts to reconstruct meaning following the devastation of their baby's death. It also considers how time influences parents' loss experience and the ways in which they express their relationship with their baby. Theme 4 *Developing coping strategies* investigates a number of key coping strategies adopted by parents which they found helpful. Theme 5 *Establishing a "new normal"* assesses the evolution of parents' continuing bonds with their baby as the relationship becomes more established and integrated longer term, and considers some of the consequences associated with their loss experience.

Table 2. Emergent themes and sub-themes

| Main themes | Sub-themes |
| --- | --- |
| **Constructing and Maintaining a Relationship** | Attachment Prior to Birth<br>Creating and Evoking Presence<br>Communication |
| **Negotiating the Social Landscape** | Wanting to Share<br>Silence<br>Disclosure |
| **Journeying with Grief** | Managing the Pain<br>The Influence of Time<br>Searching for Meaning<br>Male Grief |
| **Developing Coping Strategies** | The Solace of a Continuing Bond<br>Engaging with the Natural World<br>Reflective Writing |
| **Establishing a "New Normal"** | Integrating Baby into Ongoing Life<br>Legacy Building and Posttraumatic Growth<br>Effect on Subsequent Pregnancies and Parenting<br>Ongoing Management and Reflexivity |

### 2.4.1 Constructing and maintaining a relationship

Klass (1996b) posited that parents' mental representations (i.e. thoughts, memories, associated emotions) play an integral role in the development of continuing bonds and parents' adjustment to child bereavement. Accordingly, parents' continuing bonds narratives in the current study provided insight into the many ways in which they created and evoked mental representations of their baby and attempted to construct and maintain a meaningful relationship with them in their internal and domestic worlds. Moreover, data revealed a number of interesting characteristics of the developing relationship. Three sub-themes are discussed which contribute to a comprehensive and nuanced picture of the relationship: parents' attachment to their baby prior to birth; how baby's presence is created and evoked, and communication between parent and baby. A summary to outline the salient points raised concludes this and each subsequent main theme.

#### 2.4.1.1 Attachment prior to birth

Traditionally, the term *attachment* has been applied to a specific concept within developmental psychology, underpinned by Bowlby's (1969/1982) attachment theory. In this context, attachment refers to the postnatal development of a relationship between primary caregiver and child which functions to establish a safe, stable and secure base, and it has commonly been assessed by observing parent and infant behaviours during a period of separation. Recently, it has become more common, and increasingly acceptable to use the term as an alternative to bonding, and it can be used in reference to antenatal parental attachment (Redshaw & Martin, 2013). It is used more broadly in this way in the current research.

Whilst the majority of the attachment literature focuses on bonds which develop between mother and baby during the neonatal period, there is a growing interest in the prenatal period and the mother-foetal relationship (Brandon, Pitts, Denton, Stringer & Evans, 2009). It is suggested that parents establish prenatal bonds and start to conceptualise their unborn baby during pregnancy (McFarland et al., 2011; Salisbury, Law, LaGasse & Lester, 2003;

Sandelowski, 1994; Siddiqui & Hagglof, 2000; Zeanah, Keener, Stewart & Anders, 1985). In the findings of the current study reported here, parents were keen to stress that attachment to their baby developed prior to birth. Emotional, physical and psychological bonds were forged with their baby during the course of the pregnancy, as parents, especially first time parents, anticipated imminent changes to their lives and themselves during their journey toward parenthood. Reflection on these prenatal bonds and the memories associated with the pregnancy may be particularly pertinent to the parents of stillborn babies as they are representative of time spent with their baby when he or she was alive. Therefore, it is unsurprising that the importance of the prenatal period and the course of the pregnancy is magnified following their baby's death. For parents who have so few memories available of their baby's physical presence to draw upon, interactional memories from this period are especially precious as they constitute a significant part of their baby's biography.

Parents devoted themselves to preparing for the arrival of their baby and their imminent parenthood. Complete commitment to the pregnancy and investment in their role as parent was evident. First time parents in particular spoke of seeking information and reading books about parenthood to try to ensure that they were fully equipped to successfully perform their parenting role. The psychological transition from non-parent to parent had been in progress for the duration of the pregnancy, this was not a process that could be abruptly halted or reversed once their baby had died. The formative bonds of a relationship with their baby had been created and would transcend their baby's death.

> *I think for us because* [baby] *was our first baby and our first experience of pregnancy and that kind of preparing yourself to be a parent, and I think the devastation is the fact that you've gone so far down the line of expecting to be a parent and then that's not there, and you're already ready to do it, and then all of a sudden the opportunity isn't there and they're gone, and you're just left with all this stuff inside you about, I was about to do this, my whole life was about to change and I've got all*

*this love to give you, and you know you've talked to them whilst they're inside you, you've had all these expectations about how it was going to be, and then they're not there, and actually it doesn't go away, because you've already done, I don't think you realise until you've done it that you've been on a massive journey in that 9 months towards parenthood, and that doesn't go away really…* (Participant 10, Mother)

How mothers and fathers develop attachments to their baby may differ. As mothers' experience of pregnancy is biological and physiological, it is argued that they develop more profound attachment feelings and commitment to their babies early during the prenatal period than do fathers (Peppers & Knapp, 1980). Foetal movement, the symbiotic nature of pregnancy, and childbirth, may consolidate the reality of the child's existence for the mother, as the baby becomes embedded within her, physically, and psychologically, as she assimilates her growing child and the expectations invested in this new life into her changing identity and developing parental role. By contrast, fathers' conceptualisation of the baby and emotional attachment tend to be stimulated by visual representations, such as ultrasound scans (McCreight, 2004), and may develop over a longer period of time. This theoretical notion is reflected in the following father's admission that he had required the full pregnancy period to adapt to the physical reality of the baby.

*I mean I think it took me the whole 9 months for me to get ready for him coming* [laughs]*, it was very important to me to feel that I was going to do a really good job as a dad /…/ sort of put some work in to try and prepare myself and sort of think about … just trying to get my head round what was, and I think what happened was over that period he gradually became an actual person rather than a kind of theoretical idea, and there were some keys moments, particularly like, sort of feeling him move and so on, and as he got sort of bigger in* [wife]*'s tummy then you know, there's a little person in here…* (Participant 7, Father)

Significantly, the father's observation of his wife's bodily changes and the physical, tactile connection with his baby on feeling him move, sparked the

gradual evolution from illusive idea to tangible reality, and crystallised the growing conceptualisation of his baby.

This mother reports a similar trajectory for her husband's attachment to their baby, again highlighting possible differences in the ways mothers and fathers form attachments to their unborn baby. Her sense of attachment was immediate and inherent, whereas she perceived her husband's to develop gradually, prompted by observable changes.

> *…I was attached from the minute I found out I was pregnant, whereas he only got attached to* [baby] *because obviously he could see my belly moving and we'd had the 4D scan, so he had the attachment that way, because they don't feel like you know, thinking about them, planning, watching what I ate, watching what I drank, watching how I bent, you know like, absolutely everything, whereas they go to work and think about you being pregnant when they see your belly change or you know, they don't think constantly about the pregnancy, and I think it must be hard but I think after they'd had a scan, because I think then the father probably gets that little bit of attachment, then there's something tangible.* (Participant 9, Mother)

Some parents imbued the growing foetus with its own unique character whilst in utero. Interaction between parent and baby served to develop the baby's identity as an individual entity with specific personality traits. As the following mother stresses, both she and her husband began to form a relationship with their unborn baby during pregnancy, a relationship that for them would inevitably continue beyond his death.

> *…he was our baby, we held him, we cuddled him, we kissed him, we sang to him, we had a relationship with him while he was in my tummy and he liked certain things and he had his own personality, he liked certain songs and he was always, when* [husband] *spoke to him he'd kick loads, and there were relationships there, so it's like why do we have to let that go just because he's not here, so it's really, really important to us to keep that going.* (Participant 4, Mother)

It has previously been reported that bereaved parents grieve not only for the loss of their child, but also for the loss of an anticipated future (Cote-Arsenault, 2003; Rosenblatt, 1996). Long before the devastating confirmation of their baby's death, parents in the current study had been constructing an imagined future life with their baby. As a result, the repercussions of the loss are not solely rooted in the past and present, but project in to the future as parents reflected upon a life with their baby which tragically they had been denied.

> *Erm, you dream of all the things that you're gonna do, you know, hear them say 'Mam', take them to school, and all them milestones don't occur.* (Participant 2, Mother)

It has been suggested that the confirmation of a baby's death breaks the bond established during pregnancy (see McGuinness, Coughlan & Power, 2014). However, this was not the case for the parents in the current study. The prevalence of pregnancy related rituals such as baby showers, and the growing *anthropomorphisation* of the unborn foetus in contemporary Western culture, which encourage attribution of human qualities and individualised characteristics and personhood (Kofod & Brinkmann, 2017), may influence parents' perceptions of their unborn baby as a unique person, and their subsequent inclination toward continuing bonds. As evidenced in the coming examples, for the parents in this study, bonds engendered prenatally not only remained intact, but were further developed and strengthened after death.

#### 2.4.1.2 Creating and evoking presence

Death removes the physical, embodied presence of a loved one from the survivor's life but does not necessarily signify the end of the relationship between the deceased and the bereaved (Root & Exline, 2014). Parents who have lost a child to cancer have reported that the loss of their child's physical presence is significant and keenly felt (Barrera et al., 2009). Valentine (2008) suggested that the bereaved can manage the painful paradox of the deceased's absence/presence through engagement in ritualised activities and memorialisation, thus materialising their loss. Material objects, mementos and keepsakes associated with pregnancy and perinatal loss can act as "traces of

the body" (Layne, 2003 p. 126), evoking the absent baby's presence and providing physical evidence of the baby's existence which can be displayed and cared for, thus consolidating and normalising the parental role. Moreover, memories can be stimulated, created and sustained through interaction with this material evidence (Hallam & Hockey, 2001; Hockey, Komaromy & Woodthorpe, 2010a; Layne, 2003; Radley, 1990; Riches & Dawson, 1998). For the parents of stillborn babies, physical interaction with their child is fleeting, and their reservoir of memories relatively limited. Therefore, they may be more reliant on material representations of their lost loved one than those who experience other types of bereavement. Whilst nothing could compensate for their loss, parents in the current study discussed a plethora of ways in which they appeared to create and evoke presence psychologically and physically, and materialise their baby. Continued parenting of their baby was observed as parents determined to keep their baby's memory alive and to love and care for their baby, affirming his or her significance in their ongoing life. Regret at opportunities missed to interact with their baby and to form memories was also evident.

In response to their baby's embodied absence, parents materialised their baby through engagement in rituals, including acts of memorialisation, and symbolic representations, thus creating visible and tangible evidence of their baby's existence and sustained presence. Engaging in rituals can bring positive outcomes and a sense of confidence in their ability to cope to bereaved individuals (Castle & Phillips, 2003). Easily integrated into everyday life, ritualised activities can mark transitions between dualities such as divine and human, past and future, letting go or holding on, confronting pain and experiencing comfort, and understanding and uncertainty (Anderson & Foley, 1998, as cited by Kobler et al., 2007). Thus ritual can deliver insight and clarity to some of the most complex and often confounding dichotomies central to the human condition, many of which are particularly pertinent to the parents of stillborn babies. The ongoing relationship between parent and stillborn baby embodies parents' efforts to reconcile two oppositional statuses: the living and the dead, and parents reported their engagement in myriad rituals aided this endeavour. For some, ritual provided a vestige of ordered repetition and

control over their lives at a time of great uncertainty. Consistent with previous reports, rituals enabled parents to forge meaningful and enduring connections with their baby that transcended death (Cacciatore & Flint, 2012a; Kobler et al., 2007; Romanoff & Terenzio, 1998). Moreover, the mementos and artefacts associated with ritualised activities became powerful and treasured representations of their baby and his or her enduring presence and importance in the parent's life. As discussed elsewhere in the literature, the majority of parents in the current study highlighted the value of tangible mementos, linking objects or artefacts of remembrance, finding them a comforting presence and beneficial in helping them to feel emotionally connected to their baby (Brierley-Jones et al., 2014-2015; Cacciatore & Flint, 2012a; Callister, 2006; Cote-Arsenault, 2003; Harper et al., 2011; Janzen, Cadell & Westhues, 2003-2004; Klass, 1996b; Layne, 2003; Murphy & Thomas, 2013; Riches & Dawson, 1998).

Most parents referred to having a formal ritual in the form of a funeral for their baby. Parents followed traditional funeral rites of the United Kingdom such as burial or cremation. Having a visible marker for their baby in the form of a headstone was important for some. The cemetery also provided a safe and comforting refuge; a dynamic, accommodating space in which to grieve, freely express emotion and connect with their baby.

> *…whilst we had her cremated, there's a little cemetery in the village so we do have a headstone there, so if I'm particularly struggling and it's more emotional /…/ I do go up there, and I might just go and tend to her grave.* (Participant 11, Mother)

Research has shown that visiting the grave of their child was a primary focus for many bereaved mothers (Umphrey & Cacciatore, 2011), a treasured ritual performed in an external space which can help sustain an ongoing relationship between parent and child. Moreover, Bleyen, (2010) reported that a mother of a stillborn baby found peace and strength in the natural environment of the cemetery. These findings were replicated in the current study:

> *…the only place I would go to, symbolic place, is his grave, and that, he's buried with my* [family members] *who I was very close to, so I feel I take a lot of comfort from the thought that I can imagine them looking after him, so, and, although they're the only 3 people buried there, it's where, sort of the family ashes go, it's very much a place which is visited frequently by the family, and that gives me a lot of comfort as well, like in the winter when there's snow there, and if I go and I see footprints to the grave, it's like to me, it's just, I don't know, it just lifts my heart a bit, because I think, he hasn't been forgotten*… (Participant 1, Mother)

The gravesite provides an open, accessible place for others to visit and honour the baby, this further serves to validate the baby's existence and enduring importance within the family. Evidently, this is heartening to parents of stillborn babies who, as previously mentioned, frequently report a lack of acknowledgement of their baby, and a perceived failure by others to legitimise or fully appreciate the magnitude of their loss.

However, one mother wanted the focal point for her remembrance to be closer to home.

> *…I didn't want to have a burial, I wanted to plant a tree in my back garden, erm, we've got a plaque, there's a tree in my back garden in memory of my son where I can look out every day…* (Participant 2, Mother)

Legal documentation confirming her baby's identity and birth was significant for one mother. Moreover, her desire for an increased sensory connection with her baby was implicit in her disappointment that the smell of her baby had faded from a treasured toy.

> *He had two of those* [cuddly toy] *and one was buried with him, but when he was in hospital, he was cuddled with them both so I've got kind of that now, it smells of the box now which is like really disappointing, and that was his little gown, but I've got his birth certificate.* (Participant 1, Mother)

Whilst parents made reference to formal rituals commonly associated with bereavement, the overwhelming majority of ritualised expressions described were informal in nature. Generally, depending on time since loss, hospitals provided opportunities for parents to engage in a range of memory-making activities in the immediate aftermath of their loss, and some were provided with precious physical keepsakes.

> *…I asked for an extra lock* [of hair] *because I wanted to put it into a locket that I have…* (Participant 8, Mother)

One mother initiated her own informal rituals, collecting physical reminders in the form of hand and footprint casts. Engaging in activities she had envisaged sharing with her son during his unfolding childhood, such as reading to him, was also important.

> *…and I wanted the 3D cast taken, so my brother went and got one for me and we took one of his foot and one of his hand, and I just knew that there were certain things that I wanted to do, erm, like we've got photos of us reading, you know, I always knew I wanted to read to him and stuff like that so I've got pictures of reading like his books to him and nursery rhymes.* (Participant 2, Mother)

The time spent with their baby either in hospital, or at home, was unquestionably valuable and precious to parents, but this opportunity for physical bonding was fleeting. As a result, parents reported how they constructed and maintained an ongoing relationship with their baby by engaging in diverse informal rituals in the months and years following their baby's death. Many of these varied and creative expressions appeared to have been developed intuitively by parents, as exhibited by the following excerpt:

> *…everything I've made, everything, memory wise, is something I've created myself /…/ I've got a cross-stitch, I started a birth sampler for her when I was pregnant which 4 years later I finally finished, it's on the wall…* (Participant 3, Mother)

Born of a desire to nurture a meaningful nexus with their stillborn, and perhaps influenced by an initial longing for physical proximity with their baby, parents not only invested their time and energies into making mementos themselves, but also bought, designed and commissioned others to make artefacts which served to hold their baby close. Memory boxes, tattoos and pieces of jewellery were examples of visual representations and physical, tactile reminders of their baby.

> *…so we got her to make us one* [memory box]*, so we put quite a lot of energy into kind of going and picking the wood, designing it, thinking through how it would look, inside, kind of all that, it is a really beautiful box, and we've got lots of his stuff in there, including his ashes /…/ so it's crammed, and all the cards…* (Participant 10, Mother)

> [husband] *has a tattoo which I designed for him, which was* [baby]*'s hand and footprints on his back, angel wings and a halo…* (Participant 8, Mother)

> *…we bought some jewellery with our living children's fingerprint in the silver jewellery, and* [baby]*'s handprints, their dates of birth all in little silver discs in order largest to smallest, so my wife would wear that on special occasions /…/ that's her way of feeling her.* (Participant 6, Father)

Implicit in the above quotation, some fathers did not appear to find collecting mementos as important to forging a relationship with their baby as did mothers. More explicitly, the following father explained how physical reminders were more comforting to his wife.

> *…I don't remember getting a memory box or anything like that,* [wife] *says that we did get quite a bit of stuff, and actually we must have done because we have the hand and footprints, and we have the photos /.../ I don't think I've ever looked at them, from memory, I think I might have done right at the start, right at the beginning of the process, they're much more important, I mean I'm glad they're there,* [wife] *looks at them*

> *quite a lot, they're a much more important part of the cathartic process for her than they are for me...* (Participant 12, Father)

However, photographs were significant to most parents as lasting visual representations of their baby and continued to remain so over time.

> *…I just knew in my heart that I wanted to have as many photos as I could…* Participant 2, Mother)

> *…we've both got photos by our bed, and so does* [other son] *…* (Participant 7, Father)

> *…we still have her photographs up…* (Participant 3, Mother)

Parents frequently alluded to symbolic representations of their baby that helped them to construct lasting connections. Symbols emanated from a variety of experiences, and spanned a fascinating range of themes, including: the baby's name and ashes, colours and the natural world.

Several parents conveyed the positive impact that viewing their baby's name had upon them. Personalised artefacts were sought and treasured, and provided comfort to them.

> *I love to see his name, to see his name written, because it reinforces that he existed, and at the group we make Christmas baubles, and we decorate pebbles to go to the Sands' garden in June and things, and all things that we can write down his name, and it is therapeutic, and to look at it and think he did exist.* (Participant 1, Mother)

A perceived lack of societal recognition of stillbirth and validation of parents' loss experience, which will be discussed in detail later in this chapter, may account for a prevailing desire to see their baby's name inscribed, as it serves to substantiate their baby's identity. However, there was also a tangible sense of pride which arose from displaying these objects, concomitantly authenticating baby's existence and highlighting parents' enduring emotional attachment.

One mother devised a colour scheme that she and her partner continued to associate with their stillborn baby. This was viewed as a way of incorporating their baby into their family home and everyday life.

> *…we had a colour scheme for* [baby], *we had like a lemon, a blue and a grey, so since then a lot of the stuff that we've bought and a lot of the stuff we've decorated the house with, there's like butterflies and stars, so although nobody would come in the house and go "oh your house is covered in butterflies and stars", like me and* [husband] *know that that's what it's for /…/ and at the wedding, them were the balloons* [points to balloons in the corner of the room] *with the lemon, the blue and the grey /…/ we just try and incorporate him into everyday life kind of thing.* (Participant 4, Mother)

As the above quotation suggests, a need for subtlety when integrating reminders or symbolic representations into their ongoing lives was implicit in some parents' narratives. Whilst others confidently asserted that they displayed anything they wished in their own homes without concern for visitors' reactions, a number of parents showed certain reservations about causing discomfort to those who entered their homes. Some parents appeared to be negotiating oppositional feelings as they tentatively evaluated which expressions of their continuing bond may be deemed socially acceptable, and which may transgress social boundaries. This is explored further in the theme *Negotiating the social landscape.*

For parents who chose cremation following their baby's death, the enduring physical entity of the ashes was exceptionally precious. Parents tended to retain the ashes at home, or in a place they viewed as safe and easily accessible. Perhaps in contrast to other forms of bereavement, most parents did not appear comfortable with the notion of scattering the ashes in more remote locations, their physical proximity was important to them, and indeed requisite for their peace of mind.

The ashes represented their baby's enduring existence. One mother spoke of her fear of losing her son's ashes whilst travelling abroad. She movingly

expressed that losing any of the ashes, no matter how small the amount, would equate to losing a part of him.

> *…'cos I thought I couldn't live with myself if I'd lost a piece of him, although it's a little tiny bit of his ashes, it's still him...* (Participant 4, Mother)

The portability of ashes was essential to some parents. One mother had some of the ashes incorporated into hers and her partner's wedding rings.

> *…when we got married we had our wedding rings made with a bit of his ashes, so there's a bit of his ashes in* [husband]*'s and a bit in mine…* (Participant 4, Mother)

For the following mother, being able to take her baby's ashes with her should she and her partner relocate in the future was also important.

> *I know she's in the house* [laughs], *I suppose that's our own little way of coping with that, and then as I say we can take her wherever we go…* (Participant 9, Mother)

Generally, there was a feeling of uncertainty when discussing parents' long-term plans for their baby's ashes.

> *…I didn't know what to do with his ashes, I think it was like there might come a point when it feels right to do something with them, but actually I kind of quite fiercely feel I want them there, I don't want to part with them, you know in 10 years' time I might but I don't know, so actually it's in our lounge on a shelf high up so small children can't get at it, so that we can access it if we wanted to, and it's actually just a beautiful object, we'd have spent all this money on him so we put it into having this object that's part of him really.* (Participant 10, Mother)

Parents' feelings and behaviours in respect of their baby's ashes reflect the intimate nature and strength of the ongoing relationship between them. The

ashes are a powerful representation of their baby, a visible part of everyday life for some, to be held close, cared for and fiercely protected.

Acts of memorialisation, such as marking anniversaries and special occasions was another means by which parents generated their baby's presence and enabled continuity of this presence over time. Parents were keen to include their baby in family traditions, such as taking cards to the cemetery at Christmas.

> *…and then at Christmas, /…/ we'll go up to her headstone again and we do Christmas cards, so I'll still buy you know sons' and daughter's Christmas cards and then her ones go up to the cemetery…*
> (Participant 11, Mother)

These were often emotionally evocative times for parents, but involving family members in acts of memorialisation enabled them to assimilate their baby into positive family activities that served to initiate and establish their baby's status as family member, and aided parents' efforts to cope with their loss.

> *…so on his birthday we go for a walk, so now we take the kids and we all, and it's* [winter month] *so we have to wrap up but we usually just find somewhere nice for a walk, get everybody wrapped up, have some lunch and make a nice day of it, and that's our way of kind of managing his birthday…* (Participant 10, Mother)

This is consistent with the findings of Cote-Arsenault (2003) who reported that "the weaving of lost babies into the family fabric" could prove therapeutic and healing to parents following perinatal loss (p. 33).

As previously discussed, some parents found solace and nurtured connections with their baby in the natural environment of the cemetery or by planting a tree in their garden in memory of their baby. Nature played a particularly prominent and important role in the construction and maintenance of parents' relationship with their baby. Historically, the themes of nature and death have long been intertwined and there is evidence of an enduring association across numerous cultures. Scattering of ashes, laying memorial

flowers and planting commemorative trees are all rituals reflective of the inextricable link between death and the natural world. Moreover, Layne (2003) highlighted the prevalence of nature inspired imagery within the pregnancy loss community. Parents' narratives in the current study reported here demonstrated how nature, as a facilitator of rituals, symbolic representations and acts of memorialisation, is a principal architect of continuing bonds following stillbirth.

Nature contributed significantly to parents' construction of mental representations and conceptualisation of their baby; thoughts were stimulated and memories created through associative metaphorical and physical reminders drawn from the natural world. Creating and evoking their baby's presence through symbolic representations from the natural world allowed parents to further develop their child's unique identity, and affirm their enduring significance and place within the family.

Whilst these associative links tended to develop after their baby's death, some symbolic connections were pre-existing and forged prior to the loss, as illustrated by this mother.

> *My husband has always been into his birds of prey and what have you, and when we thought of the theme for her nursery, because obviously we had the nursery all ready to go because she was actually overdue, so we had owls in the nursery, and bedding was owls and various other toys were all owls, so we've always kind of associated the owls with her, so now when it's been her birthday I bought a chime for the garden which was an owl chime, and as I was saying the people from work all clubbed together and we bought this big stone owl that sits in the garden.* (Participant 9, Mother)

The prominence of the associative symbol of the owl in the garden is a constant visible reminder and material presence that pervades family life. This symbol also allowed the parents to explain the stillborn baby's existence to her siblings, and confirm her place within the family unit.

> *I have a picture I commissioned for* [other child]*'s room which is owls in a tree. There is a tiny owl for baby miscarried and a small owl for* [stillborn baby]*, two bigger owls for* [other children] *and two bigger for* [parents] *with our names on.* (Participant 9, Mother)

Layne (2003) reported that fleeting and transformative symbols such as rainbows, snowflakes and butterflies were prominent within the perinatal loss community. Parents in the current study most commonly associated the image of the butterfly with their baby. Delicate beauty, fragility, ephemerality and a somewhat elusive quality seemingly imbue this metaphorical representation with analogous reminders of their stillborn baby. For one mother, the butterfly became a prominent symbol during acts of remembrance.

> *…so butterflies just seem to be a sort of, I suppose it's the fragility of them isn't it, I suppose so, it just sort of, I made her a butterfly cake for her first birthday and it just sort of stuck, so it became the thing that I always make for her.* (Participant 3, Mother)

Physical encounters with butterflies, whilst oftentimes emotionally evocative, were portrayed as comforting and uplifting.

> *… after we'd left the hospital, there was a butterfly in the house and I've never had a butterfly come in my house, and that year I saw loads of these white butterflies, everywhere, and it's obviously the time of year that he was born was in the summer, so it's nice at his time of, the birthday, and I see all these butterflies, that's nice, you know, you get a lot of, when I see one fluttering, they're such a beautiful creature and it makes me smile, you know.* (Participant 2, Mother)

Depth psychology which focusses on unconscious feelings, thoughts and behaviours, posits the notion of a symbolic connection between the human soul and the butterfly, the latter's presence being indicative of transition (De Vries, 2000). The butterfly is presented as "the universal symbol of natural development and change, symbol of innermost archetypal transformation, a

symbol of the spiritual aspect of life…" (Signell, 1990, as cited by De Vries, 2000 p. 151). An interpretation echoed in this mother's narrative:

> *Erm, it's that they're free spirits I guess, I mean the butterfly to me is symbolic of changes, I was once told that the butterfly is like the soul of a baby, so that's where the butterflies have come from…* (Participant 8, Mother)

Ostensibly, for this parent the butterfly is representative of her baby's transition from the corporeal to the spiritual world. However, it may also reflect the considerable changes that parents report regarding their own identity, sense of purpose, and place in the world following the death of their baby.

Another recurring symbol from the natural world was the white feather, again this stimulated immediate cognitive and affective connections for parents, engendering positive and solacing thoughts of their baby.

> *…so I've got things that, butterflies and white feathers, you know and I'm probably aware that white feathers fall out of birds all the time, but particularly when I see a little, particularly a little white feather, it makes me think of her /…/ white feathers tend to be for me very special, you know I might be having a bad day, and I sit in the car, and then the other week one was caught in a cobweb on my wing mirror, and it just makes me smile…* (Participant 11, Mother)

Similarly, for one father the robin provided an uplifting presence on difficult days.

> *…we have a big thing with robins /…/ robins appear when I'm just kind of having a bad day /…/ you don't have to wait for a real robin to appear, but they tend to, and when we visit the graves robins are never far away…* (Participant 6, Father)

Nature not only provided a plethora of symbolic representations and physical reminders for parents of their baby, but also offered welcome opportunities to

share their baby with family members through engagement in communal rituals.

> *It's like snowdrops and forget-me-nots, they're the flowers that remind me, mainly we go to a snowdrop planting at* [local park area] *and it's something we can do as a family, 'cos that's important now, that things are done as a family, I never want to go and sort of kind of grieve on my own type thing, you know...* (Participant 1, Mother)

Women, in particular, have been shown to demonstrate a strong desire to engage in communal rituals to remember their lost loved ones (Vale-Taylor, 2009), suggesting their propensity toward sharing such intimate, affective experiences with others. Chapter 1 highlighted how some parents perceive limitations on their opportunities to express and share their baby with others (Cote-Arsenault, 2003; Murphy & Thomas, 2013), an issue which will be explored in detail in the following main theme *Negotiating the social landscape*. However, the natural world appeared to provide an accommodating setting in which families could come together to acknowledge the baby's ongoing significance, forge connections with them and consolidate his or her place within the family.

Other ways that parents used the natural world to create connections and evoke their baby's presence included naming stars, planting flowers and trees, and incorporating symbols from the natural world into tattoo designs.

As outlined in Chapter 1, current practice within UK hospitals dictates that parents are offered opportunities to interact with their stillborn baby and can, if appropriate and desired, carry out parenting activities such as holding, washing and dressing their baby whilst physically present. This proclivity to care for and parent their baby continued despite the baby's corporeal absence. Many parents explicitly expressed their ongoing commitment to their baby as a parent. Whilst one mother acknowledged that the relationship differed to that with her living children, she was keen to emphasise that her stillborn baby's physical absence did not diminish or detract from her innate desire to parent her daughter.

> *… it's a different relationship from the one that I have with the other children, but it's not less valuable, I still talk about it as parenting, parenting her, it's still finding ways to be a parent to a child when they're not here, so everything I do when it comes to her is about that, about how to be a parent to her, so, it's things like collecting stuff, I have a memory box for all of them and I still have one for* [baby]. (Participant 3, Mother)

This aligns with the findings of Arnold and Gemma (2008), who during their study of bereaved parents' grief, observed that parenting continued beyond death through remembering, loving and caring. In a similar vein, parents in the current study determined to keep their baby's memory alive, demonstrated an ongoing emotional bond with, and lasting responsibility toward their baby. Cacciatore et al. (2018) have recently provided further evidence of these concepts as properties of continuing bonds by identifying sub-themes "keeping the memory alive" and "alternate parenting" in their study of volunteerism following stillbirth.

Furnishing the grave with flowers and tending to the surrounding area demonstrates this mother's proclivity toward continued parenting, and lasting desire to provide for, and care for her daughter.

> *…I still like to go, sort of maybe once or twice every couple of months, take some fresh flowers, check it's sort of tidy, I like going at this time of year 'cos we planted on her first birthday, we planted daffodils around the headstone, so I like going at this time of year when they're just starting to sprout and checking that they're still coming up.* (Participant 3, Mother)

Attig (2004) maintains that an individual's ability to maintain bonds with loved ones in separation, be they dead or alive, is primarily underpinned by memory. Accordingly, a crucial aspect of continued parenting involved finding ways to keep their baby's memory alive thus ensuring they retain a contemporary presence, especially within the family.

> *…I would say you kind of try to keep their memory living on, because obviously they're not here physically, so in order to preserve their memory you talk about them all the time, and you do certain little things in their memory...* (Participant 9, Mother)

Crucially, memories were not only remembered, they were also created. Days specifically devoted to this mother's baby generated new experiences which were subsequently associated with the child, thus forming part of her ongoing narrative.

> *… what we try to do and we've done most years is that we go to a new place, so we find somewhere new to go so we're creating a new memory, that's then specifically associated with her…* (Participant 11, Mother)

Murphy and Thomas (2013) reported that parents of stillborn babies construct an alternate biography for their baby had they lived. In line with these findings, a number of parents in the current study kept their baby's memory alive by constructing an ongoing biographical narrative for their baby. For one mother, developing her baby's personality traits further established his own unique identity, and enabled him to be an active contributor to the family's narrative.

> *…Father's Day and Mother's Day, both days* [husband] *and I do presents for each other from* [baby]*, because we're still parents and he's still our child, so he always, he's very generous, he has great taste.* (Participant 8, Mother)

Whilst extending their baby's story promoted a comforting psychological presence for some parents, thinking about the life their child would have experienced if they had lived could also acutely accentuate their absence and emphasise the complexities of parenting a stillborn baby, as evidenced by the excerpt below.

> *The first day of school, what should have been his first day at school I would say was the hardest day /…/ because my group of friends all the*

> *kids are like the same age, so they were all excited 'cos their kids are starting school, and I can't say to them, "Oh it would have been* [baby]*'s first day" because I can't burst their bubble, because it's such a, you know it would have been a big deal for me, I know how important it is for them, so I think, because you want to be kind to people as well you kind of bottle it up, and then you come home and break your heart.* (Participant 1, Mother)

Another aspect inherent in parents' efforts to continue parenting their baby was enduring love. It has previously been reported that mothers often maintain a profound emotional connection with their baby following perinatal death, and many expect the strength of these ties to be unaffected by the passage of time (Uren & Wastell, 2002). Similarly, all parents' accounts of their continuing relationship with their baby in the current study were characterised by an ongoing emotional bond. Parents frequently acknowledged that maintaining meaningful connections with their baby could be, at times, a complex and difficult process. However, their affective ties remained resolute, constant, and immutable.

> *The feelings are, you appear normal on the surface, but you don't have to scratch very far down to find the emotion, and it just catches you /…/ the things you do might change but the emotions are always the same.* (Participant 6, Father)

Moreover, caring about their baby and his or her feelings did not appear to diminish for most parents. The following mother's parental instinct to protect her child caused her to abandon plans to place the ashes in the garden, locating them in the family home instead. Uneasy at the thought of her baby being in the garden, her concerns are comparable to those which may be expected to be shown toward a live, sentient baby.

> *…so anyway the plan was to scatter her ashes, but then I couldn't do it /…/ I know it sounds strange but I didn't like the thought of her being out in the garden, so I had this* [baby] *bear and I got my mother-in-law to cut the back of the bear open and put a zip in, and then we've put*

*the ashes in a bag with a little embroidered patch with her name and date of birth on and everything, and then that's zipped up and she's in the nursery.* (Participant 9, Mother)

Murphy and Thomas (2013) proposed that by continuing bonds with their stillborn child, parents' identification as mother or father might be reinforced. The current study's findings supported this notion as most parents emphasised that they still considered themselves to be mother or father to their stillborn baby, and, as evidenced above, demonstrated parenting behaviours toward their baby despite his or her physical absence.

Whilst many parents evoked their baby's presence and sustained their parental commitment over time, some also suggested that these endeavours could be impacted by missed opportunities to share intimate moments with their baby in the immediate aftermath of loss. Critically, not being able to spend as long as desired with their baby is a potential predictive factor for mothers' depressive symptoms at three years' follow up (Surkan, Radestad, Cnattingius, Steineck & Dickman, 2008). Typically the time that parents shared with their baby in the current study, although transitory, was treasured. However, a number of parents expressed regret at not being afforded more opportunities to bond and make memories with their child. This is consistent with previous reports of mothers' regret at not interacting with their baby, or having limited opportunities to engage in memory-making activities (Brierley-Jones et al., 2014-2015; Hennegan et al., 2015; Ryninks et al., 2014). Disappointment arose for parents predominantly due to hospital practices at the time of their baby's death.

> *That's so important, to have something… things have changed so much because this is what we left hospital with* [a card with baby's details recorded, a handprint and footprint, and hospital wrist tags attached], *and that was it, we didn't have a memory box, that was it, we walked out of the hospital with that, and now, and I look back at it and I think he had 2 hands and 2 feet, and I've got 1 handprint and 1 footprint, it's not fair, and somebody made that decision to do that.* (Participant 1, Mother)

Whilst improvements in recent years were generally acknowledged, some parents maintained that they were inadequately informed about the choices available to them.

> *I mean there are things that I wish people had told me right at the very beginning when we were first in the hospital, I wish I'd been told that I could baptise him, I wish I'd been told that I could strip him and bath him if I wanted to, there were so many things that I didn't know that I know now.* (Participant 8, Mother)

A paucity of photographs, or poor quality pictures left a number of parents saddened and frustrated that their baby's physical image had not been better captured.

> *…the way they* [hospital photographs] *were taken, they don't look like him, they don't look like my memories of him, and when I got them, I was devastated because they didn't look like my memories of him…* (Participant 1, Mother)

Moreover, the following mother highlights a significant implication for the care management of stillbirth regarding capturing sensitive and appropriate images. This mother had lost her baby only 8 months before the interview, suggesting that this is a current issue that needs to be highlighted and addressed.

> *…the hospital took one photograph, but it was probably the worst photograph of him because he was in this position* [crosses arms over chest to indicate position] *like a dead person, and it was just like, that's my baby I don't want to see him in that position, so the rest of the photographs we took ourselves, 'cos it just didn't feel like it was particularly sensitive, the way it was taken in the hospital, it was just like, I mean I still like the picture, but I know a lot of people don't like the pictures of their babies like that, 'cos obviously you don't want your baby to look dead. You know he's dead, but you don't want it to be so obvious, whereas a lot of the pictures we've taken are like of him, he*

> *just kind of looks asleep, which made it a lot easier really.* (Participant 4, Mother)

Brierley-Jones et al. (2014-2015) reported that seeing their baby's whole body was of special importance to mothers following stillbirth. Similarly, missing the chance to fully appreciate her son's physical characteristics was difficult for one mother in the current study.

> *…and if you've never seen him with his eyes open, so I've no idea what his eyes were like or, actually the midwife dressed him, she bathed him and dressed him because I wasn't in a fit state at that point, so I never properly saw his body…* (Participant 10, Mother)

Not having seen her son naked was a painful regret for the following mother, thankfully this regret was remedied some years later.

> *…I never saw him naked, and it upset me for years that I never saw my son naked, and it was only when I was on a training day and somebody had said that they take photos before the PM* [post-mortem] *and sometimes you can get hold of those photos, and I'd formed a good relationship with my hospital because of the group, and contacted one of the women and said "Look this may sound really stupid but are there photos of him before the PM naked? Because I would really like, it would mean so much for me to see them" and it just so happened that there were, and finally I saw my boy naked, and that meant so so much to us, so much to us…* (Participant 8, Mother)

Interestingly, one mother questions apparent social boundaries regarding stillborn babies and why her son was not afforded the same treatment as her living children.

> *I mean we got him christened, and I didn't get a picture of him being christened and I think, I did with my other kids so why, you know.* (Participant 1, Mother)

#### 2.4.1.3 Communication

Another way in which parents constructed and maintained a relationship with their baby was via communication. This finding is consistent with the findings of Foster et al. (2011) who reported family members communicating with deceased children as a means of connecting. Communication between parent and baby in the current study was multi-modal. Some parents wrote to their baby or spoke to them externally.

> *…obviously I do talk to him in my diary and sometimes I'll talk out loud, you know, if I go stand next to the tree or just sometimes in the house.* (Participant 2, Mother)

For some parents this communication remained internal, private and intimate, whilst for others it was exposed to a wider public audience, typically via internet blogs or social media platforms.

> *…so on her 6th birthday I just wrote a little "hello" to her on Facebook, and thanking her for what I'd taken from the experience, and what it had made me become, having her and having experienced that loss, and that was quite an open and explicit way of speaking to her really, there's a big audience in the social media world so that was quite a stand really…* (Participant 12, Father)

The following mother did not perceive herself to engage in dialogue with her baby as such but did feel compelled to apologise to her baby if she chose not to acknowledge him whilst in conversation with others. Again, this implies parents' enduring concern for their baby's feelings and an ongoing desire to protect them.

> *I don't really have a dialogue but I do do things like that, "Sorry* [baby]", *when I realise I've kind of not acknowledged him in a conversation or something.* (Participant 10, Mother)

In some instances parents' communication with their baby was perceived as reciprocal, and the baby was presented as an active subject during the

interaction. In line with previous studies of bereaved parents' continuing bonds with their child (Klass, 1996b; Murphy & Thomas, 2013), a number of parents related experiences during which they had sensed their baby's presence, and some attributed unexplained happenings to their baby's intervention. An ongoing spiritual connection was perceived by some parents as another way for them to maintain ties with their baby. This mother was receptive to the possibility of a spiritual link to her daughter.

> *I've had some experience with a friend, erm in terms of the whole paranormal sense of sort of spirits, and there's been a link that she had that basically links back to me and my daughter, you know I don't know, but if there is, I keep an open mind.* (Participant 11, Mother)

Spiritualism provided a channel of communication between the following mother and her baby, whilst also serving to develop her son's persona and characteristics. Having earlier in the conversation referred to her baby as a "cheeky monkey", this characteristic is evident in the interaction described below.

> *…and the fact that she* [psychic] *said "Oh you've recently bought a pair of shoes, within the last couple of days" she said "but you've taken the tags off and hidden them with other shoes", and I had. My husband went "Have you?" I thought "How can you* [baby] *grass me up!?"* (Participant 8, Mother)

Objects going missing in the house, then mysteriously reappearing were also attributed to this baby's mischievous nature.

> *Things always go missing, we have a lot of things go missing, but then turn up in a place where we both know that we've looked, in a very very obvious way…* (Participant 8, Mother)

This mother's tendency to develop an individual personality for her baby supports the findings of Murphy and Thomas (2013) who reported how parents "imputed character traits" to their stillborn baby (p. 5)

Although sense of presence occurrences are not uncommon, with an incident rate of approximately 50% within the bereavement population (Rees, 1971), an apprehension to disclose such events is frequently recorded in the literature (Daggett, 2005). Uncertainty as to how such experiences will be received most likely stems from what Steffen and Coyle (2012) refer to as their "controversial status" within a reductionist, scientifically oriented, Western culture, suggestive of a societal taboo associated with these events. Furthermore, the use of stigmatising terms such as *hallucinations* and *illusory experiences* within the bereavement literature perpetuate a somewhat disparaging view of sense of presence experiences (Olson, Suddeth, Peterson & Egelhoff, 1985).

Whilst a number of parents did allude to these experiences during discussions, they seemed mindful of the fact that by interpreting these occurrences as spiritual interactions with their baby, they were challenging the dominant scientific discourse, and therefore, were vulnerable to disparagement. There was an implicit acknowledgement from the majority of parents that these experiences may be viewed by others as being paranormal, or even pathological and were often counterbalanced with alternative explanations such as "maybe it's just coincidence" or prefaced with self-deprecating assertions such as "people will think I'm mad but…". This reflects the findings of Valentine (2008, 2018) who reported that bereaved individuals who sense the presence of the deceased often switch between supernatural and rational readings of the experience. Parents in the current study were acutely aware that their mental health may be scrutinised by others and seemed to protect themselves from potential, negative judgements by pre-empting them, or questioning their own interpretation of events. Oscillation between aligning with the dominant scientific discourse, and challenging it through personally meaningful interpretations, was evident in most parents' narratives; demonstrating a complex negotiation between denial or distancing, (through questioning the veridicality of the perceived encounter), and a welcome embracing or acceptance of the event. It should be noted that 10 of the 12 participants in the study were parenting live children at the time of the interview, with one other pregnant, therefore, this strategy may also have been

influenced by parents' necessity to prove themselves as balanced, rational, and competent parents.

Spontaneous and affective, sensing their baby's presence could be an emotionally overwhelming experience for parents in the current study. However, all parents whose narratives included these encounters, stated that such experiences were welcome, positive and comforting. This is in line with existing reports showing that the vast majority of experients deem these encounters to be helpful, pleasurable and uplifting, as opposed to unpleasant or frightening (Datson & Marwit, 1997; Rees, 1971). Furthermore, this perceived communication appeared to provide a vestige of reciprocity within the ongoing relationship between parent and baby; a key factor within most successful human relationships and associated with better mental health and well-being (Buunk & Schaufeli, 1999). However, such interactive occurrences were not common to all parents, with one mother highlighting her struggle with a perceived lack of reciprocity in her relationship with her baby.

> *…when we first lost him my step-mother had said to me, she said it was like the worst kind of unrequited love, and do you know, that is kind of what it's like.* (Participant 5, Mother)

Notably, no participants in this study alluded to any feelings of fear or undue distress as a result of sensing their baby's presence. Sormanti and August (1997) reported that bereaved parents' experience of sensing their child's presence not only helped to consolidate their identity as parents, but also provided hope of a spiritual reunion with their child, whilst reinforcing their beliefs of an enduring spiritual existence after death. The current study's findings support the notion that these experiences can be beneficial in extending hope to bereaved parents of a future, spiritual reconciliation, whilst enabling conceptualisation of their baby as an enduring entity with which meaningful interaction is still possible.

Holding mental representations or conceptualisations of their baby in spirit form did not appear to be specifically linked to formal religious beliefs for the majority of parents but were more precipitated by a search for the spiritual and

a need to believe *something*. This is in line with Walter's (2018) recent observations that those within modern Western, and increasingly secular, cultures appear to be less influenced by religious teachings and tend to derive mental representations of the afterlife from their own personal experiences of death. Spiritual conceptualisations appeared to accommodate parents' need for their baby's prolonged existence, psychologically and spiritually, if not physically embodied. Moreover, as shown by the following excerpt, they facilitated belief in a future spiritual reunion with their baby, and provided comfort and a sense of reassurance that their baby was being cared for by other deceased relatives in a parallel incorporeal realm.

> *… in my head, I imagined that she* [deceased grandmother] *was actually the first one to meet him* [baby]*, and so I did take a lot of comfort from that you know. /…/ so I have to believe that he's somewhere, because I think well why would it have happened, why do you have pregnancy and everything… /…/ If erm, that's it, if it's just ended. Do you know what I mean? So…I wouldn't say I have like a strong faith, but I have to have something, I have to hedge my bets.* (Participant 1, Mother)

Nature was the predominant facilitator of communication between parent and baby. As mentioned earlier, the butterfly was the most prevalent symbol that parents associated with their baby. However, in the following context it allowed parents to conceptualise their baby as an active spiritual being capable of asserting their presence and communicating with them.

> *…at the hotel we were staying at, was this huge butterfly that came and sat on* [husband] *and crawled up his arm and sat on his shoulder, but it was the second time it had happened, because the week after he died the same thing had happened /…/ and we were just like, well it must be* [baby] */…/ so we put it down to being, it must have been* [baby] *giving us a sign /…/ it just felt like it was a bit of something, 'cos there's not much you can get is there really, so it was nice to just think, I mean I know other people would just think "oh you've gone mad" but it was so bizarre, and with it being* [winter]*, /…/ and it was just like, coincidental*

> *but strange at the same time so, it really, it did help, just like, yeh it was nice, we were talking to him like it was him, which helped.* (Participant 4, Mother)

This finding is consistent with that of Chan et al. (2005) who examined Chinese peoples' experience of meaning-making following bereavement and continuing bonds with the deceased. They reported how bereaved individuals perceived deceased family members returning in the form of an insect. Such occurrences allowed bereaved individuals to talk to the insects as if they were talking to their lost loved one and were considered therapeutic.

In the current study, three parents also felt their baby's presence in the form of a white feather.

> *…as I was wrapping* [Father's day presents] *the window was open, and through the window something caught my eye, a white feather had landed on the carpet, you know, and just little things like that.*
>
> Interviewer: *And how does that make you feel?*
>
> *I cry my eyes out, you know the white feather made me cry but I was feeling a bit low any way, and I think the fact that I was actually wrapping presents at the time, it was like he was saying "Here's a present for dad", so it's comforting and I love it but also sometimes I wish he was here to give them himself.* (Participant 8, Mother)

This excerpt further demonstrates parents' need to reconcile the absence/presence paradox of their baby's existence, and how an ongoing relationship with a stillborn baby can simultaneously kindle feelings of solace and longing.

One mother perceived the wind as a channel through which her baby could communicate with her. The interactive nature of the mother asking a question, and the baby subsequently responding, could be critical in providing a sense of reciprocity in the ongoing relationship.

> *…and I've got like wind chimes, so I always think when they're chiming he's talking to me, erm and like the wind spinners, if they're going round, you know, and when my second son was going to be born, I didn't know what I was having, a boy or a girl, and I'd said, I went down* [to baby's tree] *you know to talk to him, and I said "Right send your wind spinner round left if it's a boy, and right if it's a girl", and it went round left! /…/ And then, I got a boy, so.* (Participant 2, Mother)

The role of nature was key in providing a channel through which these sense of presence occurrences could be experienced and interpreted by parents. Essentially, these events appeared to consolidate and strengthen existing connections, thus affirming parents' ongoing relationship with their baby. In this respect, by contributing to parents' continuing bond with their child and enriching the parent-baby relationship, it could be argued that exploration and validation of these experiences could facilitate coping and bereavement adaptation following stillbirth.

**Summary of theme *Constructing and maintaining a relationship***

The parents in this study, when faced with their baby's death, determined to create, develop, and nurture bonds with their child despite his or her corporeal absence. Parents emphasised the significant influence of prenatal bonds on their desire to pursue an ongoing relationship with their baby. Health care professionals offered parents a number of opportunities to create physical mementos and memories to facilitate bonding between parent and baby. These were varied in nature owing to the broad range in time since baby's death (i.e. 8 months to 22 years) and some parents voiced regret at opportunities missed during the time spent with their baby. Beyond this initial intervention and support, parents appeared to instinctively adopt a range of strategies when attempting to construct and maintain an ongoing and meaningful connection with their stillborn baby. Parents reported innovative ways in which they evoked their baby's presence and constructed mental representations of their baby through ritual, symbolism and acts of memorialisation (e.g. photographs, hand/footprints, jewellery, cross-stitch, colour schemes, tattoos, planting flowers/trees), thus enabling them to

develop their baby's narrative, consolidate affective ties, communicate with and continue to parent their lost child. In particular, nature emerged as a primary architect of continuing bonds by means of symbolic representations, as a facilitator of personal and communal rituals, and as a channel for communication.

### 2.4.2 Negotiating the social landscape

> *I thought I'd be teaching my baby about the world, as opposed to teaching the world about my baby.* (Participant 8, Mother)

Analysis of the construction and preservation of parents' continuing bonds with their stillborn babies in the preceding theme has shown how parents create and evoke internal, mental representations of their baby and establish a sense of their baby's presence, at least within the family sphere. Parents exuded love and a sense of pride for their baby, which naturally, as with a live baby, they felt inclined to share with others outside of the family home, as they sought wider social acknowledgement of their baby's existence and significance. Klass (1996b) emphasised the importance of parents making their continuing bonds with their deceased child part of their social reality as it was thought to facilitate adaptive integration of the child into the parent's life and contribute to loss adjustment. In line with this notion, the second theme *Negotiating the social landscape* explores the extent to which parents in the current study were able to share their baby with others. Three sub-themes emerged: wanting to share; silence, and its opposite disclosure.

Positive social support and support satisfaction may be important factors in coping with stillbirth (Cacciatore, 2007; Cacciatore et al., 2009; Christiansen et al., 2013; Horsch et al., 2015). Moreover, sharing memories following stillbirth has been linked to better maternal mental health (Crawley et al., 2013). However, little is known about social attitudes toward continuing bonds in general terms (Sochos & Bone, 2012) with knowledge relating to society's views of continuing bonds between parent and baby following stillbirth being particularly scarce. The findings presented here demonstrate that parents endeavoured to share expressions of their continuing bond with others with

varied success. Most parents reported feeling able to share their baby with some family members, friends and colleagues, and in doing so felt closer and more profoundly connected to their baby. Due to their involvement with Sands, some parents had opportunities to share more widely at charitable events and conferences. Critically, parents perceived this sharing process as a vital mechanism for maintaining their relationship with their baby over time, and as a potential aid to coping and bereavement adaptation, as it helped them to consolidate their baby's personhood and ongoing social significance, whilst simultaneously integrating their baby into their social world. However, sharing was also challenging for parents at times and a number of barriers to disclosure were identified.

#### 2.4.2.1 Wanting to share

Paradoxically, although suffering the heartbreak of stillbirth is a very personal and private experience, most parents talked of a need to share aspects of their ongoing relationship with their baby more publicly with others. This imperative to articulate their baby's story was commonly driven by a need for social acknowledgement of their loss, and validation that their baby existed and continued to effect a considerable impact upon the parent's life.

> *…and one of the things I found myself referring to a lot over the years is how important it is to talk about him really, and remind other people that he lived and he existed, albeit because he was stillborn he only lived inside me, and I think that notion of sharing /…/ that kind of sharing about things we were doing in his name and reminding people he existed is hugely important, really really important…* (Participant 5, Mother)

Historically, health professionals and society at large have characterised stillbirth and other perinatal loss hierarchically as provoking a lesser emotional response than other forms of bereavement (Lang et al., 2011; Lovell, 1983). Consequently, parents rarely receive the societal acknowledgement and empathetic support to facilitate complete legitimisation of their loss. The

following excerpt demonstrates that some parents still perceive a dismissive social response and denigration of their loss experience.

> *Because it was kind of a feeling of well he was stillborn so he wasn't a real baby, and I do think that if a baby lived for a minute, they're more valuable or important in people's eyes than a child that's stillborn, I really do believe that because they say "Well he breathed" or, so that makes it more real, and…I wonder whether these people can't bring themselves to think about how they felt during pregnancy, and how they bonded with their baby, and how they made all the plans, that's what I don't understand why they can't…erm… be maybe a little bit more sympathetic…* (Participant 1, Mother)

Cacciatore et al. (2008a) applied Boss's (1999) framework of ambiguous loss to explore the complex grief responses observed in parents following stillbirth, particularly the mother's difficulty in reconciling her intense and enduring feelings of loss with an often indifferent societal response. In the event of stillbirth, although the baby is physically absent after death, his or her psychological presence continues to pervade the bereaved family's life which can result in high levels of stress for the bereaved. Attempts to alleviate this dissonance and reconcile the absence/presence paradox may have engendered parents' efforts to represent or materialise their baby's presence in a number of creative ways in the current study, as illustrated in the preceding main theme. Moreover, a stillborn baby's uncertain or liminal status (Layne, 2003) might influence societal misperceptions of what has actually been lost, and contribute to society's failure to fully recognise the baby's existence and appreciate the true extent and gravity of parents' loss experience. Kofod and Brinkmann (2017) interviewed parents who had experienced infant loss shortly before or after (< 1 week) birth and reported that "the personhood, human status, and irreplaceability of infants who die before, during, or shortly after birth are still culturally contested" in Western societies which typically leads parents to a process of negotiation during social interaction as they strive to assert the importance and legitimacy of their loss. (p. 12).

This finding is replicated below as one mother exposes the brutal insensitivity of this misperception by applying it to other forms of bereavement.

> *… one of the things that has always bothered me, and I know from the Sands' group people get this a lot, is "Well you know you can have another baby", and you'd never ever say that if somebody's husband had died, you wouldn't say "Well you can marry again", you wouldn't dream of it, you wouldn't ever say that, but for some reason people think that's an appropriate thing to say when you've lost a baby, they wouldn't even say it if you'd lost a child at 5 years old, or 15 years old, or if your child was an adult, but for some reason they think that because it's a baby it's ok to say that /…/ You know, so those kind of comments get said a lot to bereaved parents when they've lost their baby, and I think people just don't think it's anything sometimes.* (Participant 5, Mother)

Evidence that these views might be culturally entrenched is provided by the same mother who herself defines the status of her own perinatal losses hierarchically when comparing her stillbirth to a previous early miscarriage.

> *… if you've had a stillbirth, people think that's the same as having a miscarriage, now obviously I don't like to make huge distinctions because miscarriages are very, it's a terrible occurrence, but a stillbirth isn't the same as an early miscarriage particularly, I've had an early miscarriage in the past and it's not remotely the same as your baby dying, and then you're giving birth and having a funeral, it's a completely different experience, and I think people just think well if the baby never lived you haven't lost as much somehow, you know or if the baby's only lived for a few weeks or whatever, or they've never brought the baby home, it's not the same.* (Participant 5, Mother)

Evidently, each bereaved individual's perception of "what has been lost" is of paramount importance; it should be respected and should not be assumed by others.

As mentioned in Chapter 1, some cultures engage in a succession of rituals following bereavement which emphasise and preserve continuing bonds with their deceased relatives. For example, Buddhist influenced rites relating to the funeral, memorial services and home altars are typical in Japan (Valentine, 2018). Moreover, culturally embedded traditions are collectively celebrated in some countries, for instance, Mexico's Day of the Dead when deceased loved ones are honoured and remembered, Japan's Obon when it is thought spirits of deceased ancestors return home to be reunited with their family, or Ching Ming Festival in China during which the bereaved honour the dead by tending to their grave and making offerings. Owing to a paucity of death rituals in modern, Western society, Walter (1996) asserts that ritual is replaced with discourse, and a propensity to share mental representations and memories of the deceased with others. Discussions with others who knew the deceased act as a means of constructing a narrative, or durable biography of the individual which can serve to consolidate mental conceptualisations of them, perpetuate their personhood and identity, and allow for their co-constructed narrative to be intertwined with that of the survivors. When a baby dies in utero, very few individuals outside of the immediate family ever have the opportunity to meet the deceased (Cacciatore, 2010). Therefore, it is suggested that this notion of *conversational remembering* is more problematic for the parents of stillborn babies. However, some parents found other forums and audiences with whom they could freely express their relationship with their baby, allowing them to disseminate their baby's story and maintain his or her social presence.

> *..and then that* [charity work] *has led to more and more involvement with Sands, and being asked to then go to events, conferences, seminars etc., where I've been asked to talk about her, over the years I've given talks to every conceivable group you can think of, church groups, clinicians, politicians, you name it, I've probably stood in front of them and talked about her, told my story, or her story.* (Participant 6, Father)

Others showing interest by asking or doing something to remember or honour their baby was particularly pleasing and comforting to parents as it made them feel that their child was valued by others.

> *…you are trying to maintain a relationship and I do feel a relationship with him, but it is difficult, it is difficult, and I think what makes it easier is when other people are still interested in him, or interested in what you're doing to remember him or, and I think that's why we bereaved parents find it important to share that with people, whether it's pictures they have up in the house, or whether it's decorating a grave, or whether they're blogging about new stuff they do like we do, I think it's kind of saying my child was here and they're important, and they'll always be important to me, just because you can't see them doesn't mean that they're not….* (Participant 5, Mother)

As exemplified by the excerpt above, most parents acknowledged that maintaining a relationship with their baby who was physically absent could be challenging. However, sharing expressions of this relationship with others was perceived as a crucial facilitator of the ongoing development and maintenance of bonds with their baby.

Klass (1988; 1996b) suggested that positive social support for bereaved parents should not only provide support for the parent but also opportunities for parents to share their bond with their deceased child. Klass (1996b) observed how sharing legitimised expressions of parents' relationship with their child (e.g. sense of presence experiences) and validated the ongoing parent-child bond. Similarly, positive sharing experiences for parents in the current study, helped affirm their baby's existence and enduring significance in the world. All parents considered opportunities to share their baby's memory, and to freely express their enduring love and commitment to their baby with understanding and compassionate others as a positive and helpful process. However, as the following pages will demonstrate, support for and validation of their continuing bond was not always forthcoming to parents of stillborn babies. Interplay between the private and public experience of stillbirth was complex and frequently problematical. Parents repeatedly

alluded to a number of challenging aspects or barriers which precluded, complicated or negatively affected their ability to share their ongoing relationship with their baby with others.

#### 2.4.2.2 Silence

Silence is a recurring theme within the perinatal loss literature. An awareness of its presence surfaces the moment death is confirmed, subsequently, it pervades domestic and wider social settings and incorporates self-silencing and imposed silencing from others (e.g. Brierley-Jones et al., 2014-2015; Hazen, 2006; Kelley & Trinidad, 2012; Layne, 1997; Radestad, Malm, Lindgren, Pettersson & Larsson, 2014; Scott, 2011; Trulsson & Radestad, 2004). The majority of parents in the current study reported here alluded to a general reluctance within society to talk about babies who have died. Parents sensed a culture of silence and secrecy enshrouding the experience of stillbirth which contributed to their feeling stigmatised. Notably the use of the word "taboo" was common amongst parents. The notion of stillbirth as taboo and ineffable, together with its potentially socially stigmatising effect, reflects the findings of previous stillbirth studies (Brierley-Jones et al., 2014-2015; Burden et al., 2016; Murphy, 2012, 2013). Lewis (1983) likened social perceptions of stillbirth to "a black hole in the mind, full of intense feelings and ill-defined abhorrent thoughts which are invisible and difficult to recall and, therefore, hard to think about" (p. 209). Parents in the current study found this cultural aversion to openly discussing stillbirth, which appeared to extend into some healthcare services, perplexing and unhelpful as it seemed to compound the unexpectedness of their tragic loss.

> *I think I've kind of tried to make sense of why stillbirth is such a taboo still, because as soon as you tell people, they're like "Oh I know such and such", everybody knows somebody, or somebody that's had multiple miscarriages, or stillbirth, or neo-natal death, and it's like why are you not talking about this, why does it feel so hush hush, and even in the ante-natal services they tell you loads about cot death which is much rarer /…/ but it's not widely talked about at all and I think it's so hard for people to bear, that babies die, it was really hard for us to bear*

*that our baby died, that doesn't happen, I didn't know anything about /…/ you know we went to NCT classes, nobody ever said to me if your baby stops moving or slows down you should report that, but they'll tell you loads of other crap that you don't need to know.* (Participant 10, Mother)

Researchers have focused predominantly on the way stillbirth is managed following confirmation of the baby's death (see Ellis et al., 2016), and how interventions may alleviate parental distress (see Crispus Jones et al., 2015). The current study's findings have identified a need to further consider the level of information provided about the possibility of stillbirth as a pregnancy outcome during antenatal classes, as its omission may be exacerbating the sense of secrecy and stigma reported by parents.

One parent suggested that the uncertainty associated with discussing stillborn babies might emanate from a concern about compounding bereaved parents' emotional distress. However, she was keen to stress that emotionality should not be so feared by others and that talking about her baby was desirable and far preferable to confronting a culturally constructed wall of silence. Even close family members were unsure of how best to support their loved ones, especially over time, and could be fearful of causing further distress thus withdrawing or avoiding talking about the baby. Again, well intentioned actions paradoxically increased parents' isolation.

*I think there's this real reluctance to talk about babies that have died, from my point of view what I see is from our culture, you know we don't tend to talk a lot about people who've died and we don't want to upset people, I think particularly with babies, there is a bit of a culture of silence around babies' deaths, and particularly stillbirths and I think for me, it's partly about saying to other people it's ok to talk about it, in fact it's worse if you never ever mention him, or you never say anything about it /…/ I was very lucky that some of my friends were really supportive, family were supportive too but it was a bit mixed, for example, my mum who is brilliant in many ways, didn't, was scared to mention* [baby] *you know after a few weeks, she was like well I don't*

> *want to upset you, but I'm upset all the time anyway, so if you say something and I cry you're not making me more upset than I am to start with, so I think she found that very difficult, and I found that very hard as well…* (Participant 5, Mother)

As touched upon by the mother above, death in the UK is often hidden or sequestered by specialist services or institutions (Hockey et al., 2010a), with babies' deaths seeming particularly vulnerable to concealment or containment within the loss community. Society's tendency to marginalise, limit or suppress the discourse of stillbirth was keenly felt and challenged by some parents as they believed they were being denied opportunities to freely express their experiences to a wider audience.

> *…and we were all tucked away on this little forum, as if, where it was the only safe place we could talk, and you think well that's not right, 'cos, it's happened to so many of us, why can't we talk about it openly?* (Participant 1, Mother)

In addition to parents perceiving socially imposed restrictions on their opportunities to openly discuss their baby, they also reported being actively avoided or ignored by others following their experience of stillbirth. Parents recounted instances of being ignored at work and avoided in the street. Seemingly being cast as invisible or, as one mother termed it, "off the radar*",* they often felt like social pariahs. These incidents exacerbated parents' sense of being stigmatised.

> *People didn't know what to say, I had people cross the street, like deliberately cross the street, because they didn't know, just because they didn't know what to say…* (Participant 1, Mother)

Disturbingly, at a time when many parents were vulnerable, emotionally fragile and in desperate need of support and understanding, they frequently met with a demoralising, detrimental and deafening silence. One mother's moving account of her return to work following her baby's death, illustrates her colleagues' uncertainty and apprehension in addressing the subject of

stillbirth. As this mother was recently bereaved at the time of the interview, her experience suggests a current social issue. It would appear that wider society currently lacks the language, understanding and confidence to provide adequate and consistent support to parents of stillborn babies. Left floundering, it often adopts the safest approach of distant, disregarding inactivity.

> *…people actually ignored me, I did a 10 hour shift and people ignored me, and at the end I said to my mum "I can't do this, I'm not coming back", and she said "You can, people don't know what to say to you", and I said "That's not my problem, they should know what to say to me, talk about the weather, talk about anything, they don't have to ignore me and make me feel worse"…* (Participant 4, Mother)

Inevitably, this mother alludes to feeling isolated and misunderstood.

> *…it's the most isolated I've ever felt, after losing* [baby] *it just felt like I was just an alien, nobody knew how to take me, nobody knew what to say, and you know they were, people were nice for a few weeks and then just forgot about you…* (Participant 4, Mother)

Forrest (1983) reported that parents who had experienced an early neonatal death found that friends who were supportive in the initial aftermath of their loss gradually withdrew over time. In a similar vein, it was not uncommon for parents in the current study to describe how support that was initially forthcoming tended to diminish over time, as others' empathy faded. One mother suggested that those, outside of the immediate family, who do initially acknowledge the loss rarely maintain this communication over time. As a consequence, parents' opportunities to share their relationship with their baby with others tended to reduce over time.

> *…you get a lot of people who want to come and see you once just to say how sorry they were, and then maybe we didn't see that much of them or people that just didn't know what to say to us at all, people that*

*clearly avoided us because they didn't know how to deal with it…* (Participant 10, Mother)

Another mother continued to feel stigmatised, socially ostracised and marginalised during a subsequent pregnancy. Insightfully, she also considers the impact society's response has effected upon her own behaviour and social performance.

*…cos that's another thing, especially the toddler groups, you'd go and as soon as they'd found out you'd had a loss it was like you were a jinx, and if anybody was pregnant in the group and I went and spoke to them, my god that was like* [laughs] *don't want to jinx the pregnancy, it was really really completely ostracised, and I don't know whether that's because we put this invisible barrier up, and we become different and a bit tougher about things, or whether it is just a "Oh I don't want to jinx things and I don't really want to know what can go wrong" and you're a reminder of that.* (Participant 1, Mother)

It should be noted that not all parents experienced stigma relating to the expression of their relationship with their baby, or perceived societal restrictions to disclosure. Whilst this viewpoint was less common amongst parents, one father was explicit about feeling confident and at ease with openly expressing his relationship with his daughter.

*…and I never felt under any pressure, or that there was any stigma attached to any of the things I was doing, I've been very comfortable talking about her…* (Participant 12, Father)

#### 2.4.2.3 Disclosure

Whilst the notion of silence was common to most parents' loss experience, its opposite, disclosure also emerged during discussions. When parents challenged the pervading cultural silence surrounding stillbirth, they tended to disclose information in three distinct ways: spontaneously; in a confrontive manner; or in a protective way, that is, after considering the consequences for themselves and their audience. Two of these approaches to sharing acutely

personal information with others are similar to those observed by Charmaz (1991) who outlined spontaneous and protective disclosure as key emergent themes during interviews with individuals with chronic illness. The emergence of a third category in the current study, i.e. confrontive or challenging disclosure, provides further evidence of parents' imperative to secure acknowledgement of their stillborn baby's existence.

Spontaneous disclosure tended to occur in the early weeks and months following stillbirth, and gradually dissipated over time. As the following mother explains, propelled by a fear of her baby's social invisibility or inconsequential status, she determined to maintain her baby's social presence by including her in conversation, irrespective of the audience's response. However, over time as the relationship developed and her baby became a more integrated part of her ongoing narrative, she no longer felt compelled to seek external validation of her baby.

> *…sometimes you were very aware that you were telling people this and they didn't want to hear it,* [laughs] *they were very uncomfortable, it was, that lack of self-censorship, but I just couldn't not mention her, I was just so terrified of her not being real to people, or people not knowing about her or, and then gradually I didn't need that anymore, I didn't need other people to validate her existence to me…* (Participant 3, Mother)

Parents who perceived a lack of acknowledgment of their baby's personhood, or others' avoidant behaviour, contested this silence in a challenging or confrontive manner, thus asserting agency and control over social interplay, and resisting the dominant discourse in an effort to normalise their ongoing relationship.

> *…apart from my mother-in-law and my husband's best friend, nobody with any regularity would acknowledge it, and I now kind of force it upon everybody, that's what we do…* (Participant 11, Mother)

Parents most commonly effected disclosure in a protective or considered manner. Apprehension and uncertainty problematized social interaction and

there was a definite concern for some parents that disclosure could sometimes provoke an awkward or negative response from others. As a result, parents typically evaluated the situation prior to disclosure, assessing the social context/situation and whether it was appropriate to divulge information about their stillborn baby. This cognitive assessment included an appraisal of the level of detail deemed socially acceptable or permissible to disclose, the impact on the audience, the subsequent effect on them personally, and also the potential negative impact on, or dishonouring of their baby's memory, should the audience respond in a negative way. This complex social interplay is reminiscent of Goffman's (1963) dramaturgical theory relating to stigma and identity management in social settings. Brierley-Jones et al. (2014-2015) applied Goffman's framework to qualitative data from mothers of stillborn babies and reported that stillbirth, as an unexpected event can be conceptualised as "off-script" and result in "confusion and a disintegration of the social setting" (p. 157). Subsequently, mothers often felt responsible for the responses of others and attempted to counter the uncertainty of others by taking control of the situation. Similarly, in the current study, parents often attempted to manage social interactions.

Disclosure was predominantly influenced by three key factors, firstly parents' concern for their own self-protection.

> *I mean it gets easier, I think in the beginning I was much more militant about telling everybody, everybody must know, and then I started to realise I need to protect myself about what I need when, what I tell people and when you don't.* (Participant 10, Mother)

Secondly, by a responsibility to protect others.

> *…I've been thinking about me and my promise to* [baby], *and somebody who I really don't know very well will say "How many kids have you got?" and I say "I've got 3 but my first child was stillborn" and that's my commitment and my promise, but what I was never really thoughtful of, is the quite significant impact that can have on the person you've just shared that news with* [laughs], *'cos they're not expecting a deep and*

> *meaningful expression, and they just wanted to know what the weather was like /…/ I haven't changed that but I try to get a sense now of erm…/…/ it's more about being respectful to those present.* (Participant 12, Father)

Finally, by a desire to safeguard their baby's memory.

> *I think I'd be concerned about how people would take it, would they think it's as important as I do, and then if they didn't I'd be offended, I'd feel like they were, like, disrespecting* [baby] */…/ the more I can keep it to myself, and keep it to* [husband] *and my mum and my dad, the more protected, the more I feel I can protect him* [baby]. (Participant 4, Mother)

Parents often struggled with social dilemmas such as whether to disclose information about their stillborn baby when asked how many children they had, or whether this was their first child during subsequent pregnancies. Such social predicaments have previously been reported in the stillbirth literature (Brierley-Jones et al., 2014-2015; Murphy, 2013). Murphy (2013) described "a weighing-up of the situation" by parents redolent of the evaluation process outlined above (p. 11). In the current study, choosing not to mention their stillborn baby often precipitated feelings of anguish and guilt as parents felt complicit in the devaluation or denial of their baby's existence.

> Interviewer: *And if you feel that you're not in the mood for that, or it's not the right situation so you haven't mentioned it, how does that make you feel?*
>
> Participant: *I always feel crap, I feel like I've denied him, you know, I need to find the language for this, I've talked to* [friend] *who I've made friends with who lost her little girl and she said she's the same actually, she picks the right kind of situation /…/ we do a similar thing /…/ and what you need is a kind of script, so something that you say, so that's the thing that you say, 'cos that's how I kind of cope with it day to day /…/ so having a script that you can roll out to people and say "Well*

*actually this isn't the first, actually we've had three" so I'll work at that, 'cos probably we won't have any more so I need to kind of work out how to explain what our family consists of.* (Participant 10, Mother)

Self-denigrating, problematic emotions such as guilt have been shown to positively correlate with maternal grief and can have an adverse effect on mental health outcomes (see Barr & Cacciatore, 2007-2008). Moreover, as evidenced by the current findings, increased anxiety and uncertainty in social situations, together with cognitive exertion associated with frequent assessment and attempted management of social situations, must be draining and resource depleting for parents. Developing pre-set answers to difficult questions or a script with which parents felt comfortable, appeared to help exert some control over social encounters and was another example of a self-protection strategy.

It has been suggested that "society polices bereavement /…/ Those who do not conform to social expectations are labeled aberrant" (Neimeyer et al., 2014, p. 493). Some parents in the current study expressed feeling socially and morally judged by others when they shared their relationship with their baby and their desire to maintain his or her presence in their everyday life. This appeared to be more keenly felt as time passed. The following mother's emphasis that it is "healthy" to talk suggests parents experience sharing as an adaptive function, but also highlights society's tendency to pathologise parents' ongoing desire to incorporate their baby in social interaction, years and decades post loss.

*I think it would help for people to understand that it's healthy, for the families to be allowed to talk about it, and that we have just got a short time-frame of memories, and so if we talk about those memories over and over again, it's because it's all we've got to talk about, and that's why they're so precious, if you want to support somebody then you have to allow them, to give them permission to talk, and not think it's weird or* [laughs] *and it's not contagious.* (Participant 1, Mother)

The majority of parents alluded to sensing a growing societal pressure to "move on" from their baby over time, and thus align with a seemingly dominant discourse promoting emotional disengagement from the deceased.

> *…but I just couldn't understand, people who I'd been friends with from being little and gone through school with, and gone through so many times, and they just, their attitude towards it, in that perhaps I should've, I should move on and oh am I still talking about him*. (Participant 1, Mother)

Walter (2005a) highlighted the potential for individual family members to respond differently to bereavement, disparities which can apply pressure to family units. Evidence of this emerged in the findings of the current study reported here. For example, divergent perceptions of continuing bonds expressions often caused tension in relationships, as even close family members made judgements about what constitutes a socially appropriate expression of parents' relationship with their baby. Parents who were perceived by certain others to be transgressing or challenging these social boundaries, tended to meet with opposition and judgemental responses thus exerting pressure on existing relationships.

> *I mean I had a very big disagreement with my husband's older sister in the first year, because I wanted to have a celebration of him on his first birthday, I wanted to be around the people who would have made a huge impact in his life, so that was the people who we'd chosen as god parents and our families, his one sister, husband and three children didn't turn up, and she said to me "I couldn't sit there with a party hat and cake and jelly" and I was like "I've no idea where you've got that impression from there wasn't cake and jelly, there wasn't party hats, I just wanted us all to be together on this difficult day".* (Participant 8, Mother)

An increasing societal expectation that parents would eventually "let go", and not continue to engage in a relationship with their baby, seemed to cause some parents to seek to justify their ongoing relationship. Quintessentially, one

mother explained how she needed a valid reason to talk about her baby, his birthday providing that socially permissible opportunity.

> *…because as time goes on it's less acceptable to talk about him /…/ he is talked about but because he hasn't got a big occasion all through the year, when it's his birthday that's the one day that we can, that it's acceptable to talk about him, and if I go to school and I'm feeling a bit tearful and somebody says "Are you alright?" and I say "Oh it would have been* [baby]*'s birthday" that's different to in the middle of summer I go and I'm upset and I say "Oh I'm thinking about our* [baby]", *'cos it's not, it's not, I haven't got a reason why.* (Participant 1, Mother)

As illustrated by those who reported sense of presence experiences, parents were acutely aware that their behaviour might be adversely judged or pathologised by others. Therefore, they often employed a similar counter-balancing strategy by pre-empting potential social denigration with acknowledgements that others might consider them or their behaviour "mad" or "weird". This provided further evidence that acceptance of continuing bonds expressions is not embedded within contemporary society, and that more traditional notions of emotional detachment from the deceased and moving on are still prevalent.

> *… I just knew I wanted to have pictures, so, this might be weird, well why were you taking pictures of yourself with your baby that was, had died, but I just thought it's memories*. (Participant 2, Mother)

> *…I think some people probably think I'm raving mad, you know especially when it comes to Christmas and things and I'm saying you know "We bought* [baby] *this" or "I've bought* [husband] *this from* [baby]*" and you can see their faces as if to say "Why?" But the people that matter to me understand and that's all I care about…* (Participant 8, Mother)

As previously stated, many parents reported muted social responses to their loss experience characterised by silence and avoidance. However, parents

also recounted a number of instances when social responses were ill-informed, insensitive, inappropriate, and as a consequence, unhelpful.

Whilst parents acknowledged that support from others was generally well-intentioned they often encountered ignorant and hurtful responses. Critically, bereavement support groups offered some parents a safe and understanding environment in which to offload their upset and frustrations.

> *…we also had people say stupid things, and I said you just have to kind of, we were both quite good, I mean, our Sands' group can often be a place to rant about these things, you know, you come in and you bring it "And somebody said this to me!"* (Participant 3, Mother)

The following mother spoke of a lack of understanding from others who could not conceive of the pain and magnitude of their loss, and a propensity from some to want to remedy the situation.

> *…you know that you now have to deal with that "other people just don't understand", we're still in that whole world of "unless you've experienced it, you'll never get it", you can empathise and you can have an idea and all the rest of it, but that deep pit of your stomach pain, the grief, unless you've experienced that you'll never relate, or understand people's behaviour, and I think that's the other thing, it does make you behave a bit oddly sometimes* [laughs], *you know obviously it feels normal to you but other people want to be able to fix things, and just for me it's very much you just go with what feels right, and actually people get used to it or they don't…* (Participant 11, Mother)

Inherent in most parents' narratives was the notion that engaging in a relationship with their stillborn baby could at times evoke both solace and pain. However, the pain seemed to represent their enduring love and would be borne in order to remain connected to their baby in a meaningful way. This is reminiscent of the Romantic conceptualisation of grief (Stroebe et al., 1992) discussed in Chapter 1, with grief and love being inextricably linked and emotional pain accepted as a testament to deep and perpetual love for the

deceased. This view is redolent of mindfulness practices, underpinned by Eastern spiritual teachings which promote an open, non-judgemental and accepting attitude toward life's experiences (Bishop et al., 2004; Kabat-Zinn, 2003) and is in contrast to modern day Western tendencies to quickly eradicate emotional pain. Social pressure to recover from emotional pain is discussed further in the following main theme *Journeying with grief*.

In the current study, those who had not experienced child loss appeared to find the continued presence of pain difficult to comprehend or accept, and imagined that it would dissipate if the parent relinquished their ongoing relationship with their baby. This highlights the need to amplify and disseminate parents' experiential knowledge more widely in society to ensure that the discourse of stillbirth and continuing bonds is heard beyond the perinatal loss community, with the intention of improving society's understanding and subsequent response to parents' enduring relationship with their stillborn baby.

In line with Klass's (1996b) suggestion that sharing mental representations of the deceased child with supportive others can potentially facilitate parents' loss adjustment, most parents explicitly referenced the beneficial effect of discussing their baby with compassionate listeners.

> *…I just wanted to talk about her, and that was my way of coping, and as I say I've had some really good friends who were happy to talk about her…* (Participant 9, Mother)

Sharing online, especially via charitable websites and forums was also common as it offered an immediate channel of communication and support to parents any time of the day or night.

> *…in the first year I spent most of my time online, in support forums, and that was my form of support…* (Participant 11, Mother)

Most parents predominantly sought support and empathy from other bereaved parents. Again drawing on Goffman's (1969) work on stigma, Riches and

Dawson (1998) have previously noted how members of the loss community provided a “trusted” environment for bereaved parents in which they could discuss their child more freely and with fewer restrictions than they would experience in wider society. Consistent with these observations, parents in the current study found those with similar experiences to their own provided an accommodating safe haven in which to experience their ongoing relationship.

> *…because I’ve got a network of friends who are bereaved parents anything I do or say with regards to my relationship with* [baby] *is really well understood, outside of that network, and the friends I have outside of that network and other kinds of people, colleagues or acquaintances or whatever, I think it is less understood, and I think there is still a feeling of, kind of “Oh why are you still talking about him?” or “Why are you still doing those things around his birthday?” or whatever, every year, you know this many years on*. (Participant 5, Mother)

The loss community and other bereaved parents not only understood their stillbirth experience but also empowered parents to freely express their continuing bond with their baby, in an open and intuitive way, thus affirming and normalising their ongoing relationship.

> *…you get a chance to have a chat with other parents about their loss, so it may have been how long ago it may have been, and you discover that no matter when your baby died, or what reason your baby died, you’re left with the same grief, and so you feel that you’re not going mad and everything’s quite normal actually, the way you’re feeling, and so that’s, that allows you then to think even more about your baby if that’s what you want to do.* (Participant 6, Father)

Moreover, the loss community created environments of understanding, devoid of the judgement and pressure to move on experienced in society at large.

> *…I thinks it’s that, going into a room and realising that every one of those people in that room are on the same journey as yourself, you build special bonds with people, you realise that at certain times of the*

> *year they're going to be feeling exactly how you're going to be feeling, and you don't have to explain to them, and they don't expect you to get better, or move on, they understand.* (Participant 8, Mother)

These findings reflect those of previous studies (Cacciatore, 2007; Klass, 1996b; Laakso & Paunonen-Illmonen, 2002). Klass (1996b) observed how sharing mental representations of their child with other members of self-help groups who had experienced similar losses, helped to validate parents' bonds with their deceased child. Laakso and Paunonen-Illmonen (2002) highlighted the importance of bereavement support groups and their enabling environment on mothers' experience of social support following child loss, as they were found to encourage, or provide *permission* to talk freely about their child's death. In a similar vein, Cacciatore (2007) reported that support groups provided a protective, understanding, mutually nurturing environment for women following stillbirth, as a result, they felt less weighed down by expectations of recovery encountered in wider society. Online peer support has also previously been shown to benefit bereaved mothers. Offering and receiving emotional, cognitive and community support via an internet discussion forum was found to engender a strong sense of communality which helped mothers to forge friendships with empathic others (Aho, Paavilainen & Kaunonen, 2012).

As evidenced in the preceding pages, society in general does not fully appreciate or accommodate parents' ongoing relationship with their baby over time. Moreover, a number of parents were left disappointed by the response of certain family members and friends, with some relationships becoming destabilised or breaking down irrevocably. Consequentially, many parents re-structured their social support systems in order to accommodate their relationship with their baby.

> *…I mean there were some friends we've never spoken to since, and I would probably be confident in saying that certainly within those 12 months to 2 years that those people to start with all but changed completely, and I could count on one hand probably the family units that*

*we're still in touch with, all our friends now are really a new set…* (Participant 11, Mother)

This process of re-evaluation of existing relationships and restructuring new affirmational sources of support that share and validate parents' experience of enduring connections with their baby is redolent of the culture of bereaved parents described by Riches and Dawson (1996). Socially isolated and stigmatised, parents often immerse themselves in bereavement communities whose like-minded ethos "legitimates the need for time to grieve, to share memories of dead children, and to search for meaning behind the loss" (p. 144). It should be noted that the majority of participants in the current study were actively involved with Sands and therefore may have been more inclined to forge mutually supportive relationships with other bereaved parents whom they encountered through their association with the charity. For this reason, parents' tendency to predominantly share, and find support for their continuing bond with their baby from other bereaved parents was further examined with a larger, more diverse sample in Study 2 (see Chapter 3).

**Summary of theme *Negotiating the social landscape***

Society's expectation of an enduring relationship between a bereaved parent and their stillborn baby appears to be limited, consequently, social attitudes toward the relationship were often ill-informed. A number of parents perceived a cultural devaluation of their stillborn baby's existence and personhood which appeared to fuel their efforts to seek wider social validation, to establish and crystallise their baby's social status/personhood and ongoing significance in the world through sharing their relationship with their baby with others, whilst also asserting their own status as parent. Parents disclosed information about their baby spontaneously and in a protective manner in line with observations made by Charmaz (1991) during a study of chronic illness. In the current study, a third category emerged i.e. confrontive or challenging disclosure, indicative of some parents' efforts to secure acknowledgment of their baby and normalise their ongoing relationship. Typically, parents felt comfortable sharing their relationship with their baby with some family members, friends and colleagues. However, most also alluded to barriers to disclosure. Some

parents perceived a general reluctance to talk about stillbirth in social settings which left them feeling stigmatised, marginalised and socially isolated. Parents did not feel their relationship with their baby was widely understood. Most felt less able to talk about their baby and more pressure to justify their relationship over time. Hence, most shared their ongoing relationship with their baby with other bereaved parents who validated their child's existence, and supported their continued presence in parents' lives.

### 2.4.3 Journeying with grief

*I mean the grief was immense, the grief was huge…* (Participant 10, Mother)

Manifest in all parents' narratives was the sheer magnitude and intensely debilitating nature of their grief following the death of their baby. The third theme identified was *Journeying with grief* consisting of four sub-themes which explore the nature of grief and how parents manage the pain, the influence of time on their loss experience, parents' search for meaning, and aspects of male grief.

#### 2.4.3.1 Managing the pain

Grief has been defined as an emotional response to the loss of a loved one which can also encompass physiological, psychological, behavioural and spiritual reactions (Brier, 2008; Gross, 2018; Stroebe et al., 2001a; Worden, 2009). The death of a child has been found to provoke more intense, enduring and complicated grief reactions than other types of bereavement (Zeanah et al., 1995). Complicated grief is generally considered to be grief that is too intense, persists over too long a duration, and impairs functioning (Walter, 2005b). Evidently, grief responses that significantly compromise physical, psychological or relational wellbeing over an extended period are serious and a potential threat to physical and mental health. Implicit in all parents' accounts was the acknowledgement that impaired functioning over time was insupportable and undesired, both for them and their families, and was especially pertinent to those who had ongoing parental responsibilities.

However, persistent and at times emotionally intense grief was common to the majority of parents in this study.

Contrary to many prominent models of grief developed during the latter part of the 20th century which posit coping with bereavement as a succession of phases to be passed through, or tasks to be executed, in order to achieve a successful outcome encompassing recovery (e.g. Bowlby, 1980; Worden, 1991), many parents stressed that their grief experience did not reflect or adhere to a progressive, linear trajectory. Notions of fluidity, unpredictability and continuation seemed to better encapsulate parents' perceptions of their journey with grief.

> *…one of the blog posts that I wrote was how I could go through the whole grief cycle in twenty minutes and then back to the beginning again, and then some days it would last, get stuck in a place for months, and you know how it wasn't linear, it wasn't a neat progression from "oh I'm in this stage today".* (Participant 3, Mother)

Similarly, another father articulates the often unpredictable fluctuations in his response to his son's death.

> *…actually the graph of how hard I found it was something like* [draws line to indicate difficult at first then a dip and then another peak], *very very hard, very very difficult, gradually gradually easier, but then actually got harder again…* (Participant 7, Father)

One mother spoke of the need to consciously micromanage her time to survive the day.

> *I took every day as it came, so how I felt one day was probably different to how I felt the next day, so I just had to, I mean when I first started I remember saying to* [husband] *"Right we'll just take this 20 minutes at a time", and we were literally, it was taking our day 20 minutes at a time to get through the day, and then you would just be pleased when the day was over because it's so bad.* (Participant 1, Mother)

Whilst acute grief subsided and functionality improved over time, overwhelming sadness and emotionality resurfaced on occasion for one mother over a decade after loss.

> *… I mean it is still there but you know, it shifts, it's less intense, it's not quite as, you know that grief as it were, it softens and it changes, you know I've gone with it, I mean I still have very dark days about it, but far less.* (Participant 11, Mother)

Again, the following mother explains that grief can rise unexpectedly at times over the years, and whilst those occurrences of heightened emotionality become fewer over time, they remain an ongoing part of her loss experience.

> *It's the proof, it's just the reinforcement that I didn't dream it all, 'cos sometimes I can, I do think about him every day but some days I'm kinder on myself, and then some days I wake up and think "My baby died" and that's it, I can't, it just, it could have happened, it feels as if it happened yesterday, and I don't get those days as often now, but they're still there, and you don't know what triggers it.* (Participant 1, Mother)

Seven years on from his daughter's death, one father spoke of pervasive grief as an accepted part of his life.

> *…the pool of grief that's always there now /…/ this is part of your life, this has happened to you, so just a reminder that it's not good, it's not bad, it just is, and it's fine for it to be just is, it's probably not fine for you to try and just forget about it unconsciously.* (Participant 12, Father)

The overwhelming magnitude of grief for some parents appeared indicative of their ongoing emotional attachment to their baby and testified to the strong affective ties already forged with their baby prior to their death, and subsequently developed despite their baby's physical absence.

> *There's something about acknowledging it you know, acknowledging that you've had this kind of horrendous experience, you know you don't*

*grieve like that unless there's a connection, you know you don't grieve for people that don't mean anything to you, the fact that it was such a huge grief said a lot to us about the journey that we'd already made to try and become parents, so I think we do keep him alive, /…/ and I think that just feels like really important 'cos he's part of us so if you hold onto something in that way he's still part of us, if that makes sense.* (Participant 10, Mother)

Critically, if grief is a reflection of enduring love for some parents, they do not hold the same expectation as society that there will be a complete *recover*y from grief. Again this puts them at odds with the prevailing discourse, as they contest traditional frameworks for coping with bereavement which promote a desired terminable state. In addition, the following observation reinforces the point (previously made in 2.4.1.2 in relation to creating and evoking presence), that society does not view stillbirth as a legitimate loss, and fails to fully validate baby's existence or appreciate parents' ensuing grief experience, especially over time. This mother perceives a societal pressure on parents to recover from their grief over time.

> *…I suppose you do think what people might think of it all, when you're sort of 5 years down the line, I think people forget that you're still grieving for that child, it's still a child that you've lost…* (Participant 10, Mother)

Similarly, the following mother alludes to a societal expectation that she will "get over it".

> *…they* [society] *think that you'll get over it, and it's not possible, it's completely impossible because it's your baby…* (Participant 4, Mother)

Following controversial changes to diagnostic criteria for major depressive disorder (MDD) in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5*;* American Psychiatric Association, 2013), a number of concerns have been raised in relation to parents who have suffered a traumatic loss. The changes removed the existing bereavement exclusion that discouraged

diagnosis of MDD in bereaved individuals who had experienced a bereavement within the last two months, and introduced a new bereavement specific disorder pertaining to intense and prolonged grief presenting 12+ months after the death of a loved one, referred to as persistent complex bereavement disorder (PCBD). It has been argued that arbitrary timescales and diagnostic criteria, which include intense grief-related symptoms indicative of a continuing bond with the deceased, increase the risk of pathologising a normative response and a "legitimate form of human suffering" following the tragic loss of a child (Thieleman & Cacciatore, 2013a, p. 6; Thieleman & Cacciatore 2013b). Moreover, Doka (2017) challenges the notion that grief follows a timetable, or is a state from which the bereaved will recover, rather suggesting that "grief involves a lifelong journey" (p. 17). The narratives of the parents in this study would certainly indicate that intense grief rarely adheres to published cut off points, and whilst most parents discussed experiencing recurring dark periods of intense emotional pain over the years, their stories concomitantly suggested continued functionality and indeed demonstrated positive personal transformational growth.

Parents' acute awareness of their ongoing emotional vulnerability was clear during discussions. The majority of parents reflected on a lasting need to consciously and actively manage their enduring pain following their baby's death. This management appeared to encompass a process of confrontation of, and retreat from their loss. Whilst all parents were comforted by and thankful for their sense of a continuing bond with their stillborn baby, and determined to maintain that nexus in some form for the remainder of their lives, they acknowledged that caution had to be exercised at times to avoid being subsumed in a maelstrom of emotional pain and overwhelming distress.

One father likened reading personally written accounts of his loss experience to handling dynamite. The use of such a powerful simile emphasises his caution toward becoming engulfed by grief, and the ongoing necessity to mindfully manage his emotional state.

> *… it feels a bit like handling dynamite, I'm really happy it's there to be read but the act of reading it, well I suppose my worry is that it would*

> *just be very upsetting in a way that would be difficult for me to manage, and this is possibly a difference between me and* [wife], *that I think right the way along she's been more ready to, well more ready to think about* [baby], *to sort of face the distress of it really…* (Participant 7, Father)

A number of parents highlighted the potential dangers of being drawn into a world of overwhelming sadness. Attending a support group meeting, whilst initially comforting, became too oppressive and all-consuming for one mother. Interestingly, she describes a struggle to redefine and reclaim her personal loss experience, reframing it in a less negative light.

> *You're just providing sort of comfort to each other, but then I think for me there came a point where…I was getting dragged too, too deep down into it and I couldn't separate… sort of my own life from, that was becoming my life. Living in this world…erm, where it was all I was thinking about. /…/ And in the one sense that was good because I felt closer, because that was the only thing I knew about how I felt about my son, but then on the other hand I was battling because I didn't want that experience to all be about negative thoughts.* (Participant 2, Mother)

Evidently, all parents who took part in the study experienced an ongoing bond with their baby. Engagement in this relationship demonstrated a willingness (to varying degrees) to confront their loss and the concomitant pain which invariably accompanied it. However, constant exposure was deemed deleterious to their well-being. As a consequence, parents spoke of a definite need to retreat from their loss experience at certain times in order to protect themselves and their family.

> *…and I dunno if you get better at blocking some things out in a sense, you know, I think you allow in what you can, as time goes on, you allow in what you can cope with, because it would be too painful I think to expose yourself to everything*. (Participant 2, Mother)

Oscillating between submersion in the loss, and safe retreat from it, appeared to be an important process in safeguarding parents' long-term mental health and well-being. The following mother explains how visiting her daughter's grave is sometimes too difficult but at other times vital.

> *…there are times when it's actually quite hard, there can be months when I don't go at all because I don't want…want to but, erm, sometimes I just get an absolute compulsion to think, yes this, I need to go, you know, I know when I've been away too long.* (Participant 3, Mother)

Stepping back from the pain of loss was particularly relevant to those parents who worked for stillbirth charities, and were frequently immersed in the bereavement experience of others which can be reminiscent of their own.

> *…I mean even now I'm taking a bit of a step back again from the meetings because now working for* [charity] *I'm finding it that my whole life is becoming* [charity], *which when you start looking at photos of babies' graves and you start talking about babies' deaths as part of your everyday life, you realise that sometimes you need to take a little bit of a step back, because it's not normal and you shouldn't start thinking of it as normal, when you do you need to take a little bit of a step back…* (Participant 8, Mother)

This process of submersion and retreat employed by parents to manage their pain is concurrent with the regulatory mechanism of oscillation described in Stroebe and Schut's (1999) Dual Process Model. As outlined in Chapter 1, this coping-adaptation paradigm defines key components related to coping following the loss of a loved one, specifically loss-orientation, and restoration-orientation. The former refers to a focus upon, or confrontation of the pain of the loss itself and includes continuing bonds, conversely, the latter incorporates attention to the secondary consequences of bereavement. It emphasises the importance of respite from grief as well as grief work. More recently Stroebe et al. (2010) have posited an integrative framework drawing upon attachment theory, the Dual Process Model and Mental Representations

Theory (Boerner & Heckhausen, 2003) which allows for examination of the relationship between continuing bonds and bereavement adaptation. Essentially, securely attached individuals are able to oscillate easily between loss and restoration orientation, as a result, the bond with the deceased is maintained but adaptively relocated over time. In contrast, the insecure attachment styles are characterised by either extreme loss/restoration orientation, or disturbed oscillation, which can result in relinquishing bonds in a maladaptive manner, or in confused connections to the deceased. As previously discussed, a number of parents in the current study were keen to emphasise significant attachment to their baby during the course of pregnancy and prior to birth. This may have resulted in secure attachments to their baby which have fostered a positive ongoing connection with them and enabled adaptive oscillation between loss and restoration orientation, and integration of their baby into their ongoing lives.

It should be noted that whilst the DPM framework is more dynamic, fluid, less prescriptive and more sensitive to individual differences than linear stage models, it is criticised for retaining an expectation that grief has an endpoint, and that there is a time restricted progression towards a state of recovery. Moreover, it has been argued that it does not fully encapsulate the notion that the deceased can be permanently integrated in to the survivor’s everyday existence (Valentine, 2008; Valentine, Bauld & Walter, 2016). As with the aforementioned changes to the DSM-5, pervasive expectations of a cessation of grief could exacerbate pathologisation of those who do not meet these expectations, and may further marginalise or stigmatise bereaved individuals who report feelings of social isolation, as is the case for the majority of parents in the current study. As evidenced in the data, pressure to get over the emotional pain associated with their baby’s death that is inherent in society’s response to parents’ loss experience, is unhelpful, and does not encapsulate the nature of the enduring, at times overwhelming, emotional connection to their stillborn baby.

#### 2.4.3.2 The influence of time

The subject of time permeated parents' accounts of their continuing bond with their baby in many ways. As previously discussed, the passage of time complicated parents' relationship with their baby as it exacerbated societal pressure to conform to cultural expectations promoting relinquishment of emotional ties to their child, thus inhibiting their opportunities to share mental representations of their baby with others. In addition, the passage of time served as a useful mechanism through which parents could explore their grief journey and observe changes to their loss experience.

Parents often located themselves temporally during their narratives to enable reflection on changes to themselves, and to their relationship with their baby during the bereavement process. Parents tended to make distinctions between the early aftermath of loss and their current position. This allowed parents to explore how they adopted various expressions of their continuing bond at certain times, as their journey with grief progressed and their relationship with their baby unfolded. However, the passage of time also appeared to serve to distance parents from the unbearable moment of death and initial debilitating and disorienting nature of grief. Time brought changes to how parents expressed their relationship with their baby, and a clarity to their personal perceptions of ever evolving connections.

> *I think particularly in that first year, until you get to their first birthday is the most difficult year, and then after that it becomes difficult at particular times, some random, or sometimes it's because of anniversaries or things remind you or whatever, I think in that first year, I was driving to try and forge a relationship with him /…/ but I think, longer term now nearly 4 years on, it's about maintaining that relationship with him, which we do through the doing new things, or the writing a blog post to him on his birthday, or having his scan picture or footprints out in the house and things like that, so I think it's maintaining it, whereas I think that first year particularly through all the fog of the grief that was round me, I was trying to find a relationship, and trying to*

*work out how to have that, and how to manage that when he wasn't here…* (Participant 5, Mother)

The strength of their ties to their baby did not diminish for most parents. However, for some, confronting the loss and accessing mental representations became easier over time as they were able to make connections with their baby in the midst of their everyday lives which evoked a more positive emotional response.

> *..it's not so raw, that's more about grief I guess than the connection, but it's not so raw, so I find it easier to think about him, and then shift back to whatever I'm doing, whereas if I did that before I'd just be in a terrible state, and I still have times when I'm in a terrible state, it just catches me and I'm like* [inhales], *it's actually not that far under the surface really, but I can think about him and think about that and then kind of go back to what I'm doing, much more fluidly and easily, there's something about being able to just kind of reflect on it and think about him, without it being so excruciatingly painful, it's quite nice…* (Participant 10, Mother)

The passage of time brought changes to parents' approach to the relationship and how they expressed their continuing bond. Inherent in many parents' narratives was a progression from external and material expressions of their relationship with their baby, to those that were predominantly internal, psychological, spiritual and affective.

> *…it's funny the things that were important in the beginning, that aren't as important now, I don't go to the grave as much now because I do find it upsetting, there's sometimes when I feel like I need to go, and I don't spend very long there, when he first was buried I was there all the time, and it was a big deal to kind of, when we went on holiday the first time and I had to go to the grave before I went, I had to go as soon as we came back, because I felt guilty for leaving him, and I felt guilty for…not getting on with my life but trying to get my life back together, I hated the thought that people thought I was moving on from it, but now*

> *I understand that it just changes, it doesn't get easier over time, it just kind of changes and you just cope with it, it becomes different.* (Participant 1, Mother)

Parents' need to confirm their baby's existence, as discussed in the preceding main theme, lessened for some over time. One mother explained her bereavement journey had led her to a more peaceful state when she no longer felt compelled to materialise her baby or justify their relationship.

> *… over the years I have softened and I think maybe I don't have to, justify her existence almost, as though, I know, I don't have to buy teddy bears to prove she was there...* (Participant 11, Mother)

Moreover, parents' inclination to prove their love for their baby through physical representation and frequent engagement in ritualised activities generally subsided over time. The following mother alluded to the potential addictive power, and risk involved in becoming too reliant or involved with ritualised expressions.

> *…I think I've come to find a point where I'm comfortable with what I do and that's the way I do it now, you know decorate the tree and we do that as a family now with the kids, and I write in my diary when I feel like it and, but then I think as well it's not becoming to the point when it's consuming everything I do, like with when I was saying about lighting the candle every night./…/ Because I did eventually realise that those physical things, it didn't matter if I did them or not because it didn't change how much I loved him, I still loved him the same whether I did it or not, that was the guilty feeling, like oh well if I don't do this then he'll think I've forgotten about him or I've stopped loving him.* (Participant 2, Mother)

A number of parents reported initial feelings of guilt when their engagement in certain rituals decreased or ceased. However, this change from frequent engagement in multiple external expressions to a more internalised

experience of bonds was perceived to be healthier and easier to maintain by most parents long term.

#### 2.4.3.3 Searching for meaning

Gillies and Neimeyer (2006) suggested that meaning reconstruction was central to most theoretical conceptualisations of bereavement and grief. Reflective of its centrality, a quest to find meaning in their loss experience was inherent in all parents' narratives.

Bereaved parents who perceive themselves to have been inadequately prepared for their child's death have been shown to be at greater risk of experiencing chronic or complicated grief responses (Barry, Kasl & Prigerson, 2002). Moreover, it has been argued that an unexpected death, such as the loss of a child, is in complete opposition to the assumed natural order of the world, and as a consequence, can pose a greater threat to the bereaved's existing belief system, thus causing elevated distress (Tedeschi, Orejuela-Davila & Lewis, 2018). This is particularly pertinent to the parents of stillborn babies who are rarely aware of any impending problems until their baby's death is confirmed. Parents acknowledged the shocking unexpectedness and unanticipated nature of their baby's death.

> *… because* [baby]*'s death was a total shock to us, we weren't, we didn't have any preparation time because she died at the very, very end of my labour.* (Participant 3, Mother)

The word "expecting" is commonly used as a synonym for being pregnant. It could be argued that considerable post war medical advances, an increase in hospital deliveries and a widespread medicalisation of birth (Davis, 2013) have resulted in a commonly held view or expectation that once the 12-week dating scan is complete, pregnancy effects a live baby. This kind of assumed surety left parents in the current study unprepared and appeared to contribute to their overwhelming sense of shock, disbelief and devastation at their loss. Stillbirth was an unimaginable outcome.

> *… you don’t hear about people losing babies after 12 weeks, you just don’t, and then you get your second scan which I thought was just, so you can get another picture, it never, even though they called it an anomaly scan, it never crossed my mind that it would, that there would be something wrong with my baby, you know, and there wasn’t, he was absolutely perfectly healthy, and so I kind of coasted through thinking, it never crossed my mind that anything could go wrong, so I was angry that I hadn’t been warned.* (Participant 1, Mother)

A bereaved parent often loses more than their child following stillbirth. Abruptly encountering an existential crisis (Cacciatore et al., 2013); with their extant view of, and beliefs about the world challenged, and with their former sense of self-identity fractured in the tumultuous aftermath. It has been suggested that a death that is sudden, shocking or premature that deprives a person of an important figure on whom his or her identity depends, can provoke a challenging search to re-establish or reconstruct meaning post loss (Neimeyer & Hooghe, 2018). Accordingly, data in the current study showed that this disorienting and wholly unanticipated tragedy commonly precipitated a search for meaning and ensuing process of reconstruction, as the majority of parents struggled to assimilate such a brutal and senseless occurrence into their wounded worldview. For most, this search for meaning was intensive and often prolonged.

> *…but you just think why? Why is it me? /…/ I’d be up during the night, I couldn’t sleep, and I was just searching for answers, as if I was going to get this great answer that was gonna change things.* (Participant 1, Mother)

The prevalence of parents’ attempts to find meaning in their negative life experience is consistent with previous studies suggesting the process is common for a variety of populations (Lehman, Wortman & Williams, 1987; Silver, Boon & Stones, 1983). The process of meaning-making is thought to favourably contribute to bereavement adaptation (Cacciatore, 2013; Gillies & Neimeyer, 2006). Furthermore, finding positive meaning is integral to coping (Stroebe et al., 2001c). Three primary tenets of meaning-making have been

proposed: comprehensibility or making sense, significance or finding worth, and identity transformation. (Davis et al., 1998; Gillies & Neimeyer, 2006; Janoff-Bulman & Frantz, 1997; Park, 2010). Bereaved parents who engage in the least amount of sense-making have been shown to be at greater risk of experiencing higher levels of grief intensity (Keesee et al., 2008). Critically, sense-making can alleviate complicated grieving associated with unexpected loss (Coleman & Neimeyer, 2010). Moreover, higher levels of benefit finding and positive identity change have been linked to better grief outcomes (Neimeyer, Baldwin & Gillies, 2006). In addition, assimilation and accommodation have been posited as key facets of the meaning-making process. Assimilation involves a reduction in the discrepancy between global and situational meanings by re-assessing or altering situational appraised meanings to better align with extant global meaning (see Chapter 1, p. 21 for definition of global and situational meanings). Conversely, accommodation transpires when global meanings evolve to better incorporate situational ones (Park, 2010).

More recently, Kunkel et al. (2014) have offered an integrative view of the meaning reconstruction process in grief-related discourses through analysis of meaning reconstruction formed at the intersections of comprehensibility, significance, assimilation and accommodation. See Figure 1 for Kunkel et al.'s (2014) diagrammatic representation of their typology. This paradigm provides a useful framework for exploring the meaning-making endeavours of parents in the current study. Examples of these four proposed realms of meaning-making were present in parents' accounts and are presented below. Efforts to comprehend their loss were most prevalent during discussions, and appeared particularly intense in the initial period following their baby's death. Time tended to affect a sense of resolution for some, but certainly not all parents, with some indicating that they expected the search for meaning to continue indefinitely.

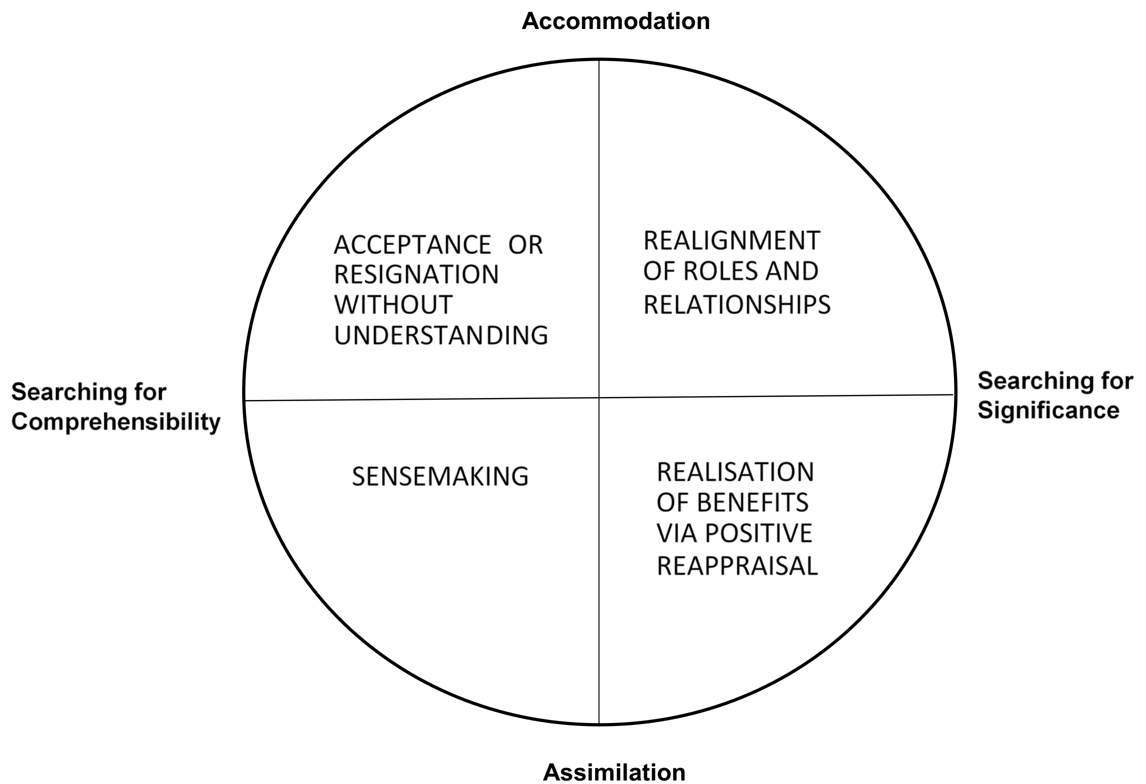


Figure 1. Four types of meaning reconstruction formed at the intersections of meaning-making processes (Kunkel et al., 2014).

Sense-making: Formed at the Comprehensibility / Assimilation Intersection (Kunkel et al., 2014)

Some parents attempted to make sense of their loss in part, usually in terms of medical causes, reasons or failures and achieve assimilation.

> *…he'd stopped growing at 35 weeks, but there was nothing wrong with him, he had, you know… it was, it was my fault he died because it was, he wasn't getting the nutrients, I mean really he starved to death, so there was nothing wrong with him, and it was hard for people to understand that, how can a baby die when there's nothing wrong with him…* (Participant 1, Mother)

Struggles with causality of loss or reasons why this tragedy had happened to them pervaded mothers' accounts. As evidenced in the excerpt above, self-blame was manifest in a number of mothers' narratives, and whilst this was a

negative way in which to make sense of their baby's death, it appeared to allow assimilation to occur, and reconcile situational appraised meanings with global meanings. Whilst knowing the cause of death might help make sense of the experience, self-blame can be corrosive and detrimental to mental health and coping following loss. Society's persistent non-validation and devaluation of stillbirth, coupled with the fact that a large percentage (41.8%) of stillbirths in the UK remain unexplained (MBRRACE-UK, 2018), can lead to critical self-examination and self-blame by some parents. Internalised devaluation of self, encapsulating negative feelings of self-hate, self-blame, shame and guilt, has been shown to be related to reduced self-esteem, adverse grief reactions and increased vulnerability to depression and anxiety (Barr & Cacciatore, 2007-2008; Cacciatore et al., 2013). Bereaved mothers appear to experience guilt and shame to a significantly greater extent than do fathers up to three years post loss (Lang & Gottlieb, 1993; Lang, Gottlieb & Amsel, 1996; Smith & Borgers, 1988-1989; Stinson, Lasker, Lohmann & Toedter, 1992); moreover, they are more inclined than men to engage in self-blame (Jind, 2003; McGreal, Evans & Burrows, 1997).

McCreight (2004) has reported that most fathers felt responsible in some way for their baby's death following pregnancy loss, however, contrary to those findings, no fathers in the current study alluded to self-blame. A number of mothers did assume responsibility for the loss and perceived a failure on their part to protect their baby. Therefore, the current findings appear to support previous research showing that bereaved mothers have a greater tendency toward self-blame than do fathers. Societal expectations, increased scrutiny of pregnant women's behaviour and moral judgements may also be exacerbating mothers' proclivity toward self-blame (Murphy, 2012). Moreover, it may be compounded by the highly complex relationship a mother has with her body following pregnancy loss (Burden et al., 2016), as her body becomes a conflicted site of birth and death (Cacciatore, 2011), evoking anger at her body's perceived failure (Fahey-McCarthy, 2003). Critically, attributing responsibility for the loss to oneself has been shown to positively correlate with several posttraumatic symptoms (Jind, 2003).

Acceptance or Resignation without Understanding: Formed at the Comprehensibility / Accommodation Intersection (Kunkel et al., 2014)

Some parents demonstrated acceptance through adjustment of their global meanings which allowed a seemingly senseless loss to be accommodated into their now altered assumptive world. For some, an acceptance that senseless, unfathomable things can happen in the world seemed to bring a sense of peace and resignation over time and this appeared to alleviate the need to search for a specific cause or reason.

> *…it's changed in a couple of ways, one is an element of acceptance, erm I couldn't tell you when but it was a good number of years, sort of an acceptance of the reality of what happened I think is probably the best way to describe it, you know for, I was almost in a bit of a, looking back on it now, I wasn't aware of it at the time, almost in a bubble of disbelief that it actually happened…* (Participant 11, Mother)

Similarly, the following mother alluded to a gradual shift in her world view to encompass an understanding of an unpredictable and potentially unjust world where terrible events can befall individuals indiscriminately. This shift facilitated accommodation of the experience and assuaged her initial inclination to question her own culpability.

> *Looking for answers, and nothing really changed, just time really, just gradually, I remember somebody else, another bereaved parent saying "I've moved from sort of, why me? To why not me?" Kind of gradually you come to an understanding of, horrible things happen, and it, you know, when it first happens you assume there must be a reason, you assume you've done something...* (Participant 3, Mother)

Realisation of Benefits via Positive Reappraisal: Formed at the Significance / Assimilation Intersection (Kunkel et al., 2014)

Active, positive reappraisal of the loss and benefit finding enabled some parents to assimilate the experience into their assumptive world. One father in

particular, spoke about the way in which he reframed his daughter's death as a catalyst for positive benefits. Interestingly, he speaks of a conscious choice in how the loss is defined, thus taking control of his daughter's narrative. Unusually, he appears to have adopted a pro-active, agentic approach to mentally framing his daughter's death in the hospital in the immediate aftermath of the loss. For most, the meaning-making process was emotionally onerous and prolonged. However, this excerpt suggests an almost immediate reappraisal of the situation as an opportunity to affect positive change in his ongoing life, whilst simultaneously honouring his daughter's memory; weaving his daughter's narrative into his own life story and providing markers or touchstones on which to build their relationship.

> *…I remember being in the ward /…/ talking to* [baby], *making the statement and putting down the markers that were going to, that said "Look, I'm going to honour your memory and continue our relationship by doing this thing, this thing and this thing", and it went from there for me really /…/ That was one of my realisations in this whole thing about taking personal responsibility for how you feel, so it's not anybody else's fault, anything can happen to me but it's down to me how I choose to respond to that, I can't blame anybody else /…/ you just have to accept that and take what you will from it /…/ I have the same sense of gratitude for who I've become off the back of that experience, and off the back of having* [baby's name]. (Participant 12, Father).

<u>Realignment of Roles and Relationships: Formed at the Significance / Accommodation Intersection</u> (Kunkel et al., 2014)

A perceived change in identity was reported by a number of parents, to differing degrees. In addition, a concomitant reassessment of values, goals and relationships was evident during discussions. Some considered themselves to be a completely different person following their experience of stillbirth, whilst others alluded to less dramatic alterations to their identity and sense of purpose in the world.

> *…it's changed my outlook on everything now, my whole life has just been…my perspective has completely been changed. Absolutely different, different, completely different person, my priorities have changed, I'm certainly no longer afraid of the medical profession, you know and I would question everything, so I tend to go into things a lot more, and especially when it's got something to do with the kids…* (Participant 1, Mother)

As expressed above, a few mothers alluded to a new found confidence that had led them to be more questioning of the medical profession.

Increased compassion and empathy were commonly reported alterations to identity, with the majority of parents perceiving a positive transformation.

> *I mean I do hate the world at times because I've lost him, but I try and embrace it, I try to be a better person, for going through what we've been through…* (Participant 4, Mother)

Meaning resolution was not common to all parents. Previous research has indicated that receiving details about the cause of perinatal loss can facilitate meaning-making (Nikcevic & Nicolaides, 2014). However, even after being told a probable cause of death, this mother's search for answers continued.

> *… I think a lot I still write about how I'm feeling, trying to find some kind of answer, 'cos we did have a post-mortem done but it didn't reveal that there was anything wrong or anything that, was just cord compression we think… so I think I'll always search for an answer. So perhaps those feelings will always surface throughout the, the diary and I think that's what, when time goes on and I didn't write as often, is because I felt like I was saying the same things over and over again.* (Participant 2, Mother)

As shown in the above excerpt, it has been suggested that a lack of acceptance and a prolonged and possibly fruitless endeavour to make sense may result in frustration and rumination about the causes (Kunkel et al., 2014).

Moreover, rumination, specifically brooding rumination, has been linked to an increased risk of depression (Nolen-Hoeksema, Larson & Grayson, 1999; Treynor, Gonzalez, & Nolen-Hoeksema, 2003). Evidently, parents' search for meaning was an integral part of their unanticipated loss experience and could potentially influence their short and long-term mental health. In light of these findings, meaning-making and coping following stillbirth was examined further in Study 2 and is reported in Chapter 3.

Although some parents did engage in co-constructed sense making with their partner, there was little evidence that communal meaning-making occurred outside of their immediate social support network. Generally, others appeared to construct meaning at the comprehensibility / assimilation intersection. However, the situational appraised meanings constructed and assimilated by others into their existing global meaning framework, were frequently incongruent with those of parents. Essentially, others rationalised the loss.

> *…you'll have heard all the classics of what people say to try and make you feel better, you know, "How God only keeps the best", "Things happen for a reason" and "Karma" oh karma, when people talk about karma now, and I think oh I don't know what I did in my life for it to happen to me.* (Participant 1, Mother)

As previously reported by Cacciatore (2010), a surprising number of parents in the current study referred to others' platitudes which commonly started with "At least"…

> *"At least you have a living child" "At least you could get pregnant" "At least you know you can get pregnant, at least you can go on and have another one", or "At least she didn't die of cancer when she was seven or you know", it's like, I'm not sure it's you know, we basically have the principle that if the sentence has "At least" at the start of it, or is implied in it, it's probably not helpful.* (Participant 3, Mother)

This may be symptomatic of what Layne (2003) describes as a collective imperative to contribute to the collective happiness of modern society, thus

precipitating a general compulsion to highlight the positives in even the most profoundly tragic of circumstances. Indeed, as previously discussed, the heart-rending sadness and challenging nature of stillbirth is rarely welcome, or addressed adequately in wider society. This imperative to accentuate positive aspects of the tragedy links to the aforementioned modern day tendency to eradicate emotional pain which is also at odds with parents' long-term experience of stillbirth and continuing bonds.

Moreover, it could be argued that others try to assimilate the loss into their existing assumptive world by appraising the loss in a manner that better aligns with their extant global meanings, that is, they tend to trivialise the loss.

> *… you don't say to somebody "Oh well that's just the way it is" or "You're having another baby so it's ok" or "Oh well it's just god's way", it's like, well no it isn't, there's nothing about this that's ok, there's no way that I'm gonna say "Yeh you're right, let's just move on", because it's just so far from it, I couldn't even explain to somebody how it feels, but I know that it's just not right, it'll never be right, I can have another 10 kids and it's not going to be any easier, losing him, it's not gonna make it any better.* (Participant 4, Mother)

In contrast, parents appraise the loss as significant and profound. Consequently, most parents appeared to alter their global meaning framework, or assumptive world in order to accommodate the loss. During their study of volunteerism following stillbirth, Cacciatore et al. (2018) also recently observed this tendency for parents to more frequently accommodate rather than assimilate the loss during the meaning reconstruction process.

Parents often encountered others' misperceptions of stillbirth, typically, the misguided assumption that had the baby lived they would have had some physical problem or mental defect.

> *I mean one of my close friends she said "Well you know, if he'd lived he might have struggled and you would've had to look after him" and I just said "Well I would've looked after him because he's my child" /…/ but*

> *she just assumed that something was wrong with him*. (Participant 1, Mother)

Parents frequently reported a gulf between their personal meaning-making efforts and society's attempted rationalisation of the loss, a discrepancy which invariably caused tension and distress.

#### 2.4.3.4 Male grief

It has been posited that the manner in which a person grieves can be shaped by social context and cultural norms (Valentine, 2008), and gender differences (Stroebe et al., 2001c). Extant literature pertaining to gender differences in coping with bereavement is inconsistent. With reference to Stroebe and Schut's (1999) Dual Process Model (DPM), women appear to be more loss-oriented, immersing themselves in the pain of loss, confrontive of their emotions, and profoundly feeling and expressing their distress; whereas men tend to be more restoration-oriented, actively engaging with the secondary problems and practical issues presented by the loss (Stroebe et al., 2001c). Umphrey and Cacciatore (2011) observed these tendencies as emerging from the narratives of mothers and fathers who had lost a child and were attending a bereavement support group. Fathers were inclined to discuss how coping had affected them in their place of work, any ensuing financial impact, or how they were attempting to manage their relationship with their spouse. Mothers appeared to focus on visiting the cemetery and their emotional responses, and consistently recounted details of the day their child died. However, some studies have found little evidence that coping strategies are dichotomised by gender, concluding that similarities in coping strategies between men and women are as likely to be noted as any dissimilarities (Malterud, Hollnagel & Witt, 2001). Similarly, Feeley and Gottlieb (1989) reported that bereaved mothers and fathers differed in their use of only three of the fourteen coping strategies examined. Mothers used seeking social support, escape-avoidance strategies, and preoccupation to a significantly greater extent than did fathers. Therefore, mothers' and fathers' coping strategies were more concordant than discordant. Moreover, Riches and Dawson (1997) observed that whilst most bereaved fathers remained strong and resolute whilst supporting their partner

and actively attempting to rebuild their lives, some continued to suffer from depression and indeed expressed their emotions as openly as some mothers. While most mothers reported recurring feelings of despair and felt able to express affect uninhibitedly, a large number had resumed full-time employment, or were engaging in other activities relatively soon after bereavement, thus appearing to be exhibiting coping styles more commonly associated with men.

Historically, fathers have been infrequently included in studies addressing reproductive loss (Layne, 2003) and whilst efforts have been made in recent years to explore the male perspective (e.g. Cacciatore, Erlandsson & Radestad, 2013; McCreight, 2004; Samuelsson, Radestad & Segesten, 2001), the focus still tends to be more commonly on the mother's experience. Therefore, it was imperative to try to include fathers' accounts in the current study. Admittedly, only a quarter of the participants were men but their rich, expressive narratives, together with some mothers' perceptions of their male partners' experience of loss revealed a number of interesting aspects of male grief.

A number of parents conveyed that a father's response to his baby's death is often disregarded as he is cast into the stereotypical male role of strong, stoic survivor. This is consistent with previous studies who reported that fathers frequently feel ignored, marginalised or invisible in the aftermath of loss (Burden et al., 2016; Cacciatore et al., 2013; Kavanaugh, Trier & Korzec, 2004; Lang et al., 2011; O'Leary & Thorwick, 2006). Both mothers and fathers in the current study alluded to fathers' reactions often being overlooked. In hospital following their traumatic loss, one mother remembered how her husband's needs seemed secondary to her own. Although equally affected, consumed by fear, anguish and concern for his wife's welfare, his experience was peripheralised.

> *…and my husband, I mean it was horrendous for him because I was getting all these interventions /…/ he was looking out for me but nobody was looking out for him, and he was terrified, he had to phone our parents and tell them, I didn't have to do any of that, and that doesn't*

*really get acknowledged, and then men are left on the side-lines to deal with it, it's not good, he was in as big a state as I was, and he was terrified something was going to happen to me.* (Participant 9, Mother)

Lack of recognition of fathers' loss experience is not confined to the hospital environment in the aftermath of their baby's death. Layne (2003) suggested that women tend to be the main focus for personal and wider support systems following pregnancy loss. The following father's perceptions are consistent with this view as he discusses fathers' experiences and their need for support being relegated in terms of gravity and importance.

> *…you know there is the potential for dads' experiences to be sort of side-lined a bit really./…/ I mean a lot of people would say, you know in the immediate aftermath would want to talk to me about how* [wife] *was doing, and perhaps not so much about me, and there might be a number of reasons for that which might be to do with, you know often people feel more comfortable with a roundabout way of getting at what's happening rather than asking directly, but you know I suppose if I was feeling sensitive about it then I could take the implication from it that she'd been sort of more traumatically affected by it than people would have expected me to be…* (Participant 7, Father)

In a similar vein, another father explains how others' primary concern following his baby's death was for his wife's welfare. He also alludes to being socialised from a young age to demonstrate emotional restraint.

> *Dads are asked the question "How's your wife? It must be awfully hard or difficult for her, it must be terrible", if you're very lucky you'll get "How's your wife, it must be really difficult for her…oh and you too", so you're thrown in there as an afterthought, and of course because you're a bloke, and because your dad when you were small and you fell off your bike, and your knees were cut open and you were bleeding, your dad would pick you up and say "Now don't be crying, you're a big strong boy, don't cry", you're kind of conditioned not to show your emotions, erm, and it's seen as a sign of weakness…* (Participant 6, Father)

Another important aspect of fathers' response to their baby's death to emerge was emotionality. As suggested above, the magnitude of fathers' grief and subsequent need for support may be being overlooked due to their tendency to contain and internalise their feelings, especially overtly emotional responses, behaviour which for some has been conditioned since childhood. Women have reported both experiencing and expressing emotions more intensely than males, behaviour which has traditionally been more socially acceptable for females than males (Fischer, 2000, as cited by Fivush, 2002). In essence, female emotion is given voice whilst male emotion is silenced or suppressed (Fivush, 2002). Gender-specific socialisation during critical childhood developmental stages may in part be influencing some fathers' grief responses and their proclivity toward emotion suppression. For example, parents have been observed talking with their daughters about a broader spectrum of emotional experiences, and evaluating and validating emotional experience to a greater degree than with sons (Fivush & Buckner, 2003). Research has shown that women are more likely to express grief openly, whereas men have a tendency to present a less affective, stoical, socially acceptable response (Stinson et al., 1992). Furthermore, Dyregrov and Matthieson (1991) suggested that fathers are more reluctant than mothers to openly express their feelings or articulate their affective state when grieving the loss of a child. Critically, it has been suggested that the burden of containing their feelings may lead to suppression of grief which could potentially increase the risk of negative psychological sequelae (Burden et al., 2016). Data in the current study showed that fathers were expected to be able to control their emotional response to their baby's death, and there was an inherent societal assumption that they were managing their grief and would cope with the trauma.

Despite this assumption, some father's narratives did refer to emotional expression and instances of affective outpouring in public.

> *…you know if I'm doing my talk, and I break down and cry, before I start I give everyone a health warning, and say that I might break down and cry, and I always say if you have a problem with a man crying, it's your*

*problem not mine, because the tears that I shed, or may shed today, are my daughter's tears that she never got the chance to cry…* (Participant 6, Father)

This supports findings from a number of previous studies which suggest that fathers experience their loss at an emotional level (McCreight, 2004; O'Leary & Thorwick, 2006). However, their opportunities to share their affective responses may be more limited than those of mothers. As one father explained, he perceived a stigma associated with men attending support groups which could result in a reluctance to seek help in this way. Typically, his initial intention was solely to support his wife. However, his concerns were gradually allayed as he confronted his preconceived ideas about the group, his scepticism about how it could help him, and his apprehension about emotional expression.

> *…there's an awful stigma around support and support groups and all of that stuff, and we, I particularly as a man thought it's not for me, it's too touchy feely, it's too emotional, it's, to be honest I went to the support group hoping that they could help my wife /…/ and so I thought I'll put myself through this once, and then I'll never have to do it again, but on the night, we were welcomed into the room, and there were 14 women and no men, and I thought I really don't want to be here, but I'm here, I'm not here for me I'm here for my wife /…/ everyone else in the room, little pieces of their story were putting together our story, and I was starting to think this isn't bad at all, this is actually quite good, and thinking I hope* [wife] *is getting something out of this, 'cos I can bring her here once a month and drop her off, and I can wait in the car outside, or I can go for a drive or whatever…* (Participant 6, Father)

Having told the story of his daughter's death to the group through "pain in [his] chest kind of sobs" his initial reluctance subsided, and he concluded that the experience had been transformative and brought solace.

> *…that's kind of when I realised it's not difficult, you just have to talk, you just have to get it out…* (Participant 6, Father)

Unfortunately, not all fathers found opportunities in a safe and supportive environment to discuss their experiences. This mother highlights the general reluctance of men to talk to each other about emotive life events, and how, in her view, a lack of support both personally and professionally impacted on her husband's mental health.

> *…I think my husband found it difficult to get support as well, because being a man he wasn't on those online forums, and naturally there is a bit of a gender divide and men don't talk about these things as much amongst themselves /…/ he went back to work far too early after a bit of pressure from his boss, having 4 or 5 months at work then developing depression and having to go off for 3 or 4 months, and that was a direct result of what happened and the way he was, or wasn't supported or able to process his grief…* (Participant 5, Mother)

The notion that men are not as inclined to discuss their experience of perinatal loss especially with other men was reinforced by the following father. Interestingly, he realised whilst recounting his experience that generally he had not sought or found support from other men.

> *I can't remember really any other men in particular, fathers or not, who were kind of big sources of support, which is interesting, I've never really thought about that before…* (Participant 7, Father)

Previous research examining the attitudes toward the grieving behaviours of men and women found that women tend to be more sympathetic toward grieving individuals than men, and argued that women may better identify with others' emotions than do their male counterparts (Versalle & McDowell, 2004-2005). A dearth of male support for bereaved fathers was also suggested by Samuelsson et al. (2001), who reported that some fathers had regretted not having a man to talk to at the time of the stillbirth and afterwards as they struggled to make sense of their baby's death.

Failure to express and vent the emotional pain of loss can be unhealthy (Martin & Doka, 2010). Moreover, the availability and quality of social support can

potentially influence parents' ability to cope following their baby's death (Cacciatore, 2007; Cacciatore et al., 2009). The following excerpt highlights how one father struggled to release his emotional pain in an adaptive manner. An initial denial of his need for help, together with some family members' failure to acknowledge his loss or provide adequate support, severely inhibited his ability to process his grief and cope with his baby's death.

> *…he* [husband] *just lost the plot, /…/ because he didn't have any counselling, and he kept saying "No I don't need it, I don't want somebody telling me how to deal with losing my baby, it's nothing to do with them" and he wouldn't go to Sands' meetings, and his mum and dad just didn't care, his dad never contacted him after* [baby] *died, and his mum contacted him once, and came to the funeral, and nobody since then for 8 months has asked him how he is, so it's been all on my shoulders, or my mum and dad, and no wonder he couldn't cope with it, so he went down a really bad path, /…/ it took something big for* [husband] *to say "I need some help", whereas I was quite lucky, 'cos from the beginning I started seeing a counsellor and I started going to Sands, and I dealt with it from day one really, and* [husband] *didn't, so it was a completely different way of coping, and even now* [husband]*'s a lot more quiet than I am in terms of what he's going through, but every now and again he'll get really upset about* [baby], *and find it really difficult and then he'll tell me how he's feeling, but he keeps it to himself a lot more, whereas I'm a lot more open with it.* (Participant 4, Mother)

As demonstrated in the passage above, parents can respond to their baby's death in different ways. Partners' incompatible grief responses can put considerable strain on some relationships. Incongruent grieving has previously been cited as creating tension, distress and emotional distance within relationships after the death of a child (Rando, 1985) and perinatal loss (Avelin et al., 2013; Burden et al., 2016; Callister, 2006; McGreal et al., 1997). Evidence of the potentially destabilising effect of partners' grief incongruence was provided by the following mother.

*I mean we split up for a year, which just sort of shows how different it was, because you grieve very differently don't you, he has to go back to work a lot sooner than I have to go back to work, most people were focussing on how I am as opposed to how he is, and I think it was about a year after we lost* [baby]*, while I was starting to rebuild myself, he just completely went to pieces, so we had very different times…* (Participant 8, Mother)

Also inherent in this mother's observations is her husband's delayed grief. Delayed grief has been found to be more common in fathers than mothers following pregnancy loss (Janssen, Cuisinier & Hoogduin, 1996). It has been argued that avoidance of loss orientated stressors, for example, failing to fully confront the emotional pain of the loss whilst focussing on restoration oriented daily life tasks, such as work, can result in delayed grief (Stroebe, Schut & Stroebe, 2005). This type of asynchronistic grieving could also exacerbate feelings of isolation and distance within partnerships.

Evidently, differences in parental grief reactions can exacerbate emotional strain and uncertainty within a relationship. At a time of immense vulnerability when a parent's need for support is heightened, they can feel isolated even within their own relationship. An acceptance of, and respect for, divergent grief reactions may be a significant factor for relationship stability. Therefore, parents should be informed about different grieving styles and approaches to coping following stillbirth as it may lead to a better understanding of individual responses and maintain relationship stability.

Whilst differences in partners' response to their baby's death caused relationship tension in some instances, it should be noted that all parents stated they were still in a relationship with their baby's other parent. Moreover, there was clear evidence that their loss experience had brought some couples closer. An increased cohesion and deepening of feelings between partners following their experience of stillbirth has previously been reported (Avelin et al., 2013; Cacciatore, DeFrain, Jones & Jones, 2008) Similarly, in the current study the following mother spoke of mutual dependency and reciprocal

support as hers and her husband's grief journeys intertwined in a strengthening and unifying way.

> *I think my husband and I really kind of stuck together, and I know it either pushes you apart or you hang together, and we clung to each other is what we did, so I think a lot of what we do and how we manage it and grieve and think about* [baby] *is together…* (Participant 10, Mother)

Reflective of the inconsistencies in the literature, the current study's findings relating to male grief were mixed. Some examples aligned with gender stereotypical responses demonstrating emotional suppression and internalisation, whilst others suggested that grief and coping responses are not dichotomised by gender, as some fathers found safe and supportive environments in which to openly express their pain. The lack of appropriate social/peer support for some bereaved fathers may be inhibiting their expression of grief as they struggle to find an accommodating environment. As previously argued by Riches and Dawson (1997), and highlighted again in the current study, variations in grief orientation may be explained by the type of social support which is available to each parent. It is also possible that other factors may influence an individual's experience and expression of grief such as personality type, or the history and characteristics of the relationship with the deceased prior to death. Furthermore, inadequate social support could reduce fathers' opportunities to share their baby with others and impede development of bonds with their child.

All of the participants in the current study were in heterosexual relationships with their stillborn baby's other parent. In order to fully appreciate whether the differences observed in mothers' and fathers' responses to their loss experience are influenced by gender, it may prove enlightening for future studies to examine same sex relationships and partners' grief responses and coping tendencies. It is possible that some of the distinctions in behaviour are influenced by whether the parent carried the baby during pregnancy or not. A study of gestational and non-gestational parents in lesbian partnerships could help further exploration and understanding in this area.

**Summary of theme *Journeying with grief***

Parents highlighted the magnitude, fluidity and unpredictable nature of their grief. Whilst impaired functioning improved with time, parents spoke of ongoing surges of emotionally overwhelming grief which resurfaced over years and decades, often without warning. Grief for some appeared indicative of their enduring love for their baby, therefore, the concept of a complete recovery from grief was at odds with their continuing bonds experience and not sought or expected. Arbitrary timescales promoting recovery from grief were unhelpful to parents and they sensed societal pressure to “get over it”, especially over time. Parents were acutely aware of the need to manage their grief response. Narratives showed how they vacillated between submersion in their loss and restoratively retreating, to aid maintenance of everyday functionality. Moreover, the passage of time aided exploration of their grief journey and unfolding relationship with their baby. Parents acknowledged the unexpected nature of their baby’s death and how this typically precipitated a search for meaning. Whilst the mechanisms employed during parents’ efforts to find meaning resolution varied, most parents alluded to a dramatic change in their world view in order to accommodate their traumatic loss. Parents’ personal quest for meaning often conflicted with society’s attempts to rationalise their baby’s death, inevitably this caused friction and upset for some. Incongruent grief destabilised some relationships whilst shared grief unified others. Both mothers and fathers reported that a father’s experience of loss and grief is commonly overlooked, and societal expectations of a stoical male response may be adversely affecting some fathers’ journey with grief and their ability to find appropriate social support.

### 2.4.4 Developing coping strategies

The fourth main theme identified was *Developing coping strategies*. Parents intuitively adopted a variety of strategies which they perceived to be beneficial to coping following their baby’s death. These tended to incorporate certain aspects of the theoretical frameworks associated with bereavement adaptation already explored, namely meaning-making, oscillation between emotion-focused coping and restoration-focused coping, and sharing their

experience with others. In the early days, weeks and months after their loss, parents spoke of doing anything they could to survive. The gradual development of their continuing bond emerged as an important aid to coping, as did engaging with the natural world and reflective writing.

#### 2.4.4.1 The solace of a continuing bond

In line with the continuing bonds paradigm which suggests that ongoing connections with the deceased can potentially contribute to bereavement adaptation (Klass et al., 1996), all parents in the current study alluded to deriving comfort and solace from their ongoing relationship with their stillborn baby. It provided a focus for their love and attention in the disorienting aftermath of their baby's death. One mother explained how building connections with her son had afforded her the time and space to try to process the loss.

> *It's important to have, like specific time, where you allow yourself to grieve /…/ so all the lighting candles and things gives me time, even if it be for a few minutes where that's his special time, and I can show that, how important he was and he's still at the forefront of my mind...* (Participant 1, Mother)

Furthermore, as evidenced below, some parents explicitly attributed their ability to cope to their enduring relationship with their child.

> *…without that* [ongoing relationship with baby] *I think I'd have probably been a lot colder, and I don't think I'd have been able to cope as well, whereas I think I've managed to cope somehow and that's probably why…* (Participant 4, Mother)

#### 2.4.4.2 Engaging with the natural world

In the first main theme *Constructing and maintaining a relationship*, evidence emerged to show how the natural world, as an architect of continuing bonds, helped parents to create and evoke their baby's presence and served as a channel for communication between parent and baby. Surprisingly, there is

little explicit reference to nature in the bereavement literature to date. To the researcher's knowledge, Layne's (2003) account of pregnancy loss is the only work to specifically address its prominence and potential significance within the perinatal loss community. Layne reported that for some perinatally bereaved parents, nature represents a redemptive, spiritually healing force, through which they can, by employment of symbolism, naturalise their experience, emphasise the transience of life and help make sense of their devastating loss. As evidenced by the quotation below, nature can serve to analogise the shockingly unexpected and violently disorienting impact on bereaved parents following their baby's death, helping them to reflect upon the seemingly unthinkable, and articulate their tumultuous, life-changing experience.

> When my baby died, I felt as though I was suddenly caught up in a tornado whirlwind, spinning around in circles and upside down, finally dropping at lightning speed back to earth, but in a totally different place from where I was first picked up, and unable to find my way back to the place I had been before. That place no longer existed.
> (Daniels 1988b, as cited by Layne, 2003, p. 181)

Consistent with Layne's observations, engagement with the natural world was one of the most prominent themes in parents' continuing bonds narratives in the current study, with some alluding to a heightened sense of awareness of nature since their baby's death. Parents appeared to instinctively engage with the natural world as they sought to cope with their baby's death. Nature contributed to coping efforts in a number of ways: as a sanctuary from society, as a facilitator of meaning-making, and as a therapeutic and restorative environment.

As discussed in *Negotiating the social landscape*, parents predominantly valued opportunities to share their ongoing relationship with their baby with empathetic others. However, there were times when socialising with human others was not desired or helpful and this led a number of parents to seek solace in the natural world. Social interaction was sometimes too overwhelming for some parents following their loss.

> *I did get depression and I didn't want to go out with people.* (Participant 2, Mother)

Critically, nature provided a safe sanctuary from society for those who sought refuge during periods of emotional fragility and vulnerability.

> *…so in those very fragile early days we'd just, we didn't kind of want to go out of the house but we'd manage a walk in the dene*…(Participant 7, Father)

Furthermore, over time many parents reported feeling socially isolated, stigmatised and morally judged by others if they disclosed the depth of their enduring affective attachment to their baby. Interestingly, empirical evidence demonstrates that social ostracism increases an individual's desire to connect to nature in an attempt to re-establish their threatened sense of belonging, and this might imply that exposure to nature could improve the negative consequences of ostracism (Poon, Teng, Chow & Chen, 2015).

Moreover, natural settings allowed for free, unrestrained expression of emotion in a non-judgemental environment.

> *…I think that's how we did it* [cope]*, we were kind of mourning walking in the end because we were just like "What do we do with ourselves? We're supposed to be looking after a small child, we're at home, how do we survive that?" And we just started going out walking, we'd just take a packed lunch with us, middle of winter, and just go out, and we just kept doing that the whole time we were both off together, we walked most days all day, and I'd be crying in the middle of the countryside, you know having melt downs /…/ we were like "We have to get out of the house or we'll go mad", you know a big empty house, no cot, no nothing, so we walked all over* [county], [region]*, all over the place.* (Participant 10, Mother)

Also implicit in this excerpt is a sense of wanting to escape the pressurised vacuum of nothingness, and harsh, jarring reminders of baby's absence at

home. This is reminiscent of Trulsson and Radestad's (2004) reports of women who had experienced stillbirth being thrust into a maelstrom of anger and sorrow, and wanting to escape their near unbearable situation. It could be argued that nature provides an accommodating and supportive environment capable of absorbing the turbulent emotions experienced by parents, whilst also offering momentary respite and a sense of escape. In essence, nature represents an accepting non-judgemental other with which to commune and heal.

As discussed in main theme *Journeying with grief,* searching for meaning following their baby's death was evident in parents' narratives. Nature contributed significantly to a number of parents' meaning-making endeavours. Quintessentially, for this father, walking in nature provided an opportunity for unrestricted, productive communication between him and his wife.

> *…some of the other aspects of it were the sort of things that we were doing to cope really and to manage, so things that I remember from those days are, we did an awful lot of walking, like hiking /…/ and there is something about walking and talking together which just, I think it's like you're kind of clear of distraction but you're also walking together like this* [indicates side by side] *and you can talk in a way which is, I don't know, I think it can be more difficult if you're sort of facing each other, so we would talk a lot about* [baby] *and about what had happened, and about what things were like for either of us, I think that was something important…* (Participant 7, Father)

By engaging with nature in this way, the parents were able to piece together, and make sense of, the fragments of their individual experiences, thus constructing a cohesive, collective, unified narrative imbued with personal meaning and clarity, which would evoke memories of their son, and help develop their ongoing relationship with him.

> *…so it was almost like we were kind of like making this sort of story about* [baby] *and what happened to him and who he would have been and so on, and I think in those early months particularly the hiking and*

> *the walking, the process for us, I just remember this endless talking over what had happened and trying to make sense of it and losing the details you know the way that, 'cos someone says something that happened and then you think, do I actually have a memory of that happening, or do I remember us talking about it? Eventually you get to something that sort of feels like an official version if you like, but you know which is made by the talking together…* (Participant 7, Father)

It is postulated that meaning-making occurs at least as fully between people as within them (Neimeyer et al., 2014). Sharing details of the deceased, and engaging in a negotiative process of meaning construction is thought to deliver a durable biography of the deceased which can be adaptively integrated into the survivors' ongoing lives (Walter, 1996). Furthermore, it is acknowledged that human beings and their environments can be "co-producers of meaning" (Hockey et al., 2010b, p. 9). The above account aligns with this notion of co-construction of meaning. In this case nature accommodated a process of free expression, negotiation and meaning construction, thus facilitating transformation of parents' mental representations of their baby and aiding development of their baby's narrative through sharing; a process which further serves to consolidate the continuing bond between parent and baby.

There have been relatively few efforts to develop theory driven interventions that focus on the meaning-making process to aid bereaved parents' coping following the loss of their child (Murphy, 2000). This study builds upon Layne's (2003) suggestion that parents' employment of natural imagery and symbolism can facilitate meaning-making, by highlighting natural settings as non-judgemental, accommodating environments in which to openly express emotion, and construct coherent, meaningful narratives. Further consideration should be given to the influence of the natural world on the meaning-making process, and thus to nature's potentially valuable contribution to bereavement adaptation.

Parents' narratives also revealed the therapeutic and restorative potential of nature. Echoing Layne's (2003) discussion of the redemptive quality of nature, the following mother alludes to the emergence of new beginnings and a sense

of hope following the bleakness of winter, as represented by the appearance of snowdrops. Implicit in this expression is the potential for parents' transformative growth following the desolatory experience of their baby's death.

> *Well the snowdrops is like the new beginnings, you know, and sort of the hope after the winter…* (Participant 1, Mother)

A number of parents referred to places they associated with their baby that maintained a lasting significance in their lives. This is concurrent with the findings of Jonsson and Walter (2017) who reported that meaningful bonds with a deceased loved one can be embedded in a particular place. They found that place associated bonds could be comforting but also unsettling to some. In contrast, participants in the current study who associated places or environments with their baby solely framed the experience positively. This may be due to parents being drawn instinctively to certain places that make them feel closer to their baby and provide solace, as opposed to having pre-existing associations between the deceased and place predominantly based upon memories (positive and negative) of the person in that place when they were alive.

> *…but just the beach generally, but especially that sort of wild coastline. I've always found being near the sea quite therapeutic anyway…* (Participant 3, Mother)

The sea and coastal environments appeared to be particularly important for many parents, and critically were also perceived to be therapeutic settings. One mother suggested the seaside evoked a feeling of inner peace and heightened her sense of connection to her daughter.

> *… the seaside, there is the seaside, I mean there was no real link other than the fact that for me I feel more peaceful, and there is some sort of connection, whenever I go I tend to bring something back…* (Participant 11, Mother)

Several other parents' narratives alluded to an affiliation with the sea and coastal settings, and their peaceful, calming effect. This is consistent with Ulrich's psycho-evolutionary Stress Reduction Theory (SRT). Emotion is the central tenet of this paradigm and suggests an innate affective affiliation with nature. According to SRT, visual exposure to nature results in positive emotional responses which it is thought attenuate stress symptomatology, including decreases in negative affect and reductions in physiological arousal (Ulrich, 1979; Ulrich 1981; Ulrich 1983; Ulrich et al., 1991).

A number of parents alluded to the peacefulness of natural settings, and whilst this quiescence may contribute to restoration, it is posited that peacefulness is not solely due to quietude, but is actually driven by natural environments' ability to capture attention modestly and by regulating directed attention (Berman, Jonides & Kaplan, 2008). The following account of a mother's relationship with the sea, indicates nature's capacity to positively affect cognitive processing.

> *I've always felt closer to the sea, whenever I'm by the sea no matter what my mood it calms me, so I used to sit on that pier for hours after we'd lost him, so having a plaque on that pier now feels even more special, it's somewhere to go really and sit and just think./…/ I think it's because it's so wild isn't it, it doesn't matter what the weather, whether it's calm or rough, it just helps me clear my mind, it always has ever since I was little…* (Participant 8, Mother)

Again, this mother refers to a lasting connection to the sea, and its ability to induce a sense of calm, but critically the above account also suggests nature's potential to effect cognitive restoration. The notion of clearing the mind is reminiscent of the initial stage of a cognitively restorative encounter as proposed by Attention Restoration Theory (ART) (Kaplan & Kaplan, 1989; Kaplan, 1995). ART argues that sustained directed attention results in mental fatigue, but that exposure to natural environments can mitigate the burden of cognitive overload and fatigue. Natural settings are thought to inherently comprise elements that evoke *soft fascination*, as a result, exposure to these environments precipitates a more involuntary engagement of indirect

attention, thus allowing the executive system's finite resources to rest, replenish and restore. Environments rich in soft fascination are said to be sufficiently captivating to hold one's attention, but not too stimulating to preclude opportunities for reflection. Moreover, environments that stimulate soft fascination "are esthetically pleasing, which helps offset the pain that may accompany reflection on serious matters" (Herzog, Black, Fountaine & Knotts, 1997, p. 166). Evidently, this is of particular relevance to bereaved parents who are reflecting on the acute gravity and harrowing trauma of their baby's death. In addition to fascination, three further attributes are thought to contribute to natural environments' restorative capabilities: *being away* or a sense of escape from everyday life; *extent*, which alludes to a setting's requirement to be "rich enough and coherent enough so that it constitutes a whole other world"; and *compatibility* that refers to an alignment between a person's purposes and proclivities, and the characteristics of the environment (Kaplan, 1995, p. 173). As already demonstrated in nature's aforementioned ability to provide sanctuary, or a sense of escape, parents' narratives appear to corroborate nature's potential to promote a sense of being away.

Extending the restoration construct further, Kaplan and Kaplan (1989) delineated four successive stages that a restorative experience would encompass: firstly, *clearing the head* of distracting thoughts which facilitates a person's progression into *recovery of directed attention capacity*; a state of *cognitive quiet* follows these two initial stages which allows for contemplation, and finally a period of *reflection* on one's life, priorities, actions and goals. These stages were subsequently subsumed into two stages: *attentional recovery* (1 and 2) and *reflection* (3 and 4) (Herzog et al., 1997). The extant literature suggests that reflection can be viewed as either an aspect of restoration, or an activity which is enabled by the restoration of depleted directed attentional resources (Roe & Aspinall, 2011).

The following excerpt is consistent with ART's more profoundly thoughtful, reflection stage. The seascape provides an opportunity for reflection on "life's larger questions" (Herzog et al., 1997), as this father considers the significant

changes and positive legacy his daughter's death has effected in his and his family's life.

> *…we've got a little plaque and it's a place called* [town] *up on the* [region] *coast, and we go up, that's where we go for her birthday /…/ but we'll go up a few times, and we'll get the Brasso out and I'll polish the plaque off, 'cos it's on the pier by the sea so it gets buffeted, and that's a kind of physical memory place if you like, but we go there to have happy family times, so they're not miserable and full of sadness, they are definitely a marker, it's kind of our opportunity to think, and just reflect, be glad of our lot and be glad of, you know try to take the best of what happened because it's made us who we are today…* (Participant 12, Father)

In a similar way, some parents related how green spaces induced a sense of restorative calm and peace:

> *I love the Sands' garden, I always feel very very at peace at the Sands' garden…* (Participant 8, Mother)

One mother found walking in natural environments not only induced a sense of peace; but collecting leaves along the way provided an opportunity to include her baby in the activity. In addition, the quiet haven of her garden where she had planted a tree to memorialise her son, seemed to bring a sense of proximity to him, and allowed for contemplative communion with him.

> *Well you do do a lot of walks actually, when we're on holidays and, I think in the beginning I used to, I would always collect leaves of what walks we've been on and I've got them in my book /…/ I would just keep them and you know, it's a kinda way of including him in the walks, something I'd done, or maybe it's because it's peaceful isn't it, I used to, we had a swing in the back garden and I spent my whole life out there, you know, after we'd lost him that first year, even if it was raining I'd go and sit out there. /…/ I had to find other ways to sort of form a relationship with my son…* (Participant 2, Mother)

Physical activity in nature, especially walking, was a common pursuit for parents, and perceived as a potential aid to coping. Research has highlighted the salutogenic benefits of walking. For example, Gidlow et al. (2016) reported that walking reduced stress, moreover, walking in natural environments resulted in additional cognitive benefits that lasted at least 30 minutes after the individual had left the environment.

Nature provided an accommodating environment in which to engage in more strenuous physical activity for this father, whilst its numinous quality simultaneously evoked a sense of spiritual and transcendent bonding with his daughter.

> *In the country I can go out and run, yeh I'm always out in the hills somewhere. /…/ I think it probably makes me closer to her, I feel like I'm closer to her, because you're not separated by anything physically, and it is about, it's about losing yourself in the exercise and the moment, and actually if it's in the gym and you're surrounded by other people, or you're taking it in turns to use the exercise machine because it's busy, it has a very different sense to it /…/ I like being at the top of the hills and that might be because I associate* [baby] *with heaven and I'm probably a bit closer to it when I'm outside and up, than I am in a gym in a hotel basement somewhere…* (Participant 12, Father)

Significantly, compared with exercising indoors, exercising in natural settings has been shown to be associated with increased feelings of revitalisation and positive engagement, decreases in tension, confusion, anger and depression, and increased energy (Thompson Coon et al., 2011).

Environmental conditions, in this instance the powerful effect of the weather, also appeared to contribute to nature's restorative and recuperative capabilities.

> *…actually* [island] *holds dear to us because that was the place we went to recuperate after we lost* [baby] */…/ for a week and just take stock, and you know it was, you got blown away really, it was very windy, it*

*was the back end of winter, so it physically felt better for being there, it blew you away really and sort of shook you down…* (Participant 12, Father)

Whilst symbolic associations with the cycles of life and death inherent in the natural world can help parents to make sense of their traumatic loss, and naturalise their experience (Layne, 2003), it is possible that these cycles could also induce painful and emotive reminders for some. Death reflected in nature was perceived by some parents in the current study as symbolic of their baby's death and as a result they found it upsetting.

> *Some of my colleagues at work bought us a rose plant but* [baby] *died in the* [winter month] *and we'd left it out in the back yard so it died that felt quite symbolic somehow that it had not made it, and I did have a rose at one point that was out in the front garden but that didn't do very well either and I found that quite upsetting…* (Participant 10, Mother)

It is important that any future studies of nature as a potential aid to coping remain mindful of possible adverse effects for some individuals. That said, this study's novel findings are encouraging and are explored further in relation to bereavement adaptation in Study 2 (Chapter 3).

As outlined in the previous main theme, parents of stillborn babies refer to an interminable grief (Cacciatore et al., 2008a), and whilst the passage of time often brings a sense of manageability, one mother suggests "You just have to let it take you where it will" (Cacciatore et al., 2008c, p. 367). The findings of the current study suggest that it often takes them intuitively into the realm of the natural world.

#### 2.4.4.3 Reflective writing

Bereavement is an inherent thread of the (auto)biography, the biographical imperative to make sense of oneself and others in a developing narrative (Walter, 1996). Moreover, empirical evidence suggests that engaging in expressive writing (i.e. repeated expression of deepest thoughts and feelings)

following traumatic life events can yield biological, physiological and psychological benefits (Pennebaker & Evans, 2014).

Writing, in some form, was alluded to by the majority of parents, and perceived as a cathartic and valuable activity.

> *…and writing in the diary, that's helped me work through my feelings and perhaps tell him in a way how much I love him and miss him…* (Participant 2, Mother)

Writing was performed within both the private and public spheres and took the form of letters, poems, diaries, blogs and social media posts. Writing served a number of functions: it assisted parents in their search for meaning, allowed unrestricted expression or release of emotions, and enabled parents to chart their bereavement journey over time. Moreover, writing provided parents with the opportunity to connect with their baby, and communicate with others, to seek support, and provide support to other bereaved parents through sharing their baby's story.

> *…when he first died I wrote a diary, just like a written paper diary and then once we, and then once me and these 2 other mums developed the blog /…/ I always write something on his birthday, which I tend to direct directly to him, and I write as if I'm writing to him, and the rest, I never realised I did that actually,* [laughing], *and the rest of the year if I write things it tends to be about reflections on grief and how that's changing over time, that's quite an important part of the process of grieving for me but also of maintaining that link with him really.* (Participant 5, Mother)

In addition, the products of the writing process were perceived to constitute lasting material records of their baby's existence, and treasured memorials to them. One father spoke of affording time, care and attention to finding the right book in which to record his baby's story. Writing consolidated memories of his son, whilst serving as a mechanism to construct a coherent narrative for

him which could be interwoven with his own, and his family's narrative, thus potentially facilitating integration of the baby into everyday life.

> *…the other thing that I did that was really important to me was writing /… it has a number of functions I think, one was just to kind of help me make sense of it, and what was happening /…/ and there was something about the act of trying to find the words to describe this essentially indescribable thing that happened that felt very important /…/ And start to sort of form a description in my mind that I could then write, so, and if I hadn't had that I think it would have been much more of an unmanageable kind of jungle of memories and emotions and so on, so that was one thing, the second thing was something about trying to, I don't know whether this is quite the right word, but almost have a bit of a memorial, or part of a memorial for* [baby] *so the fact of putting it down on paper, 'cos we know what happens with memories, it is that a lot of the detail kind of evaporates, so there was something about getting it down before it was too late, and then it's there…* (Participant 7, Father)

This account demonstrates the cognitive processing inherent in the expressive writing paradigm that advocates "translating the chaotic swirl of traumatic ideation into coherent language" which can facilitate sense-making (Harber & Pennebaker, 1992, p. 360). Moreover, writing helped this father to evoke and develop mental representations of his son, and critically, to manage powerful emotional responses to his death. It is thought that expressive writing enhances affective modulation by improving resilience and tolerance of negative affective responses, heightening an individual's sense of mastery over negative emotions and developing self-empathy and an acceptance of personal emotional reactions (Greenberg, Wortman & Stone, 1996).

One mother regretted not having kept a written record of the time following her baby's death, as she thought it would have aided consolidation of her memories, and helped her to make sense of the turbulent period that followed her loss.

> *I feel as if there's a period of my life where I don't remember it /…/ and I would like to look back to see how far I came /…/ there's probably 2 years of my life that I've lost, and so I wish I'd kept a journal so I could get that time back /…/ because it feels like a blank, I wish I could go back and just understand what went on in that time.* (Participant 1, Mother)

Writing a poem from his daughter's perspective, allowed this father to explore and eventually resolve complex feelings of guilt arising from not wanting to hold her.

> *I started to write some poems, some of them are rubbish, but there's one or two that I'm really proud of, one called "Forgiven", and it talks about when I was asked by the midwife "Do you want to see and hold your baby?" I was, the word I use is revulsion, I was just filled with, I just thought there's nothing worse, but they handed her to me before I could say yes or no, and it's the best thing I've ever done in my life, was hold her, but for a long time I felt guilty, because I didn't want to hold her, and so I wrote this poem from her point of view, and it says, you know, "You didn't want to hold me dad, but you did, and I forgive you for that, not wanting to because you were afraid, but since then you've gone on to talk about me, and cry in public and shed the tears that I couldn't"…* (Participant 6, Father)

For the following mother, writing was viewed as a safe way to release suppressed emotions and channel anger more positively, thus enabling her to regulate her affective responses in a manner that did not threaten her relationships with others.

> *…the thing with grief as you probably know, it comes in so many different ways, and there were times when I was feeling so much anger that if I'd said what I was feeling I don't think anyone would still talk to me, but if you're writing it all down and venting it in that way then you're releasing it so it's not building up inside you, and creating this big crater,*

> *you're getting it out, and even when you're having a really low day you're able to get that out.* (Participant 8, Mother)

It has been posited that expressive writing may be of particular benefit to individuals who have suffered traumatic experiences associated with social stigma, and who, as a consequence, feel inhibited in disclosing to members of their social network (Lepore & Greenberg, 2002). As discussed previously, a number of parents referred to feelings of social isolation and stigmatisation, and reported a cultural silence surrounding stillbirth and barriers to disclosure of their relationship with their baby. It is suggested that parents who encounter restrictions to disclosure of their continuing bond, both domestically and in wider society, may find a welcome and liberating freedom of expression during the writing process.

Writing online allowed the following mother to find validation of expressions she feared would be more generally deemed as socially unacceptable, and empathy toward her experiences from the loss community at any time, day or night.

> [Writing] *it's just how I process, it was just, having a place to pour out whatever, it didn't matter what you wrote, even if it was stuff that would be completely sociably unacceptable to say and somebody else, you know would say, yes, and also the fact that, because it was a worldwide community, there'd be somebody else online when you were, could be 3 in the morning, could be 4 in the morning, when you weren't sleeping, you knew there'd be somebody.* (Participant 3, Mother)

Whilst some parents continued to write to their baby on special occasions over time, or wrote blogs or comments in support of other bereaved parents, the intensity of the imperative to write tended to fade for most parents over time.

Prior studies have suggested that writing could be an effective coping strategy for some following sudden and unexpected losses such as stillbirth (Crawley et al., 2013; Pennebaker, Zech & Rime, 2001). The current study's findings would support writing's potential as a cost effective intervention, especially in

the initial post-loss period, as it not only enabled parents to forge deeper connections with their baby, and others, but also helped parents to process their experience in an honest, unrestricted and coherent way. However, it should be noted that Pennebaker (2013a) has suggested that writing within the first two to three weeks after trauma may not be advisable as an individual may not have sufficient coping defences available in the immediate aftermath. This should be considered when designing any future intervention. Further research exploring writing as a coping strategy for perinatally bereaved parents is needed, particularly in relation to mental health outcomes. This topic is considered further in Chapter 4, Future Research Directions.

**Summary of theme *Developing coping strategies***

All parents alluded to their continuing bond with their baby as an aid to coping. Parents' accounts were also rich in references to nature and it appeared to serve myriad functions. Nature enabled parents to establish and further develop connections with their baby through place association, whilst creating and consolidating mental representations of their child. It facilitated parents' search for meaning and aided their construction of a coherent, meaningful loss narrative. Furthermore, natural settings afforded sanctuary from society at times of affective fragility and vulnerability, and offered a non-judgemental environment in the face of social scrutiny, stigmatisation and moral judgement. Peaceful, reflective environments allowed the solace of spiritual communion between parent and baby. Parents' perceptions of natural settings as calming, contemplative and therapeutic suggest nature's potential healing and restorative capabilities. Writing, whether to or about their baby, privately or in the public domain, was also employed by parents as a coping strategy. As with nature, writing contributed to meaning-making, aided affective expression and facilitated communication with their baby. Moreover, it enabled parents to chart their bereavement journey, seek and provide support, and share their baby's story with others whilst writing his or her narrative into their own personal history.

### 2.4.5 Establishing a "new normal"

Bereavement "uproots our souls /…/ shakes our spirits: It disrupts the life patterns within which we have found meaning, it confronts us to find the courage, hope, and faith we need to stretch into the inevitably new" (Attig, 2004, p. 350). In line with this view, the final main theme shows parents *Establishing a "new normal"*. Most parents alluded to an altered reality and much changed life following their baby's death, as they looked upon the world with a transformed post-loss perspective. Enlacing and consolidating their baby's essence within their new everyday lived experience was of the utmost importance to parents. Evidence of parents' legacy building in their baby's honour and personal posttraumatic growth emerged. Moreover, residual effects of their baby's death on subsequent parenting and ongoing management of their loss experience were also observed.

#### 2.4.5.1 Integrating baby into ongoing life

Parents' narratives provided an insight into their perceptions of the ontological status of their stillborn baby as they endeavoured to integrate their child and lasting relationship with them into their life longer term.

Parents frequently employed references to time to emphasise their baby's constant and enduring psychological presence, and their unwavering devotion to their child. They were keen to stress that their baby's memory pervaded their everyday lives, and their enduring love for them remained undiminished over time. Phrases such as "every day" and "always" were commonly used to accentuate this constancy.

> *…I think about him every day…* (Participant 2, Mother)

> *…there really isn't a day goes by where I don't think of him, and there's so many things around that remind me about him…* (Participant 1, Mother)

> *I think it's kind of saying my child was here and they're important, and they'll always be important to me, just because you can't see them doesn't mean that they're not…* (Participant 5, Mother)

Whilst some parents continued to predominantly conceptualise their baby as a baby, the following excerpt shows how one father's mental representations of his daughter had transformed over time. Through sharing her story with others, his daughter had grown and her ongoing narrative developed. Imbued with changing personal characteristics over the years, his daughter is conveyed as an enduring comfort and strength, as her story intertwines with his as the years pass by.

> *…well that's what makes me feel connected to her* [giving talks at conferences etc.]*, and it's almost if you like, I've almost seen her grow up over the last 22 years, because I've been talking about her, in front of people, and I always tell my Sands' friends that I have seen her grow up, because in the early days of doing my talk she was a little girl at the back of the room who was proud of her daddy, and then as she got older in to her teens, she was an embarrassed, awkward girl at the back of the room, embarrassed by her daddy, and I like to think now that she's in her twenties, she's the girl at the back of the room who's proud of her daddy again, who's talking about her, and so that's in my own mind, how I kind of get through the talks, because I think well she's here listening to this*. (Participant 6, Father)

This sophisticated and transformative conceptualisation is consistent with the continuing bonds paradigm's assertions that internalisation of the deceased is not merely a prelude to emotional disengagement and mental representations are not static and pathological, but rather they can be "colourful, dynamic and interactive" and open to change over time (Silverman & Klass, 1996, p. 16). To the researcher's knowledge this difference in how parents' conceptualise their stillborn baby over time (i.e. as a baby or as a growing entity) is a novel finding. This variation in parents' conceptualisation of their child is examined further in a larger, more varied sample in Study 2 reported in Chapter 3.

It has been suggested that the deceased can be conceptualised as existing in an external domain or inhabiting the internal being of the bereaved, or indeed as both transcendent and immanent (Walter, 2018). Moreover, "a 'bond' can be pictured either as a close connection between two separate objects or as two objects glued so tightly together that they become inseparable, fused into one" (p. 51). In the findings of the current study reported here, parents' efforts to psychologically locate their baby in their ongoing lives over time were diverse and enlightening, reflecting both external and internal positioning of their stillborn baby. It was important for parents to both represent their baby as a separate, validated entity and to experience them as part of their own self-concept. One mother envisaged her daughter occupying a more benign or utopian external dimension and found comfort in the thought of her baby interacting with her bereaved friends' children.

> *…I have to believe that she's gone to a nicer place, and I kind of draw comfort from the fact that you know, the people I've met through work and obviously through losing her, people who've had a similar experience, we then strike up a friendship, you know and in the same way that we're friends on earth then I imagine them to be friends somewhere else, wherever that might be…* (Participant 11, Mother)

A number of parents alluded to a sense of integration or conflation with their baby as time passed, with many describing their baby as feeling part of them as his or her essence became absorbed into their everyday existence.

> *I described it as being infused with her now. That kind of, just, I don't have to consciously think about her, she just is now, you know, she's just, she's just part of me…* (Participant 3, Mother)

> *…to be honest I think he's with me all the time…* (Participant 8, Mother)

> *… they're a huge part of you, they're part of your life, part of your story as a person, hugely important…* (Participant 10, Mother)

Baby's integration into their wider family was also important to some parents, providing both acknowledgment of their child and comfort.

> *…'cos there's load of kids, there's loads of them, grandchildren, so there are pictures of everyone, but there's a very prominent picture of* [baby], *which is a kind of statement from them, this is still our grandchild, so that's nice, that's really nice.* (Participant 10, Mother)

> *...so he's kind of not hidden away, and that's very important to me because he was born and he was part of the family, and kind of is part of the family…* (Participant 1, Mother)

This is consistent with the notion of *identification* previously reported by Klass (1988; 1996b) when the deceased child becomes an integrated part of the parents' internal and social reality.

As discussed in the theme *Journeying with grief*, parents' need to materially represent their baby tended to fade over time, and for most this seemed to coincide with a deepening sense of integration with their baby. As the following mother explains, her connection to her son had now become part of her everyday lived experience and assimilated into her "new normal".

> *…and I remember right at the beginning, having to tell everybody because I felt as if, if I didn't I would have betrayed his memory and I was hiding in some way, that I wasn't proud of him, and I was incredibly proud of him but people couldn't understand that so I had to try and get it into conversations as much as possible, you know if I had any jewellery or anything that reminded me, I had to make that point, that this is the connection with him, you know, but as time's gone by I don't have that need to do it now because erm, maybe I started, I've found my new normal now…* (Participant 1, Mother)

However, some parents still found benefit in acquiring new physical reminders over time, as a means of including their baby in family activities.

> *…if ever we go away, or you know on holiday or anything, I'll buy something and it'll probably be a butterfly or something* [laughs] *and I hang it on his tree when we get back, so he's always with us whatever we do.* (Participant 2, Mother)

Psychologically locating or integrating him or her was not always an easy process for parents. One father explains his struggle to mentally locate his baby over time and define his continuing bond with his stillborn son, most notably following the birth of his second son.

> *…'cos one of the things that's changed over time is the kind of, there's some distance now and I think it's hard, I'm sort of trying to make sense of this as we talk, but I feel like my relationship with him has got more distant as the years have gone on and that's, that's quite hard to acknowledge really, and I'm not sure I want that to have happened really /…/ I'm not really sure what my relationship is with* [baby], *having felt it was very strong and quite real, particularly in that first period before* [other son] *came, yeh I have a hard time knowing where he kind of sits in my mind really now…* (Participant 7, Father)

In line with Boerner and Heckhausen's (2003) suggestion that a social context that restricts sharing mental representations of a lost loved one can adversely impact upon the deceased's adaptive integration into the bereaved's ongoing life, it is possible that the arrival of his second son reduced this father's opportunities to talk about his stillborn son. Moreover, existing mental representations of his stillborn son may have become obfuscated in the wake of his second son's birth making it difficult to clarify his attachment to his stillborn baby. As a consequence, mental representations might not be adaptively transformed but rather confused, thus integration may have become increasingly complicated and problematic.

#### 2.4.5.2 Legacy building and posttraumatic growth

Treasuring a lost loved one's legacy can potentially mitigate the pain of their loss and physical absence (Attig, 2004). In accordance with this notion, many

parents described nurturing a living legacy in their baby's honour which appeared to bring an element of pride and solace. Death may have denied the babies in this study the opportunity to physically make their own mark on the world, but most parents thought that through their own actions and deeds, their baby could still effect a positive impact on the world.

> *…because I kind of feel that he can't make his mark on the world, so we've kind of had to do it for him.* (Participant 5, Mother)

> *… the way I've always looked at it and explain it is, I have three living children and they will succeed or fail in their life, and I'll love them no matter what they do, but with* [stillborn daughter] *it's different, I have to do it for her because she never got the chance, so I'm kind of trying to succeed for her, if that makes sense.* (Participant 6, Father)

As the initial pressing need to physically and publicly represent their baby diminished over time, and their bonds predominantly became more internalised, parents sought practical and meaningful ways to build a lasting legacy in their baby's honour. Contributing to charity, either financially, through fundraising activities or by donating their time was common.

> *…that need isn't there anymore, that almost, that recognition or that demonstration is less, less public maybe, so I might do things in her memory, so I might make a donation in her memory but what I do do is more, what's the word I want, kind of practical, has more meaning…* (Participant 11, Mother)

Klass (1996b) observed that parents consolidated their mental representations of their deceased child over time by making their life count for something through helping others. This finding was replicated in the current study. For some parents, altruistic acts extended to setting up new support groups for other perinatally bereaved parents, which served to help others whilst also maintaining meaningful connections to their baby. This mother derived benefit by means of supporting others through the trauma of baby loss.

> *I thought about a year after we lost him, it would be a really good thing to set up a local group because we didn't have one /.../ my role is as a befriender to listen to other people, they do often want to know about my own experience, so they want to know that what they're feeling is normal, and so I do then, if they want to I talk about things we do with* [baby] *or my relationship with him, or what happened, or whatever aspect of it, so that does for me, it is another way of maintaining that link really, knowing that I'm doing something positive after something so horrible is really good for me as well.* (Participant 5, Mother)

Similarly, another mother found helping others through social action, raising awareness and driving change personally valuable. Investing her emotional energy in this manner appeared to be helpful as she developed a renewed sense of purpose. These findings support those of Cacciatore and Bushfield (2007) who viewed mothers' altruism following stillbirth as characterising an evolution in their grief which enabled derivation of purpose and meaning from their personal loss experience.

> …*I've met a couple of people online through support forums and we were integral to setting up the baby loss awareness campaign over here, so that's where I kind of channelled my energies, I didn't know how to deal with the emotional side of it I guess, in any way other than doing that.* (Participant 11, Mother)

Actions that are commemorative and altruistic, as described in the examples above, may bring profound meaning to the lives of the bereaved and allow for, albeit painful, transformative growth (Berzoff, 2011). Some studies show that despite extensive adverse psychosocial consequences associated with stillbirth, parents' personal growth, resilience and acquisition of new life-skills and abilities is possible (see Burden et al., 2016). As mentioned earlier with reference to parents' fluid grief journey, the use of the term "recovery" is not always helpful and has courted controversy within the bereavement literature. Some point to its limitations and potential to pathologise grief (Tedeschi & Calhoun, 2008), whilst others appreciate the reflexive qualities of the notion of "recovery from bereavement" as for them it encapsulates the recovery of self,

redefined and reintegrated into an altered reality (Balk, 2004). Nevertheless, there is a growing body of work which explores the theoretical possibilities and empirical evidence of positive transformative outcomes, or posttraumatic growth (PTG), as a result of efforts to cope with bereavement (Calhoun, Tedeschi, Cann & Hanks, 2010; Krosch & Shakespeare-Finch, 2017; Murphy, 2013; Tedeschi & Calhoun, 2004).

Tedeschi and Calhoun, (2004) define posttraumatic growth as:

> …the experience of individuals whose development, at least in some areas, has surpassed what was present before the struggle with crises occurred. The individual has not only survived, but has experienced changes that are viewed as important, and that go beyond what was the previous status quo. Posttraumatic growth is not simply a return to baseline – it is an experience of improvement that for some persons is deeply profound. (p. 4)

This change is thought to occur within the following key domains: greater appreciation of life and changed sense of priorities; relating to others; personal strength; new possibilities and spiritual development (Tedeschi & Calhoun, 1996). Positive outcomes have previously been reported following pregnancy, perinatal and child loss (Barrera et al., 2009; Cacciatore & Bushfield, 2007; Klass, 1996b; Krosch & Shakespeare-Finch, 2013; Murphy, 2013; Uren & Wastell, 2002). Understandably, positive outcomes following the devastating experience of their baby's death were difficult to countenance or explicitly express for many parents in the current study. However, some narratives did relate aspects of personal change and posttraumatic growth as outlined above by Tedeschi and Calhoun (2004). Riches & Dawson (1996) suggested that bereaved parents' experience of loss can be transformative, leading some to forge new career paths.  The current findings support this idea, with many of the interviewees attributing their current professional positions or involvement with charities to their experience of loss and their connections to their baby.

> *I ended up being a* [professional position] *for* [charity] */…/ none of which was planned, I just wanted to do more and more and more for* [daughter]… (Participant 6, Father)

Moreover, another father believed his daughter's death had catalysed personal betterment, as he acknowledged positive changes to his and his family's life-style behaviours, and was thankful to his daughter for the ongoing inspiration her existence had provided.

> *…so what I did at the time was I'd look for, in amongst all the grief, a couple, 2 or 3 things that I could hold on to that were positive, or had happened in a positive vain, off the back of her existence in the first place, so for me those things were specifically, having given up smoking and lost a lot of weight, 'cos I knew I was going to be a dad, I knew I wanted to be a healthy dad, not an overweight smoking dad, kind of getting financial arrangements in place, from quite a poor baseline in terms of how well we looked after our money and how responsible we were with our spending /…/ it weaves* [baby]*'s existence through my own existence and my own ongoing life and life expectancy, but also then drip feeds into the benefits that her brother and sister have off the back of her having been conceived, so that's kind of where I am psychologically with the ongoing relationship, it's the legacy of the memory and keeping those going because of her /…/ for all the horrible crapness around it, there were some really fabulous things that live on as a result of that very challenging experience, so yeh, consciously for me I think that's how it all weaves together…* (Participant 12, Father)

One mother explained how she thought her daughter's existence had prepared, and enabled her and her family to care more effectively for her son. Her daughter is perceived as a guiding light that continues to illuminate her family's way.

> *…I kind of believe that everything does happen for a reason, and I have to accept that you know for us as a family, if she'd have survived we'd never have had* [son], *and that's like a trade-off, but actually, I mean*

> [son] *is poorly as well, it was almost as though she taught us how to be able to deal with him, there are a lot of similarities in terms of how people disappeared, lack of support, didn't understand, life goes back to normal but you've now got a new normal…* (Participant 11, Mother)

#### 2.4.5.3 Effect on subsequent pregnancies and parenting

Ustundag-Budak, Larkin, Harris and Blissett (2015) found that mothers of stillborn babies had unrealistically high expectations of themselves following subsequent pregnancies. Similarly, in the current study, some parents' altered perception of the world as potentially unsafe and unjust seemed to fuel a need for them to prove that they were worthy of parenting live children. One mother discussed the punishing demands she placed upon herself when caring for her new-born twins.

> *…and when they were born I had to become this perfect mother…like I breast fed them both exclusively until 19 months, I fed them as well, but you know what I mean, I didn't give them any formula, because then, because people would say "Oh gosh she's done that", and so it reinforced that I deserved them, and I couldn't, I had to, I put so much pressure on myself, I'd be absolutely fit to drop, I'd been up all night, and I wouldn't admit I was tired, I wouldn't have any help because I felt as if the first time I had any weakness I would lose them, and so I put so much pressure on myself for them and I was grieving for* [baby]… (Participant 1, Mother)

Increased anxiety and feeling overprotective when parenting subsequent children has previously been identified as a potential consequence of perinatal loss (Cote-Arsenault & Morrison-Beedy, 2001; Ustundag-Budak et al., 2015), and was present in the narratives of mothers in particular in the current study. One mother's use of the term "helicopter parent" epitomised this hypervigilant parenting style.

> *…anxiety about the other children, you know constantly envisaging that something was going to happen to them, and I still have to force myself*

> *not to be a helicopter parent* [laughs], *I still, you know, I love the sea but if we're ever near rivers and stuff,* [husband] *knows to kind of, kind of* [laughing] *that I have to be sort of held back "Don't go near the water!" /…/ I get very nervous 'cos I'm sort of much more aware of the fragility, and I know that there's often times, as much as I would want to, there's not always things I can do to protect them, you know, I couldn't even protect* [baby] *and she was inside of me, you know I think that kind of leaves you feeling quite helpless, quite vulnerable, so I think that's kind of how I'm different, I kind of sort of… feel the fragility of life a lot more.* (Participant 3, Mother)

A renewed sense of appreciation and gratitude for their living children and their parenting role was implicit in all parents' narratives. These findings are consistent with those of Campbell-Jackson, Bezance and Horsch (2014) who reported that parents valued and prioritised time with their next-born following a stillbirth.

#### 2.4.5.4 Ongoing management and reflexivity

As the preceding pages testify, parents overwhelmingly perceived their relationship with their baby as delivering a positive and comforting contribution to their lives. However, uncertainty relating to how to maintain a relationship with a child who was stillborn, together with a pervasive social pressure to justify their ongoing relationship with their baby, also appeared to engender occasional self-doubt in the minds of some parents and led them to question the long-term effect of certain expressions of their continuing bond on their mental health and well-being. One father, whose baby died over 22 years ago, questioned himself and evaluated his behaviour in line with the dominant discourse of relinquishing emotional ties and moving on still prevalent in wider society.

> *…and she's* [other bereaved parent] *longer bereaved than I am, her baby would be 30 now, but we still have those days where you just think, even the work, she's involved with* [charity] *work as well, and even the work we do sometimes you just think, I just don't know if I can do*

> *this anymore, and there are days when you question, is it healthy still to be doing this etc. etc.* (Participant 6, Father)

It is plausible that this uncertainty and internal conflict derives from, or is compounded by, the distinct lack of socially sanctioned or validated references/markers relating to stillbirth outside of the medical environment. Moreover, there is a clear lack of expectation of any enduring relationship between bereaved parent and stillborn baby in society. It could be argued that parents' efforts to reconcile such oppositional feelings may be exacerbating and further problematizing the already acute and wide-ranging consequences of stillbirth. Clearly, there is a pressing need to promote attitudinal change toward stillbirth and parents' ongoing relationship with their baby within wider society.

**Summary of theme *Establishing a "new normal"***

Most parents alluded to integrating their baby into their ongoing life in some way or other longer term. However, parents differed in how they conceptualised their baby over time. Some parents continued to mentally represent their baby as a baby, whilst others created a continuing narrative for their child, and envisioned them growing and their character developing as time passed. Many parents located their child internally and described an essential bond with them as they became infused with their own sense of being. However, some parents also located their child in an external spiritual realm. Integration of the child into the family unit was of special importance to parents. A sense of integration typically coincided with a reduction in the regularity with which they materialised their child using physical artefacts. Evidence of positive outcomes were observed, primarily through parents' efforts to build a lasting legacy for their child and through parents' posttraumatic growth. Transformative changes in identity, personal betterment and professional development emerged. Parents also discussed residual effects of stillbirth on subsequent parenting, notably hypervigilance and gratitude for their living children. Internal tension arose for a few parents as they questioned whether some expressions of their continuing bond with their child may be less helpful over time.

## 2.5 Strengths and limitations of Study 1

Owing to the informal nature of discussions between parents and researcher, detailed and far-reaching narratives have provided a comprehensive insight into parents' ongoing relationship with their stillborn baby. The study not only shows how this relationship is expressed but also examines its key characteristics and the development of connections over time. Consideration of how various expressions of parents' continuing bond may aid coping is also a strength. Exploration of parents' engagement with the natural world has delivered a novel insight into the therapeutic potential of nature following stillbirth, as nature was portrayed as both an architect of continuing bonds, and a potentially nurturing and restorative environment. Moreover, in identifying problems associated with parents' experience of sharing their ongoing relationship with their baby with others, this study highlights the prospective impact of social responses upon parents, and their ability to fully integrate their baby into their lives and adapt to their bereavement. Whilst it is acknowledged that only a quarter of participants were fathers, the inclusion of their perspective makes a significant contribution to the subject area, as so few stillbirth studies incorporate fathers. The fact that 7 out of the 12 participants were directly associated with stillbirth charities, either as employees or befrienders may render the sample unrepresentative of a wider population and limit generalisability. Such close links to perinatal loss charities may mean that, compared to parents who do not have these links, the participants in this study were exposed to more organised events and ritualised activities that are deemed helpful following baby loss. Thus it is possible that the parents in this study were more likely to report engaging in numerous expressions than other parents who do not have a direct association with charitable organisations, and therefore are not as aware of rituals/events relating to stillbirth. Also, it is perhaps not surprising that over half of the participants were associated with charitable organisations, as these associations are themselves essentially expressions of continuing bonds. Hence, when recruiting parents who identify as continuing bonds with their stillborn baby, it could be expected that a number of those parents would

maintain links with their baby and express that ongoing relationship via charity related activities.

## 2.6 Detailed summary and conclusions

> *…most people don't recognise that relationship continues past the moment of death, especially when it's a baby lost in pregnancy, or during labour, I think they assume that because they were never, never lived, that there can't be a relationship, and most people when, if you were to turn it back on them and say "Well which of your children would you choose not to have a relationship or live without?" They understand, that, you know, this was our child and of course we're going to continue to love her and, you know, parent her, in whatever form that takes, even if it's not traditional parenting, so I don't think people do recognise that relationship exists, I think they think you grieve, you get over it, you move on.* (Participant 3, Mother)

The excerpt above encapsulates many of the core issues that emerged during this study: ambiguity surrounding the loss, others' misconceptions of parents' loss experience, a general lack of expectation of any long-term relationship between parents and stillborn baby, parents' enduring love and ongoing concern for their baby, and societal pressure to move on. If stillbirth remains largely on the periphery of the public consciousness, then the notion of parents maintaining an ongoing, perhaps life-long relationship with their stillborn baby, seemingly resides in a distant, as yet unchartered realm. Layne (2003) has linked the silence and uncertainty surrounding perinatal loss to "the absence of accepted cultural scripts for how to behave in such circumstances" (p. 69). The mother's testimony above, together with the testimonies of other parents presented during this study, suggest that contemporary British society, although culturally diverse, has so far failed to deliver a socially accessible script to inform and guide an appropriate wider social response to this relationship. Whilst displaying photographs of deceased family members, or sharing memories of lost loved ones is commonplace for many bereaved individuals, it would appear that for many parents in this study, the traditional discourse of emotional disengagement from the deceased over time still

prevails, and indeed widely dictates and influences society's expectations following baby loss.

Furthermore, parents of stillborn babies themselves are suddenly thrust into a tragic, unanticipated loss experience, and are, at times, left confounded by the profoundly painful question of whether, and how to conduct a relationship with a baby who has died in utero; a question to which society currently provides few answers. Following her study of how parents remembered their babies following perinatal loss, Cote-Arsenault (2003) concluded that "Western culture does not provide families with rituals and established means by which to remember babies who have died before they become a part of society" (p. 35). Whilst some improvements to memory-making opportunities offered by healthcare professionals have been effected in recent times, the current study demonstrates that over 15 years later there is still a dearth of markers or culturally embedded points of reference to aid construction and maintenance of a relationship with a stillborn baby outside of the hospital environment. There are a small number of socially sanctioned memory-making activities which take place in the immediate aftermath of the loss but few rituals or remembrance activities beyond this that can be drawn upon by families more long term. There is a clear need to raise awareness of perinatal loss and continuing bonds so that any enduring relationship between bereaved parent or family member and stillborn baby can be better understood, normalised, embraced and integrated into the cultural framework for understanding death. Increased awareness and deeper understanding would improve the social response to stillbirth and parents' experience of continuing bonds, thus providing better and more consistent support to those seeking to nurture an ongoing relationship with their baby.

The primary objectives of this study were to explore how parents seek to construct and maintain bonds with their stillborn baby; to examine the characteristics of the relationship and any changes over time; to investigate how bonds might be shared with others, and to consider parents' perceptions of how the relationship might aid coping. The initial expectation for this study was that it would provide a preliminary snap shot or impression of any enduring

relationship between parent and baby, giving sufficient indication as to the salient concepts that would drive the direction of a subsequent larger study. However, the willingness of parents to share their emotive experiences in detail and at length, has led to a more comprehensive and textured picture of continuing bonds following stillbirth, than was originally anticipated. Drawing on data from intensive one-to-one interviews with 12 parents of stillborn babies, five main themes emerged: *Constructing and maintaining a relationship, Negotiating the social landscape, Journeying with grief, Developing coping strategies, and Establishing a "new normal"'.*

Numerous types of bonds between parents and baby were observed: material, psychological, emotional, social and spiritual. Consistent with findings reported by Valentine (2008) in a study of general bereavement, parents' bonds in the current study could be experienced internally, or expressed externally. Parents were keen to emphasise that attachment to their baby developed prior to birth. However, some also acknowledged that finding ways to stay connected to their baby over time could be difficult. As previously mentioned, once outside of the medicalised environment of the hospital where bonding was generally supported and the relationship validated, parents found few culturally embedded rituals to guide and facilitate the development and maintenance of the relationship with their stillborn baby. As a result, they engaged in a broad range of creative and often instinctive continuing bonds activities and expressions in an effort to construct and maintain an ongoing relationship with their baby. These informal or non-traditional rituals pervaded discussions (Cacciatore & Flint, 2012a), examples include: taking and displaying photographs of their baby, making hand/footprints, wearing jewellery associated with their baby, doing cross-stitch, adopting colour schemes, having tattoos, and planting flowers/trees.

Ritualised activities including memorialisation, and symbolism served to provide a physical/material representation of their baby, forged mental representations of their baby, helped parents to develop their baby's identity, validated their baby's existence, and enabled opportunities for communal family practices which facilitated the baby's integration into their ongoing lives.

For most parents, an initial imperative to engage in multiple expressions that materialised their baby diminished over time, and this appeared to coincide with a sense of integration with their baby. Generally, the external, material and visible representations of the relationship with their baby were supplanted by more internalised, suffusive, integrated connections, as their baby's essence permeated their very existence and daily lives. This appears to reflect a previously reported gradual shift from externalised to internalised bonds thought to aid bereavement adaptation (Scholtes & Browne, 2015; Yu, He, Xu, Wang & Prigerson, 2016). Whilst the strategies for maintaining ties to their baby appeared to change over time, the affective profundity of their connection remained constant. Continued parenting was clearly evident as parents displayed an ongoing concern for their baby's welfare, and a desire to protect their baby's memory. Communication between parent and baby was apparent both verbally and in written form, and some parents sensed their baby's presence. Moreover, the interactive and reciprocal nature of the relationship was alluded to by a number of parents. Meaning-making pervaded all parents' narratives and several continuing bonds expressions facilitated this process, for example, rituals, engaging with nature, writing, legacy building, and sharing with others.

Sharing their baby with others was seen by the majority of parents as being central to validating their baby's social presence and ongoing significance. Sharing consolidated parents' mental representations of their baby, aided meaning-making and the establishment of a positive legacy in their baby's honour, thus helping parents to develop and sustain an ongoing narrative for their child which could be intertwined with their own unfolding personal biography (Walter, 1996). It enabled parents to challenge stigmatisation and silence and alleviate reported feelings of disenfranchisement, marginalisation and isolation. Consequently, positive sharing experiences were portrayed as potential aids to coping. This reflects current theoretical social constructionist perspectives on continuing bonds which emphasise not only the role of meaning-making but also the importance of social interaction with others, and the relational interplay of meaning and sharing which are viewed as fundamental to coping with bereavement (Klass, 1996b, 2006; Neimeyer et

al., 2014; Valentine 2008). Moreover, by transforming mental representations of baby, strengthening ties and allowing their baby to be integrated into parents' wider support systems, sharing experiences which affirm parents' ongoing relationship with their baby may be contributing to loss adaptation in line with Klass's (1996b) theory of bereavement adaptation.

A number of parents appeared to achieve a sense of integration with their baby at a personal level, be it individually as part of their own self-concept or as part of the family unit. However, broader social integration was sometimes a problematical process due to the indifferent, inappropriate or divergent responses of some members of close personal support systems (i.e. partner, family, friends), and wider society. Critically, the majority of parents alluded to barriers to disclosure, which restricted their sharing opportunities. This is consistent with previous reports of barriers to displaying families that incorporate a stillborn baby, and subsequent conflict as a result of display (Murphy & Thomas, 2013), and a lack of cultural understanding of continuing bonds in Western culture (Klass,1996b). For many parents in the current study, their extant social context did not adequately support or sanction their ongoing relationship with their baby and some relationships with family members and friends became strained or broke down, with some existing support systems dissolving completely. In order to freely maintain ties with their stillborn baby some parents believed they had little option but to relinquish ties with, or distance themselves from those who opposed, belittled or failed to support and understand their ongoing relationship with their baby. Their connections to their deceased baby thus proved stronger than connections to some living family members and friends. Some parents actively restructured their support systems in order to benefit from effective social support. Essentially, parents tended to adapt their social environment to accommodate their relationship with their stillborn baby.

This study provides further evidence to support the intersubjective nature of ongoing relationships with the dead and aligns with current thoughts on continuing bonds:

> … bonds with the dead are not individual; they are interpersonal: they are woven into the complex bonds individuals maintain with intimate others within the communities and the overarching narratives that structure the culture in which their lives and bonds are set. (Klass & Steffen, 2018b, p. 7)

Sharing their loss experience and subsequent relationship with their stillborn baby was a significant part of all parents' bereavement journey. However, this study has revealed how complex and problematic interpersonal communication can be for parents following stillbirth. There appears to be a marked discrepancy between the continuing bonds paradigm which is influencing professional care and support in the immediate aftermath of loss, and the discourse of emotional detachment and moving on from relationships with the deceased over time, which still appears to be prevalent in wider society. As suggested previously, contemporary British society does not have an adequate conceptual framework, based upon the experiential knowledge of perinatally bereaved families, for understanding stillbirth and the potential ongoing relationship between parent and baby. Others' misperceptions or lack of understanding of the magnitude of parents' loss commonly results in avoidance and silence, or inadequate and inappropriate responses. Moreover, society tends to rationalise the tragedy, which is often at odds with parents' profound and affective search for meaning. Whilst parents do challenge the dominant discourse by maintaining profound and diverse connections with their baby over years and decades, some parents understandably change their behaviour and moderate expression of their continuing bond to protect themselves, and their baby's memory from potentially negative responses from others. This is consistent with the process of negotiation between the continuing and relinquishing bonds' paradigms highlighted by Valentine (2008) who reported that some bereaved individuals sought to justify retaining as opposed to relinquishing bonds. In addition, it provides further support for Murphy and Thomas's (2013) observation that parents tend to be more tentative when expressing their continuing bonds in the public sphere than in the private sphere.

In the current study, open, public expression and validation of this relationship, especially over time, was most commonly experienced within the loss community. The majority of parents felt most comfortable discussing their baby with other bereaved parents, without fear of moral judgement or pathologisation of their lasting affective ties to their baby. This may be causing a self-perpetuating situation. It has been suggested that unfamiliarity can make death more difficult for society to bear (Hockey et al., 2010b). This seems particularly pertinent to stillbirth. If parents' support systems predominantly comprise other bereaved parents and sharing is mostly limited to these often hidden enclaves, or stillbirth subculture (Brierley-Jones et al., 2014-2015), then society is being deprived of the valuable and didactic experiential knowledge of the ongoing relationship necessary to inform and improve its response to bereaved parents. In effect, the stillbirth discourse is generally only being heard by those who also speak it, potentially perpetuating the cultural silence surrounding perinatal death and further marginalising parents.

There is a propensity in contemporary Western culture to scrutinise and judge the individual and their immediate family, a tendency reflected in modern psychology which commonly pathologises the individual and their behaviour (Neimeyer et al., 2014). However, as this study's findings would suggest, it may be the dominant discourse or societal response which is in need of scrutiny in this instance. If society is not adequately accommodating the experience of stillbirth, or providing a safe and supportive space for parents to conduct and freely express their ongoing relationship with their baby over time, then the spotlight should not solely be on parents and their mental health outcomes; these outcomes need to be assessed in relation to the outcomes that society will allow or accommodate. This reflects the thoughts of social psychologist and philosopher, Erich Fromm:

> …mental health cannot be defined in terms of the "adjustment"' of the individual to his society, but on the contrary, that it must be defined in terms of the adjustment of society to the needs of man, of its role in furthering or hindering the development of mental health. Whether or

> not the individual is healthy, is primarily not an individual matter, but depends on the structure of his society. (Fromm, 1956, p72)

It is suggested that future studies should give due consideration to the influence of society on parents' bereavement adaptation and ask how healthy are parents being allowed to be. The burden should not lie solely with parents to adopt successful coping strategies. It would be interesting to shift the focus from parents and families to wider support networks in order to explore the reasons why the social response to perinatally bereaved parents can be problematic. Social interventions which positively modify the cultural response to parents who wish to continue bonds with their stillborn baby, should be considered key in moulding an adaptive and supportive environment in which parents can share, integrate, validate and consolidate their relationship with their baby long term. It would appear that any theoretical framework developed to address continuing bonds following stillbirth would need to take account of parents' perceptions of their social environment. If society is insufficiently informed about stillbirth and the potential for some parents to experience an enduring relationship with their baby then it may fail to foster parents' open expression of this relationship, instead suppressing it, be it implicitly or explicitly, with ignorance and silence or judgemental opposition. In essence, society may be contributing to parents' poor mental health corollaries. A social context that denies or restricts parents' opportunities to share mental representations of their stillborn baby, and that resists inclusion in, or portrays as unhealthy, certain expressions of continuing bonds, could be adversely affecting parents' bereavement adaptation (Boerner & Heckhausen, 2003), as they struggle to fully integrate their baby into their everyday life for fear of social judgement, denigration of their baby's memory, and pathologisation of their ongoing relationship. Study 2 (Chapter 3) further examines parents' perceptions of the social context in which they conduct their continuing bond with their baby, in relation to mental health outcomes.

Another aspect of parents' loss experience which was inherently linked to their ongoing relationship with their baby, and appeared susceptible to social scrutiny and judgement was their grief response. Some parents' intense and

enduring emotional reactions were jarringly juxtaposed with their immediate and wider social circles' silent and sometimes dismissive and hurtful responses. This tension exacerbated loneliness and marginalisation suffered by a number of parents and provided evidence that grief may be disenfranchised for some (Doka, 2002). This was especially evident over time as parents perceived an intensification of societal pressure to "get over" and "recover" from their grief. Disenfranchised grief refers to "grief that is experienced when a loss cannot be openly acknowledged, socially sanctioned, or publicly mourned" (p. 160). In addition, it encapsulates contexts in which stigma associated with the loss can inhibit the bereaved from seeking or receiving adequate support, when the manner in which an individual grieves is not deemed socially appropriate, and when others do not appreciate the magnitude and meaning of the loss thus devaluing it (Doka, 2002), circumstances outlined by parents in the current study. Parents highlighted a lack of understanding of their long-term loss experience, stigmatisation, devaluation of baby, societal expectation of recovery from their grief and pressure to let go and move on.

Cacciatore (2013) suggested that disenfranchisement, cultural silence, shame and non-recognition of stillborn babies can exacerbate the psychological impact of loss for parents. Moreover, parents' enduring relationship with their baby is disenfranchised as it is rarely widely acknowledged, socially sanctioned or supported. Indeed, it could be argued that the parents in the current study are suffering a type of *double-disenfranchisement*, a concept raised by Cacciatore and Raffo (2011) when examining lesbian maternal bereavement, as they are initially isolated in the immediate aftermath of their baby's death, but this may become further, and indefinitely, compounded by not being afforded the opportunity to freely communicate to others the (inter)active nature and affective profundity of their ongoing relationship with their baby, which may endure for the remainder of their lives.

Walter (1996) suggested that "it is the retaining of the dead that in our culture needs to be affirmed, not the moving on" (p. 23). Despite this clarion call over 20 years ago, and the proliferation of the continuing bonds paradigm within

academic and medical arenas, it would appear that the cultural framework in which parents experience loss following stillbirth is still predominantly influenced by reductionist, Western models of grief promoting emotional disengagement and recovery. As outlined in Chapter 1 the ubiquitous and ongoing influence of such models may be detrimental to grievers (Attig, 2004; Stroebe et al., 2017; Valentine, 2008; Wortman & Silver, 2001). The current study's findings suggest that societal norms continue to privilege notions of *letting go*, and *getting over it*. Such terminology commonly associated with grief and bereavement adaptation is highly problematic to parents and does not reflect their experience of *moving forward* with their baby deeply and indelibly ingrained in their ongoing narrative. There was a tangible tension between some parents' personal grief journey and the expectations of a culturally-defined grief process. The dominant discourse still appears to define healthy, normative grief, as a linear process with an end point of recovery, to be achieved expediently, and within a certain timescale. Whilst all parents in this study acknowledged that acute grief subsided, and general functionality returned over time, they did not exhibit any sense of expectation that their grief would end. Arnold and Gemma (2008) reported that for bereaved parents grief is a life-long, transformative process which involves integration of the deceased into their lives and is representative of their lasting connection to their child. For the parents of stillborn babies in the current study, whose time with their baby was so brief, and whose opportunities to make sustaining memories so limited, this notion of transformative, prolonged grief may be particularly apt. The fluid, pervasive nature of their reported grief journey reflected their ongoing profound affective bonds with their baby, emotional bonds which parents fully expected to last a lifetime.

Grief changed for all parents in the current study, it became predominantly more manageable, but there was no definitive resolution. New strands of parents' post-loss lives, which included transformative growth and legacy building, became intertwined with their residual grief and enduring affective bonds with their baby, forming their new normal. Parents' loss experience is consistent with Tonkin's (1996) grief theory which posits how individuals can grow around their enduring grief in positive ways, enabling them to integrate

their loss, whilst relieving them of the expectation that their grief must reduce or disappear over time. Greater understanding of the potentially fluid and pervasive nature of grief is needed within wider society. External pressure to effect a complete recovery from emotional pain associated with their baby's death may be adversely affecting parents' bereavement adaptation, as this potentially normative response is pathologised and perceived as detrimental to health and well-being (Thieleman & Cacciatore, 2013a; Thieleman & Cacciatore, 2013b). As the parents' narratives in this study attest, unpredictable and intense emotional pain can accompany parents through the remainder of their lives but it does not preclude positive personal growth, indeed for some it can catalyse this change.

Clearly, changing the often problematic social attitudes toward stillbirth and parents' continuing bond with their baby, as outlined above, is of primary importance in order to improve support for those who experience baby loss. Raising awareness within society of stillbirth and the possibility of parents' desire to continue bonds with their stillborn baby is vital. It is of particular importance that exposure to parents' experiential knowledge transcends the loss community to ensure education in the unique and complex challenges associated with stillbirth is cascaded throughout society.

Continuing bonds calls upon parents to negotiate, contest and obfuscate defined boundaries of a number of dualities inherent in Western culture: birth /death, absence/presence, pain/comfort, silence/disclosure, denial/validation, immanence/transcendence, devastation/growth. In particular, the separation of the living and the dead has challenged the parents in this study to write their own personal script, or continuing bonds narrative, to explore the possibilities and complexities of their relationship with their baby, whilst creatively cultivating a meaningful nexus. As evidenced in the preceding pages, parents' resilience, commitment, creativity, and enduring emotional attachment have fuelled their endeavours to reconcile and entwine the traditionally viewed dichotomous statuses of that which is perceived to be living, and that which is perceived to be dead.

> *…if he was dead or alive I'd have felt the same about him when I saw him, I didn't feel any less for him because he wasn't breathing, I still felt this overwhelming love for him. I was proud of him and I just wanted to protect him, it really wouldn't have mattered if he was dead or alive in terms of that bond, and that's what I think people need to know, and then I think you can understand that a little bit more, you can understand why you don't get over it…* (Participant 4, Mother)

### 2.6.1 Summary of clinical implications

A number of clinical implications have emerged during this study and are summarised here. Some mothers were concerned by a perceived failure to address stillbirth as a possible pregnancy outcome during antenatal classes. A failure to openly discuss stillbirth within this healthcare setting may be contributing to the cultural silence and stigma surrounding their baby's death that is frequently reported by parents. Furthermore, there is a clear need to disseminate parents' experiential knowledge of stillbirth and continuing bonds with a stillborn baby more widely in society in order to increase general understanding of the experience and improve the social response to it. It is hoped that a more informed and sensitive response from others would facilitate more consistent social support for parents long term. Moreover, parents should be advised about diverse grieving styles and approaches to coping following stillbirth in an effort to improve understanding of and respect for different responses within families. It is thought that this will facilitate effective and sensitive communication between family members, thus helping to maintain relationship stability and enhance support for parents.

Another issue that arose is the need for formal and informal support systems to acknowledge fathers' experience of stillbirth equally with that of mothers'. If traditional support services such as support groups are not favoured by fathers then alternate strategies should be considered and explored, for example, an outdoor nature-guided intervention. Writing about their baby may also be helpful to both fathers and mothers in the aftermath of loss.

Parents need to be fully informed about the various informal rituals and activities that they can engage in with their baby, in hospital, or at home where

this is possible. It is vital that parents make informed choices about how they make memories, interact with and develop connections with their baby whilst he/she is physically present. These connections will help parents to construct and maintain an ongoing relationship with their baby. Additional information about the ways in which parents can continue bonds with their baby over time and how this relationship can be expressed (e.g. by engaging with nature or through legacy building activities) might be helpful for those parents who want to actively maintain a relationship. Guidance relating to the management of their baby's ashes may also be useful as there was a sense of uncertainty from some parents as to how best to incorporate the ashes into their ongoing life.

It is suggested that provision of the additional information suggested here could be provided to parents in the form of an information leaflet/booklet included in care packs. All recommendations and clinical implications are fully considered and discussed in detail in Chapter 4 (see p.246, 4.4.1 Recommendations and clinical implications, Applied/Clinical).

# Chapter 3 Study 2 Continuing bonds and bereavement adaptation

## 3.1 Chapter overview

This chapter reports the second study which builds upon the findings of Study 1. Study 2 provides a detailed exploration of bereaved parents' relationship with their stillborn baby using a larger sample and introduces quantitative methods. By using a purposefully designed online questionnaire Study 2 examines how parents continue bonds with their baby and any changes to the relationship over time. Parents' perceptions of the social context in which they experience an ongoing connection with their baby and social support for the relationship are assessed. The study also identifies key aspects and characteristics of parents' continuing bonds experience that are related to bereavement adaptation. Results are discussed in view of the existing literature base and Study 1 findings, and conclusions drawn.

## 3.2 Introduction

For many parents, the experience of stillbirth precipitates a sudden existential crisis that sees the once stabilising foundations of their existing belief system fractured in the devastating aftermath of their baby's death. Such fundamental changes can provoke a challenging and extended period of uncertainty for some. Intense grief and negative mental health outcomes, including anxiety, depression and PTSD, are common consequences which can last for years, if not decades post loss (Cacciatore, 2013; Dyregrov & Matthiesen, 1987, 1991; Gold, Leon, Boggs & Sen, 2016; Gravensteen et al., 2013; Jind, 2003). Study 1 provided evidence to suggest that parents who retain a lasting connection with their baby largely perceive this enduring bond to be beneficial to coping with the profound negative effects of stillbirth. However, there is a distinct dearth of research exploring any potential links between continuing bonds expressions and characteristics, and parents' mental health outcomes following stillbirth.

To date, empirical enquiry within the bereavement literature has failed to deliver unequivocal evidence to support the benefits of either relinquishing, or continuing bonds (Fong & Chow, 2018; Ho & Chan, 2018; Kosminsky 2018;

Root & Exline, 2014; Stroebe et al., 2012). An association between the manner in which the continuing bond is expressed and bereavement adjustment has been theorised; efforts to maintain a more concrete tie through prolonged physical proximity (e.g. use of the deceased's possessions to derive comfort) have been shown to be predictive of more severe and lasting grief responses, whereas a more internalised, symbolic connection (e.g. evoking memories of the deceased) was not predictive of increased distress (Field et al., 1999; Field et al., 2005). Critically, when considered in the context of stillbirth, persons with unexpected loss who retain strong bonds have been shown to be the least well adapted and remain so over time (Stroebe et al., 2012).

Parents' search for meaning following their baby's death was prevalent in the majority of narratives in Study 1, with some quests yielding more clarity and cognitive calm than others. Although a number of studies suggest a positive association between searching for meaning and better adjustment following traumatic life events, such as the death of a loved one (Davis et al., 1998; McIntosh, Silver & Wortman, 1993), the findings are somewhat mixed, with some studies reporting that a quest for meaning may not be universally adaptive, and can be linked to increased distress (Bonnano, 2013; Coleman & Neimeyer, 2010). Indeed, the primary factor may not be the search for meaning itself per se but the individual's perception of resolution, that is, how much meaning has actually been made as a result of the searching process.

As outlined in Chapter 1, empirical evidence relating to the beneficial impact of creating memories through parents' interaction with their stillborn baby on long-term mental health outcomes also remains largely inconsistent, with some studies supporting the practice's value (Cacciatore et al., 2008b; Radestad et al., 1996; Surkan et al., 2008), whilst others report some unfavourable effects (Hennegan et al., 2018; Hughes et al., 2002; Redshaw et al., 2016). Following a review of the literature pertaining to parent-baby contact following stillbirth and mental health sequelae, Hennegan et al. (2015) similarly concluded that the findings remain inconclusive. Nonetheless, many parents value spending time with their baby as it enables them to create memories and

build connections with their baby in the immediate aftermath of loss (Kingdon et al., 2015a, 2015b; Ryninks et al., 2014; Schott & Henley, 2009).

Other potential predictors of mental health sequelae following perinatal loss include time since death (Cacciatore et al., 2008b; Crawley et al., 2013; Turton et al., 2001), not being with baby for as long as desired (Surkan et al., 2008), a lack of concrete remembrance mementos (Radestad et al., 1996) and professional support (Crawley et al., 2013; Murray & Callan, 1988). In addition, the availability and quality of social support has been highlighted as potentially influencing parents' ability to cope following their baby's death (Cacciatore, 2007; Cacciatore et al., 2009). Bereaved mothers especially have found the support of other bereaved mothers particularly comforting and beneficial (Kavanaugh et al., 2004). Moreover, Gear (2014) reported that bereaved parents found talking about their child and sharing memories particularly helpful in facilitating their continuing bond with their child. Crucially, sharing memories of the baby following stillbirth, has been shown to be associated with better maternal mental health outcomes (Crawley et al., 2013).

It has been suggested that the potential for continuing bonds expressions to contribute to coping with loss may be compromised if bereaved individuals do not feel such expressions will be deemed socially acceptable (Root & Exline, 2014). Perceptions of social and moral judgement by others, feeling pressure to justify talking about their ongoing relationship with their baby, especially over time, and inappropriate responses from others, were common aspects of parents' continuing bonds experience reported in Study 1. In essence, the results highlighted a tension between parents' private experience of their relationship with their baby, and the public's expectation of a continuing bond between bereaved parent and stillborn baby. It was theorised that this discrepancy may represent an impediment to parents' free and open disclosure of their relationship with their baby to the full extent that they desire, and thus may be impacting upon parents' mental health. The current study allowed for detailed analysis of the social context in which parents construct and maintain a meaningful nexus with their baby, and parents' perceptions of social support and understanding of their continuing bond with their baby, in

order to determine whether such factors are associated with bereavement adaptation, and to pinpoint those factors which appear to be predictive of better/poorer outcomes. Moreover, other key aspects of the continuing bonds process prevalent in Study 1 narratives which appeared to be contributing to coping, e.g. engagement with nature, legacy building and parents' sense of integration with their baby, were also assessed.

### 3.3 Rationale and research questions

Whilst there is a body of literature examining continuing bonds and bereavement adaptation, there is a paucity of studies specifically addressing the experience of parents of stillborn babies. Furthermore, the stillbirth literature predominantly focusses on parents' interaction with their baby in the hospital environment immediately after loss, with little attention being given to parents' lasting ties to their baby, and how aspects of this ongoing relationship may be related to mental health. Therefore, building upon Study 1 findings, and in response to gaps and inconsistencies in the existing literature, the primary objectives of this study which used a larger sample and different methods were as follows: to explore how parents continue to have a relationship with their stillborn baby, to determine whether time has any effect on this relationship, to examine parents' perceptions of the social context in which they conduct the relationship with their baby and opportunities they have to share it with others, and to identify core aspects and characteristics of parents' continuing bonds experience that might be associated with bereavement adaptation. Research questions were arranged into three main areas of interest: Expressions of continuing bonds and changes over time; Sharing and social context, and Continuing bonds and coping. Owing to a paucity of existing literature relating to these specific research areas and insufficient extant results, it was not deemed possible to confidently hypothesise expected results for each research question. However, for the research question relating to changes in engagement over time, specific hypotheses can be tentatively predicted in light of Study 1 findings, and these are explicated after the corresponding research question below.

**Expressions of continuing bonds and changes over time**

- How do parents express their continuing bond with their baby?
- Are there any changes in engagement over time?

With reference to changes in engagement in continuing bonds over time, it is hypothesised that parents will report engaging in more expressions of continuing bonds in the first year post loss than in the last 12 months. Furthermore, it is predicted that parents will report more frequent engagement in continuing bonds expressions in the first year post loss than in the last 12 months.

**Sharing and social context**

- How do parents share their ongoing relationship with their baby with others?
- Which expressions appear more socially acceptable?
- How broadly are parents sharing their relationship?

**Continuing bonds and coping**

- What factors predict mental health outcomes (i.e. anxiety, depression and PTSD)?
- What factors predict posttraumatic growth?

## 3.4 Methodology

### 3.4.1 Design

A cross-sectional online study was designed to further explore parents' ongoing relationship with their stillborn baby, and any associations between pivotal features of this relationship and bereavement adaptation.

### 3.4.2 Participants

Participants were parents of stillborn babies. Inclusion criteria specified participants must be parents 18+ years old, whose baby died at 24 weeks' gestation or later, over 1 year ago, and who felt they had an ongoing relationship with their stillborn baby. Of the 177 respondents, 7 did not meet the published criteria and were excluded, resulting in a final sample of 170 parents of stillborn babies.

### 3.4.3 Recruitment

Twenty one worldwide, relevant charitable organisations were contacted to request assistance with publicising the online questionnaire. A further 22 regional UK Sands' support groups were approached to help with recruitment. The study was subsequently publicised on Facebook by 19 charitable groups from Australia, the USA and the UK. In addition, details of the study were hosted on the Child Bereavement UK website. Participants from Study 1 were also invited to participate in Study 2. The questionnaire was available online for 7 months (December 2016 to June 2017). All participants provided informed consent online prior to accessing the questionnaire.

### 3.4.4 Sample characteristics

Sample characteristics are presented in Table 3. Largely, participants were British women who had given birth to a stillborn baby in a UK hospital. Parents' ages ranged from 18 to 61 years and time since baby's death spanned 13 months to 39 years.

Table 3. Sample characteristics (*N* = 170)

| | | No. | % |
|---|---|---|---|
| Gender | Female | 162 | 95.3 |
| | Male | 6 | 3.5 |
| | PNA | 2 | 1.2 |
| Education | Secondary | 39 | 22.9 |
| | Further education | 131 | 77.1 |
| Marital status | Single | 7 | 4.1 |
| | Separated/Divorced | 12 | 7.1 |
| | Married | 116 | 68.2 |
| | Partner | 35 | 20.6 |
| Ethnic Origin | Australian | 8 | 4.7 |
| | British | 156 | 91.7 |
| | German | 1 | 0.6 |
| | Greek | 2 | 1.2 |
| | Irish | 2 | 1.2 |
| | Serbian | 1 | 0.6 |

| | | No. | % |
|---|---|---|---|
| Religion | Christian | 80 | 47.1 |
| | Other formal religion | 5 | 2.8 |
| | Spiritual no formal religion | 3 | 1.8 |
| | No religious/spiritual belief | 80 | 47.1 |
| | PNA | 2 | 1.2 |
| Country of residence at time of baby's birth | Australia | 24 | 14.1 |
| | Canada | 1 | 0.6 |
| | USA | 3 | 1.8 |
| | United Kingdom | 142 | 83.5 |
| Place of birth | Hospital | 162 | 95.3 |
| | Birth centre/Midwife-led unit | 4 | 2.3 |
| | Home | 1 | 0.6 |
| | Other | 3 | 1.8 |
| Age (years)* | Range | 18-61 | |
| | Mean (*SD*) | 38.1 (8.0) | |
| My baby died | Before labour | 129 | 75.9 |
| | During labour | 32 | 18.8 |
| | Not known | 9 | 5.3 |
| Number of children born before baby's birth | 0 | 103 | 60.6 |
| | 1 or more | 67 | 39.4 |
| Number of children born after baby's birth | 0 | 42 | 24.7 |
| | 1 or more | 125 | 73.5 |
| | Currently pregnant | 3 | 1.8 |
| Gestational age of baby (weeks) | Range | 23.9-42.1 | |
| | Mean (*SD*) | 35.3 (5.4) | |
| Time since baby's death (years:months)* | Range | 1:01-39:00 | |
| | Mean (*SD*) | 7:06 (7.92) | |
| Offered a post mortem | No | 6 | 3.5 |
| | Yes | 164 | 96.5 |
| Consented to a post mortem | No | 58 | 34.1 |
| | Yes | 106 | 62.4 |
| | N/A | 6 | 3.5 |

Notes. PNA = Prefer not to answer; * $n$ = 169 due to missing data.

### 3.4.5 Ethical approval

Ethical approval for Study 2 was granted by the University of Sunderland Research Ethics Committee (UREC) on 11/08/16 (see Appendix I for certificate). Following a short pilot conducted by one participant from Study 1, an amendment request relating to the clarification of instructions, minor changes to wording and the inclusion of nine further questions was submitted in line with the UREC Amendment Procedure, this was subsequently approved via email on 24/11/16.

### 3.4.6 Materials and procedure

Key, emergent themes from Study 1 were used to design a comprehensive online questionnaire which would allow for detailed analysis of the continuing bonds process, and investigation of any association between various aspects of parents' relationship with their baby and mental health outcomes (i.e. anxiety, depression and PTSD) and posttraumatic growth. Questions were formulated pertaining to: parents' engagement in a broad range of expressions of continuing bonds, e.g. rituals and memorialisation activities, and any changes over time; the characteristics of the ongoing relationship between parent and baby; the social context in which parents conduct this relationship and their experience of sharing it, and parents' perceptions of meaning-making, coping and potential personal transformation.

Sections 1-4 of the Continuing Bonds and Coping questionnaire (see Appendix J) were developed in consultation with the researcher's supervision team, a parent representative and a Sands' liaison officer. Detailed feedback was provided by Sands to try to effect a sensitive approach to questioning, and a thoughtful and informed use of terminology in order to prioritise and safeguard the welfare of parents. This consultation process was comprehensive, lasting approximately eight months and resulted in multiple revisions of the questionnaire. As advised by Sands, full contact details for relevant support services were provided in the information sheet prior to participation, and again in the debriefing information on completion of the questionnaire. In addition, parents were advised to consult their GP if their

participation in the study caused undue distress, or raised any issues or concerns.

The questionnaire was built concurrently online using the Qualtrics Survey Manager and its performance tested extensively. Section 1 requested personal information about the participant and their stillborn baby. Sections 2-4 included items relating to the myriad ways, and the extent to which, parents maintain an ongoing relationship with their baby, parents' experience of sharing this relationship with others, and meaning-making. Section 2A required parents to rate the degree to which they agreed or disagreed (on a 7 point Likert scale) with statements relating to certain characteristics of their ongoing relationship with their baby, which were observed in Study 1, e.g. Attachment and Integration. Using a frequency scale, participants' engagement in certain expressions of continuing bonds over time (i.e. in the first year post loss, and in the last 12 months), and the frequency and scope of opportunities to share, or include others in these activities, were measured in Section 2B. The list of continuing bonds expressions was compiled using Study 1 data, and bereavement rituals cited in prior studies (i.e. Castle & Phillips, 2003; Crawley et al., 2013; Vale-Taylor, 2009). Parents were asked to indicate whether they had engaged in or shared 28 different expressions of continuing bonds, which were organised into 10 categories: Physical Reminders (e.g. Displayed or looked at photographs of baby); Memorialisation (e.g. Marked baby's birthday or other special occasion); Symbolism (i.e. Associated certain symbols with baby); Legacy Building (e.g. Done something positive in baby's honour); Communication (i.e. Talked to baby either in head or out loud); Writing (e.g. Written about baby); Sense of Presence (e.g. Had a sensory experience that made me feel baby's presence); Mental Representations (e.g. Thought about baby); Emotion (i.e. Felt an emotional attachment to baby) and Nature (e.g. Actively engaged with nature in some way that made me feel connected to baby). Parents' perceptions of the reaction of those with whom they had shared these expressions of continuing bonds, and the frequency with which they had held back from sharing them with others in case of a negative response, was also recorded in this section. Parents' perceptions of social support for their ongoing relationship with their

baby and the social context in which they conduct the relationship, were measured using a 7 point Likert scale in Section 3. In addition, participants were asked to rate the degree to which they had been able to make sense of their loss, or find benefit from their experience of loss, and whether they thought their sense of identity had changed as a result of their experience in Section 4 (Currier, Holland, Coleman & Neimeyer, 2008; Neimeyer, Baldwin & Gillies, 2006). Sections 1-4 of the questionnaire also included open text boxes to allow parents to provide any other information they deemed to be relevant.

Section 5 comprised two standardised measures of mental health, and a validated measure of posttraumatic growth. The presence of anxiety and depression symptomatology within the last month was assessed using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The HADS is a 14-item self-report screening measure comprising two 7-item scales, one for anxiety, the other for depression, and both with a possible score range of 0-21. The HADS has good psychometric properties (Bocerean & Dupret, 2014) and has been used effectively in previous studies examining women's mental health outcomes following childbirth, miscarriage and perinatal loss (see Bastos, Furuta, Small, McKenzie-McHarg & Bick, 2015; Horsch et al., 2017; Nikcevic & Nicolaides, 2014; Scheidt et al., 2012). PTSD symptoms experienced within the last month were measured with the Impact of Event Scale Revised (IES-R) (Horowitz, Wilner & Alvarez 1979; Weiss & Marmar, 1997). This is a 22-item scale measuring PTSD symptoms relating to intrusion, avoidance and hyperarousal. Each item is measured using a 5 point scale (0-4) resulting in a possible global score range of 0-88. The IES-R is a standardised screening tool commonly used in childbirth, pregnancy loss and parental bereavement research (e.g. Cacciatore, Lacasse, Lietz & McPherson, 2013-2014; De Graaff, Honig, Van Pampus & Stramrood, 2018; Krosch & Shakespeare, 2017). Posttraumatic growth was measured with the Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996), a 21-item measure used to assess positive outcomes following traumatic events, with a score range of 0-105. The PTGI has been used effectively within the bereavement and stillbirth literature (e.g. Cacciatore et al., 2018; Englekeymeyer & Marwit, 2008; Krosch & Shakespeare, 2017). For the current

sample, the HADS, IES-R and PTGI showed high internal consistency, with Cronbach's $\alpha = .89$, .93 and .90 respectively.

Three questions specifically assessing frequency of parents' engagement with nature following their loss were included. Participants that answered positively to these questions were invited to answer further questions relating to nature as part of an external collaborative study (not reported here).

### 3.4.7 Data analysis

Descriptive statistics were employed to show parents' engagement in a wide range of continuing bonds activities, experiences and expressions. Inferential statistics (i.e. related *t* tests) were used to compare the number of continuing bonds expressions in which parents engaged in the first year post loss and the last 12 months, and also parents' frequency of engagement in continuing bonds expressions in the first year following their baby's death and in the last 12 months, in order to investigate engagement over time. Multiple regression models were used to examine predictors of mental health following stillbirth, enabling exploration of any association between a number of expressions and characteristics of continuing bonds, and bereavement adaptation. All statistical analyses were performed using SPSS. All results are presented below, but only the most salient results have been chosen for further comment and are reported on in detail. This is primarily a quantitative study and the qualitative data provided in open text boxes were mainly used to clarify and enhance interpretation of quantitative results.

Preliminary analyses using Cronbach's Alpha showed internal consistency for composite items: Attachment ($\alpha$ =.510), Integration ($\alpha$ =.798) and Meaning-making ($\alpha$ =.525). Meaning-making item *I have tried to look for answers as to why my baby died* was removed from the scale, as its omission increased the value of alpha ($\alpha$ =.652), essentially this resulted in a "Meaning-made" scale which included: Sense-making, Finding benefit and Perceiving personal change. Whilst it is acknowledged that two of the alpha values are relatively low, it has been suggested that in the early stages of exploratory research, values as low as .5 are acceptable (Nunnally, 1967), moreover, Hinton,

Brownlow, McMurray and Cozens (2004) consider .5 as showing moderate reliability.

## 3.5 Results

The results are presented in three sections: Expressions of continuing bonds and changes over time, Sharing and social context, and Continuing bonds and coping. These sections correspond to the main research areas into which the research questions were arranged (see 3.3).

### 3.5.1 Expressions of continuing bonds and changes over time

The percentage of parents engaging in every activity/experience within each of the 10 categories (e.g. Physical Reminders, Communication) once or more was calculated. These percentages were then used to calculate the mean percentage of parents for each category. Table 4 provides an overview of parents' engagement across all 10 categories of continuing bonds expressions in the first year and the last 12 months post loss, and shows the mean percentage of parents who engaged in each category once or more. Parents expressed their continuing bond with their baby in a broad range of ways. More than 50% of parents engaged in 9 of the 10 different types of continuing bonds expressions in the first year post loss, and 7 out of 10 in the last 12 months. Parents most commonly reported engaging in expressions of continuing bonds relating to mental representations of their baby, emotional connections to, and communication with their baby, in both the first year and the last 12 months. Expressions relating to sense of presence experiences were the least commonly reported by parents in the first year, whilst writing was the least common experience in the last 12 months. Parents' engagement in 9 of the 10 different types of expression decreased over time, with writing showing the greatest reduction.

Table 4. Mean percentage of parents engaging in continuing bonds expressions once or more.

| | Phys | Mem | Symb | Legacy | Comm | Writing | SoP | Mental | Emo | Nature |
|---|---|---|---|---|---|---|---|---|---|---|
| 1st year | 83.1 | 80.1 | 75.9 | 50.4 | 93.5 | 61.2 | 45.3 | 99.8 | 99.4 | 70.4 |
| Last 12 mnths | 77.1 | 71.3 | 74.8 | 48.8 | 91.2 | 37.9 | 40.3 | 99.8 | 98.8 | 69.0 |

Notes. Phys = Physical; Mem = Memorial; Symb = Symbolic; Comm = Communication; SoP = Sense of Presence; Mental = Mental Representations; Emo = Emotion.

A full breakdown of all 28 continuing bonds activities and experiences is presented in Table 5, which shows the percentage of parents engaging in each individual expression once or more in the first year and the last 12 months, and any changes over time. All parents thought about their baby, and what their baby would be doing now if he/she was still alive, in both the first year and the last 12 months, with all bar one parent thinking about the time they had spent with their baby in both the first year and the last 12 months. Aside from thinking about their baby, in the first year, the vast majority of parents (≥80%) displayed or looked at photographs of their baby, looked at a memory box, carried or wore something associated with their baby, visited somewhere in honour of their baby, lit candles or lanterns in remembrance of their baby, marked their baby's birthday or other special occasion, talked to their baby and felt an emotional attachment to their baby. Notably more than half of parents engaged in these activities frequently (see Appendix K for further breakdown of data relating to frequency of engagement). In the last 12 months, the overwhelming majority of parents (≥80%) displayed or looked at photographs of their baby, looked at a memory box, lit candles or lanterns in remembrance of their baby, marked their baby's birthday or other special occasion, talked to their baby and felt an emotional attachment to their baby, with ≥50% of parents still frequently engaging with photographs, marking special occasions, talking to, and feeling an emotional connection with their baby, and just less than half frequently carrying or wearing something associated with their baby (see Appendix K, Table K1). This highlights the

importance of more informal rituals that can be easily integrated into parents' everyday lives. The majority of parents had sensed their baby's presence in some way, in both the first year and the last 12 months. The majority had also engaged with nature to connect with their baby, used associative symbols from the natural world and engaged with nature to aid coping, in the first year and the last 12 months post loss. Other continuing bonds activities/experiences not included in the questionnaire checklist which were reported by parents in the free text boxes were: Educating others and raising awareness through conference speaking; listening to music or singing; having a tattoo; praying, creating an online memorial website and reading the midwife's notes.

The percentage of parents engaging in continuing bonds expressions once or more decreased for the majority of activities and experiences over time. However, there was no change over time in the percentage of parents who thought about their baby, or marked their baby's birthday or other special occasion, and a minimal reduction (0.6%) in the percentage of parents feeling an emotional attachment to their baby. Dedicating something in their baby's honour, attending a memorial service/remembrance event and writing to and about their baby, became notably less popular with the passage of time. Actively helping other parents affected by stillbirth, and engaging with nature in some way that helped parents, became marginally more popular over time.

With reference to changes in engagement in continuing bonds over time, it was hypothesised that parents would report engaging in more expressions of continuing bonds in the first year post loss than in the last 12 months. Moreover, it was predicted that parents would report more frequent engagement in continuing bonds expressions in the first year post loss than in the last 12 months.

In order to determine whether time had an impact on parents' general engagement in continuing bonds expressions, the difference between the mean number of expressions (out of 28), in which parents engaged in the first year, and the last 12 months, was analysed using a related *t* test. The results showed that parents engaged in more expressions of continuing bonds in the first year ($M$ = 20.82, $SE$ = 0.36) than the last 12 months ($M$ = 19.26, $SE$ =

0.38). This difference was significant, $t(169) = 6.83$, $p < .001$ and represented a medium sized effect, $r = .47$.

Similarly, a related *t* test was conducted to assess any difference in parents' frequency of engagement score in the first year (across all 28 expressions), and the equivalent score recorded for the last 12 months. Frequency of engagement was measured for each item using a 4 point scale ranging from 0 (Not applicable) to 4 (Frequently). The sum of all 28 items resulted in a possible maximum frequency of engagement score of 112 for the first year and for the last 12 months. Parents' frequency of engagement in all 28 expressions of continuing bonds in the first year ($M = 80.26$, $SE = 1.13$) was significantly greater than that in the last 12 months ($M = 72.45$, $SE = 1.12$); $t(169) = 10.17$, $p < .001$, with a large effect size, $r = .62$.

The results supported both hypotheses relating to changes over time as parents' general engagement in expressions of continuing bonds (i.e. number of expressions engaged in and frequency of engagement) reduced significantly from the first year post loss to the last 12 months.

Nevertheless, whilst parents' engagement in continuing bonds expressions significantly decreased over time, the mean number of expressions in which parents had engaged during the last 12 months was still relatively high, and suggests that parents are still using many different ways to remain connected to their baby, even over time.

Other important characteristics of the ongoing relationship between parent and stillborn baby are shown in Table 6. A high percentage of parents (96.4%) said that they felt attached to their baby during the pre-natal period, and whilst this decreased to 85.9% of parents who felt attached to their baby immediately after birth, the vast majority (97.0%) agreed that they felt attached to their baby now, indicating that parents' sense of attachment to their baby endured over time. An ongoing feeling of responsibility toward their baby was very common amongst parents (93.5%), as was a lasting desire to protect their baby's memory (99.4%). Parents more commonly reported that they still thought about their baby as a baby (80.0%), however, more than half (65.3%) said that when they thought about their baby they thought about him/her at the age

he/she would have been if they had still been alive. The majority of parents expressed feeling a sense of integration with their baby, as part of themselves (95.2%), as part of their family (91.2%), and as part of their everyday life (88%), with 95.9% of parents expecting to have a relationship with their baby for the rest of their life. Notably, over three quarters (77.7%) of parents considered their ongoing relationship with their baby to be an aid to coping with the bereavement.

Table 5. Percentage of parents engaging in continuing bonds expressions once or more, and changes over time.

| | | 1st year | Last 12 months | Difference over time |
|---|---|---|---|---|
| Physical Reminders | Displayed or looked at photos of baby | 94.2 | 89.4 | -4.8 |
| | Looked at a memory box | 92.9 | 81.8 | -11.1 |
| | Collected objects that made me think about baby | 76.5 | 73.0 | -3.5 |
| | Bought or made gifts for baby | 71.2 | 65.9 | -5.3 |
| | Carried or worn something associated with baby | 80.6 | 75.3 | -5.3 |
| Memorialisation | Visited somewhere in honour of baby | 84.2 | 78.2 | -6.0 |
| | Dedicated something in baby's honour | 66.4 | 45.3 | -21.1 |
| | Lit candles or lanterns in remembrance of baby | 91.2 | 87.7 | -3.5 |
| | Marked baby's birthday or other special occasions | 90.0 | 90.0 | 0.0 |
| | Visited baby's grave/site of ashes | 78.2 | 75.4 | -2.8 |
| | Attended memorial service or other remembrance event in memory of baby | 70.5 | 51.1 | -19.4 |
| Symbolism | Associated certain symbols with baby | 75.9 | 74.8 | -1.1 |
| Legacy Building | Done something positive in baby's honour | 68.2 | 64.2 | -4.0 |
| | Actively helped other parents affected by stillbirth | 48.2 | 52.3 | +4.1 |
| | Tried new experiences on behalf of baby | 34.7 | 30.0 | -4.7 |
| Communication | Talked to baby either in my head or out loud | 93.5 | 91.2 | -2.3 |

| | | 1st Year | Last 12 months | Difference over time |
|---|---|---|---|---|
| Writing | Written directly to baby | 57.6 | 32.3 | -25.3 |
| | Written about baby | 64.7 | 43.5 | -21.2 |
| Sense of Presence | Had a sensory experience that made me feel baby's presence | 55.9 | 43.6 | -12.3 |
| | Sensed the presence of baby in another way | 68.1 | 67.1 | -1.0 |
| | Communicated with baby through a spiritualist | 11.8 | 10.1 | -1.7 |
| Mental Representations | Thought about baby | 100 | 100 | 0.0 |
| | Thought about the time I had with baby | 99.4 | 99.4 | 0.0 |
| | Thought about what baby would be doing if he/she was alive | 100 | 100 | 0.0 |
| Emotion | Felt an emotional attachment to baby | 99.4 | 98.8 | -0.6 |
| Nature | Engaged with nature in some way that made me feel connected to baby | 71.2 | 67.0 | -4.2 |
| | Engaged with nature in some way that helped me | 73.0 | 74.1 | +1.1 |
| | Associated a symbol from nature with baby | 67.1 | 65.9 | -1.2 |

Table 6. Characteristics of parents' ongoing relationship with their stillborn baby

| | | Agree (%) | Disagree (%) | Neither (%) |
|---|---|---|---|---|
| Attachment | Felt attached to baby before he/she born | 96.4 | 2.4 | 1.2 |
| | Felt attached to baby immediately after he/she born | 85.9 | 11.2 | 2.9 |
| | Feel attached to baby now | 97.0 | 1.8 | 1.2 |
| Ongoing relationship and coping | Relationship with baby has brought me comfort | 84.7 | 8.8 | 6.5 |
| | Relationship with baby has helped me through bereavement | 77.7 | 13.5 | 8.8 |
| Relationship with baby over time | It has changed over time | 68.8 | 21.8 | 9.4 |
| | It has become stronger over time | 47.6 | 21.2 | 31.2 |
| | It has become weaker over time | 18.3 | 68.2 | 13.5 |
| Continued parenting | Feel ongoing responsibility toward baby | 93.5 | 1.8 | 4.7 |
| | Want to protect baby's memory | 99.4 | 0.0 | 0.6 |
| Mental representations | When think about baby now, think of him/her as a baby | 80.0 | 12.4 | 7.6 |
| | When think about baby now, think of him/her at age would have been | 65.3 | 23.5 | 11.2 |
| | Mental images of baby have changed over time | 45.3 | 44.1 | 10.6 |
| Integration | Baby feels part of me | 95.2 | 2.4 | 2.4 |
| | Baby feels part of everyday life | 88.3 | 8.8 | 2.9 |
| | Baby feels part of family | 91.2 | 4.7 | 4.1 |
| | Expect to have relationship with baby for rest of life | 95.9 | 0.6 | 3.5 |

### 3.5.2 Sharing and social context

The percentage of parents who had: wanted to share, shared physically and/or by telling, received a negative response to sharing, and held back from sharing to avoid a negative response once or more, for every activity/experience within each of the 10 categories of continuing bonds expressions, was calculated. Calculations were adjusted to exclude “not applicable” responses to ensure data were not skewed. These percentages were then used to calculate the mean percentage of parents who had: wanted to share, shared physically and/or by telling, received a negative response to sharing, and held back from sharing to avoid a negative response for each category.

Table 7 presents an overview of how common parents’ sharing behaviours were across all 10 different types of continuing bonds expressions. Expressions relating to emotion, mental representations, physical reminders and memorialisation were the types of expression parents most commonly reported wanting to share, and actually shared with others, either physically or by telling. Parents wanted to share, and actually shared with others expressions relating to communication with their baby the least. The majority of parents also wanted to share expressions relating to physical reminders of their baby, symbolism, legacy building, and nature. Generally, parents more commonly reported sharing continuing bonds expressions by telling.

Table 7. Mean percentage of parents sharing continuing bonds expressions once or more.

| | Phys | Mem | Symb | Legacy | Comm | Writing | SoP | Mental | Emo | Nature |
|---|---|---|---|---|---|---|---|---|---|---|
| Wanted to share | 70.9 | 76.6 | 65.8 | 57.0 | 37.4 | 42.8 | 42.6 | 85.3 | 87.1 | 60.4 |
| Shared physically | 69.3 | 72.8 | 58.5 | 50.7 | 29.4 | 34.3 | 36.6 | 72.7 | 77.9 | 55.6 |
| Shared by telling | 71.2 | 75.0 | 63.3 | 57.6 | 38.5 | 41.7 | 41.7 | 79.2 | 81.0 | 55.4 |
| Negative response to sharing | 18.9 | 16.3 | 15.7 | 13.3 | 8.7 | 3.7 | 8.4 | 21.2 | 21.1 | 6.8 |
| Held back from sharing to avoid negative response | 43.8 | 31.7 | 28.6 | 22.0 | 34.1 | 21.5 | 25.3 | 44.3 | 40.4 | 23.3 |

Notes. Phys = Physical; Mem = Memorial; Symb = Symbolic; Comm = Communication; SoP = Sense of Presence; Mental = Mental Representations; Emo = Emotion.

A comprehensive breakdown of all continuing bonds activities and experiences and parents' sharing behaviours are reported in Table 8. Parents most commonly reported wanting to share and actually sharing (physically and by telling) photographs of their baby (89.6%). For this activity, and across the other 27 expressions parents more commonly reported wanting to share or actually sharing either occasionally or frequently rather than only once (see Appendix L, Table L1).

In considering the social acceptability of all 10 different types of expressions of continuing bonds, it should be noted that the majority of parents had not received a negative response from others when sharing. Expressions relating to mental representations (21.2%), emotion (21.1%) and physical reminders (18.9%) most commonly triggered a negative response from others when shared. When sharing photographs of their baby with others, 37.9% of parents stated they had experienced a negative response from others with 24.0% reporting this had occurred occasionally or frequently (see Appendix L, Table

L2). Sharing photographs was the activity/experience most commonly reported by parents as provoking a negative response. Only 3.7% of parents reported receiving a negative response to sharing writing related expressions, however, writing was not shared by the majority of parents. Of the expressions shared by more than half of parents, nature and legacy building related expressions received the fewest negative responses from others. Writing directly to baby (3.0%), and about baby (4.3%) were the activities which received the fewest negative responses, however, again neither of these activities were shared by the majority of parents. When considering the activities or experiences which were shared by ≥50% of parents, active engagement with nature in some way that helped, received the fewest negative responses from others.

Perhaps unsurprisingly, parents most commonly reported holding back from sharing expressions to which they tended to receive a negative response from others; with 44.3% of parents reporting that they had held back from sharing expressions related to mental representations in case they provoked a negative response from others, 43.8% for expressions connected to physical reminders, and 40.4% for emotion related expressions. The majority of parents reported holding back from sharing the activity which most commonly triggered a negative response from others, namely sharing photographs of their baby (66.7%). The association between parents experiencing a negative response from others when sharing, and a tendency to hold back from sharing to avoid a negative response, was supported by a strong positive correlation ($r$ = .63). These two variables were calculated using the mean frequency score of receiving a negative response to sharing, and the mean frequency score of holding back from sharing to avoid a negative response, across all 28 activities/expressions. Of the expressions that the majority of parents wanted to share, only 22.0% held back from sharing legacy building related expressions, and 23.3% held back from sharing expressions linked to nature. Whilst only 12.9% of parents stated they had held back from sharing the specific legacy building related activity *tried new experiences on behalf of my baby*, this was not an activity most parents wanted to share. Of those expressions that most parents wanted to share, only 22.2% of parents had

held back from sharing with others their experience of associating a symbol from the natural world with their baby, in order to avoid a potential negative response.

It is interesting to note that the percentage of parents who shared expressions relating to physical reminders, legacy building and communication by telling, actually exceeded the percentage of parents who wanted to share these expressions. While prima facie this may appear unusual, Study 1 findings revealed that parents sometimes spontaneously disclosed information about their ongoing relationship with their baby, especially in the immediate weeks and months following loss, and so sharing may not always be precipitated by a conscious desire to share.

Table 8. Percentage of parents sharing continuing bonds activities and experiences once or more.

| | | Wanted to share | Shared physically | Shared by telling | Received negative response to sharing | Held back from sharing to avoid negative response |
|---|---|---|---|---|---|---|
| Physical reminders | Displayed or looked at photos of baby | 89.6 | 87.9 | 83.6 | 37.9 | 66.7 |
| | Looked at a memory box | 64.8 | 58.3 | 68.5 | 11.5 | 44.2 |
| | Collected objects that made me think about baby | 67.5 | 66.7 | 66.4 | 17.5 | 39.1 |
| | Bought or made gifts for baby | 63.2 | 62.8 | 67.3 | 14.5 | 32.6 |
| | Carried or worn something associated with baby | 69.6 | 71.0 | 70.1 | 13.3 | 36.5 |
| Memorialisation | Visited somewhere in honour of baby | 80.6 | 75.2 | 81.2 | 17.7 | 38.3 |
| | Dedicated something in baby's honour | 68.7 | 64.8 | 67.8 | 13.7 | 28.6 |
| | Lit candles or lanterns in remembrance of baby | 82.3 | 78.4 | 78.4 | 14.9 | 28.8 |
| | Marked baby's birthday or other special occasions | 85.3 | 81.5 | 82.3 | 18.5 | 34.9 |
| | Visited baby's grave/site of ashes | 78.5 | 76.6 | 79.5 | 18.5 | 31.3 |
| | Attended memorial service or other remembrance event in memory of baby | 64.1 | 60.2 | 60.8 | 14.5 | 28.0 |
| Symbolism | Associated certain symbols with baby | 65.8 | 58.5 | 63.3 | 15.7 | 28.6 |

| | | Wanted to share | Shared physically | Shared by telling | Received negative response to sharing | Held back from sharing to avoid negative response |
|---|---|---|---|---|---|---|
| Legacy building | Done something positive in baby's honour | 75.9 | 68.6 | 75.5 | 16.0 | 26.8 |
| | Actively helped other parents affected by stillbirth | 62.1 | 54.3 | 62.6 | 18.0 | 26.2 |
| | Tried new experiences on behalf of baby | 33.0 | 29.2 | 34.6 | 5.8 | 12.9 |
| Communication | Talked to baby either in my head or out loud | 37.4 | 29.4 | 38.5 | 8.7 | 34.1 |
| Writing | Written directly to baby | 35.5 | 30.5 | 35.5 | 3.0 | 21.0 |
| | Written about baby | 50.1 | 38.2 | 47.9 | 4.3 | 21.9 |
| Sense of presence | Had a sensory experience that made me feel baby's presence | 47.0 | 39.7 | 45.8 | 9.4 | 31.9 |
| | Sensed the presence of baby in another way | 57.8 | 48.6 | 55.6 | 8.2 | 29.4 |
| | Communicated with baby through a spiritualist | 23.1 | 21.4 | 23.7 | 7.6 | 14.5 |
| Mental representations | Thought about baby | 89.6 | 78.5 | 83.2 | 24.5 | 47.0 |
| | Thought about the time I had with baby | 83.5 | 71.7 | 79.2 | 19.6 | 42.3 |
| | Thought about what baby would be doing now if he/she was alive | 82.9 | 68.0 | 75.1 | 19.5 | 43.7 |

| | | Wanted to share | Shared physically | Shared by telling | Received negative response to sharing | Held back from sharing to avoid negative response |
|---|---|---|---|---|---|---|
| Emotion | Felt an emotional attachment to baby | 87.1 | 77.9 | 81.0 | 21.1 | 40.4 |
| Nature | Engaged with nature in some way that made me feel connected to baby | 63.8 | 58.6 | 58.3 | 6.7 | 24.1 |
| | Engaged with nature in some way that helped me | 60.2 | 54.4 | 52.4 | 6.4 | 23.7 |
| | Associated a symbol from nature with baby | 57.2 | 53.9 | 55.6 | 7.3 | 22.2 |

In considering how widely parents shared their ongoing relationship with their baby with others, Figure 2 illustrates that parents generally thought that understanding of, and support for their relationship with their baby decreased as social distance increased. The majority believed that their partner (88.5%), family (77.2%) and friends (76.8%) understood and supported their relationship with their baby, whereas less than half (41.4%) agreed that people outside of their family and friends understood and supported the relationship, and only 17.6% perceived society as being understanding and supportive of their continuing bond. Over half of parents (62.2%) stated that some family members did not understand and support their relationship with their baby, compared with 54.9% of their friends, and 52.0% of support systems outside of parents' family and friends. Partners were highlighted as being the most understanding and supportive of the continuing bond, and parents were most comfortable talking to their partner (83.0%), then with friends (67.7%), family (60.5%) and least comfortable talking to people outside of their family and friends (46.5%). Notably, parents felt least comfortable talking to family about their relationship with their baby as time passed (60.0%). Parents tended to feel less pressure to move on from their partner (22.4%) and friends (32.3%), than from their family (40.1%), people outside of their family and friends (40.7%), and society in general (44.7%).

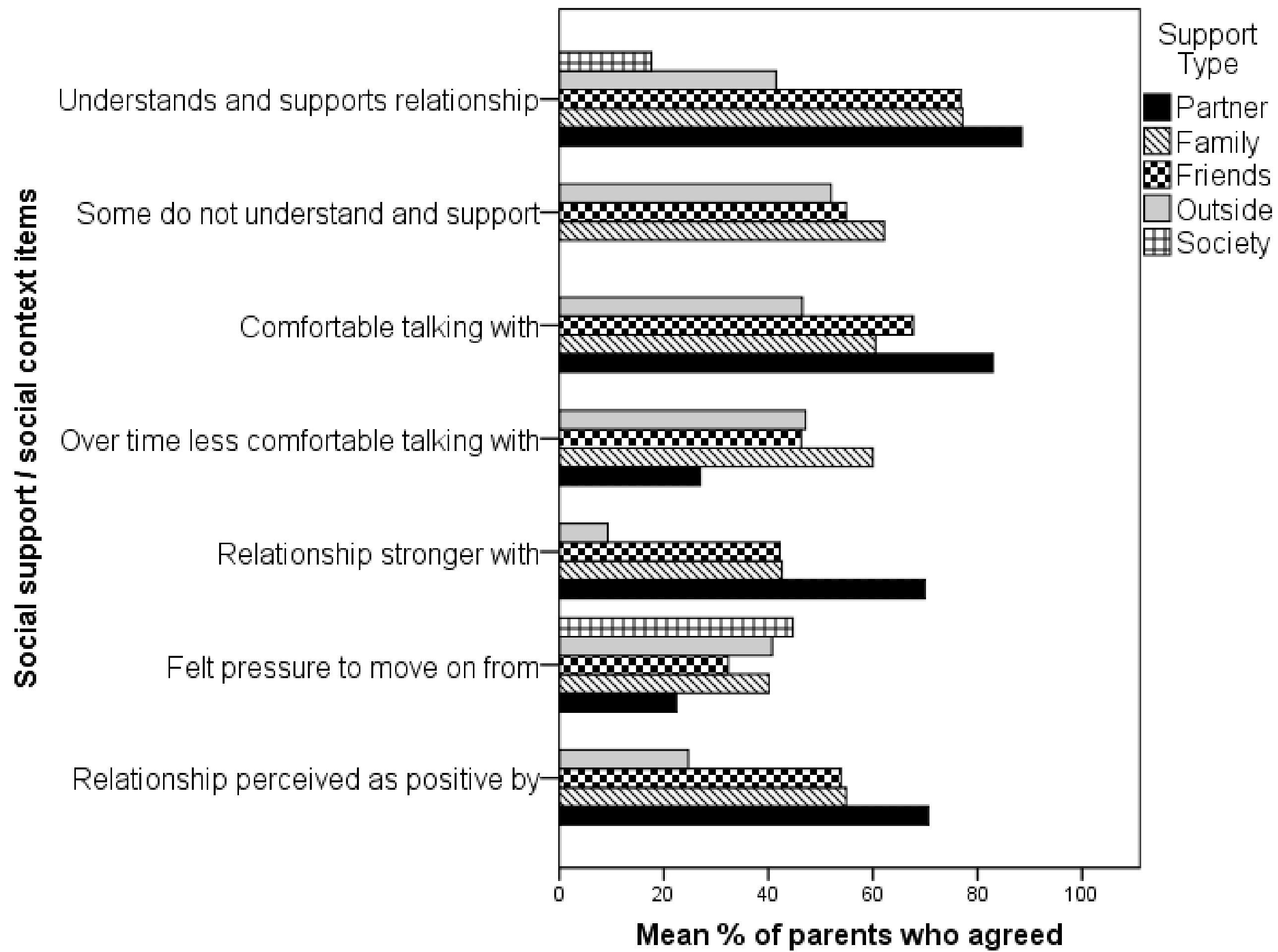


Figure 2. Mean percentage of parents who agreed with items relating to social support and social context

Parents' general perceptions of social support, and other sharing behaviours are presented in Table 9. This shows that nearly three quarters of parents (74.7%) agreed that they avoided talking about their relationship with their baby with some people, in case they reacted in a negative way. Moreover, 69.4% of parents stated they would like to be able to talk more freely about their relationship with their baby.

Table 9. Social support and general sharing behaviour

| | Agree (%) | Disagree (%) | Neither (%) |
|---|---|---|---|
| Avoided talking about relationship with baby with some in case of negative response | 74.7 | 20.3 | 5.0 |
| Most of friends now are other bereaved parents | 18.3 | 77.6 | 4.1 |
| Share relationship with baby mostly with other bereaved parents | 45.1 | 45.3 | 9.6 |
| Would like to talk more freely about relationship with baby | 69.4 | 18.2 | 12.4 |
| Share relationship with baby online | 45.3 | 43.5 | 11.2 |

### 3.5.3 Continuing bonds and coping

The cross-sectional design of this study does not allow for attributions of causality. Whilst it is acknowledged that the standard language used here to report regression analyses results (e.g. predictor and outcomes variables) can imply cause and effect, this is not the intention. This language has been used in order to comply with existing conventions relating to the reporting of regression analyses. The following results section should be read with this in mind.

Participants had a broad range of symptoms of anxiety (range = 0-20, *M* = 9.8, *SD* = 4.3), depression (range = 0-16, *M* = 5.1, *SD* = 3.7), PTSD (range 0-72, *M* = 26.0, *SD* = 16.7), and posttraumatic growth (range = 0-95, *M* = 49.2 *SD* = 20.2). A correlation matrix was generated to identify potential predictors of mental health outcomes and posttraumatic growth (see Table 10). The 15 potential predictor variables shown in Table 10, were chosen based upon Study 1 findings, extant literature and theoretical importance. Owing to the exploratory nature of the study, and the dearth of literature specifically addressing continuing bonds expressions and mental health following stillbirth, two tailed correlations were used. No *p* value correction was applied to multiple comparisons, as it has been argued that in trying to reduce the risk of making Type I errors, the risk of making Type II errors increases as a consequence, which for first stage exploratory research such as this might be more problematic (Sinclair, Taylor & Hobbs, 2013). Variables that correlated significantly ($p < .05$) with measures of mental health and posttraumatic growth were selected as potential predictors for the regression analyses. As a result of missing data relating to time since death, one participant was excluded from the regression analyses. Imputation was not considered to be appropriate in this instance, as the range of values recorded for time since baby's death was extensive.

As expected, all mental health measures correlated positively. PTSD symptoms and posttraumatic growth were also positively related. Time since death negatively correlated with all mental health measures as anticipated. In order to determine which of the independent variables were predictive factors for mental health outcomes, a stepwise multiple regression analysis was conducted for each of the outcome variables, i.e. mental health measures: Anxiety; Depression; PTSD, and Posttraumatic Growth. Potential predictors entered into the regression analysis for Anxiety were: Level of engagement in continuing bonds (number of expressions); Meaning-making; Frequency of engagement in legacy building; Frequency of desire to share continuing bonds expressions; Frequency held back from sharing to avoid negative response; Desire to talk more freely; Some family members not understanding /supporting relationship, and Time since death. For Depression the potential

predictors were: Level of engagement in continuing bonds (number of expressions); Meaning-making; Frequency of engagement in legacy building; Frequency of desire to share; Frequency held back from sharing to avoid negative response; Desire to talk more freely; Feeling society understands/supports relationship; Feeling pressure from society to move on; Some family members not understanding/supporting relationship; Avoided talking about relationship with some in case of negative response, and Time since death. For PTSD: Level of engagement in continuing bonds (number of expressions); Frequency of engagement in legacy building; Integration; Frequency of desire to share; Frequency held back from sharing to avoid negative response; Desire to talk more freely; Feeling pressure from society to move on; Some family members not understanding/supporting relationship; Avoided talking about relationship with some in case of negative response, and Time since death, and for Posttraumatic growth: Level of engagement in continuing bonds (number of expressions); Frequency of engagement in writing; Frequency of engagement in legacy building; Frequency of engagement with nature; Integration; Meaning-making; Frequency of desire to share continuing bonds expressions; Frequency held back from sharing to avoid negative response; Desire to talk more freely; Avoided talking about relationship with some in case of negative response, and Time since death. The results of the multivariate regression models for Anxiety, Depression, PTSD and Posttraumatic growth are reported in Table 11.

All assumptions for regression analysis for the 4 models were met. There was no evidence of multicollinearity. Correlations between predictor variables were <.8. The VIF values did not approach the cut-off of 10 and the values of Tolerance did not approach the lower cut-off value of 0.2. The assumption of independence of errors was met, with values for Durbin-Watson within acceptable parameters. The histograms and P-P plots suggested the residuals were normally distributed. Plots of standardised predicted values against standardised and studentised residuals indicated that the assumption of homoscedasticity was also met. Diagnostic checks including casewise, Leverage, Cook’s Distance and Mahalanobis’s Distance were reasonably consistent with expected values.

Some family members not understanding/supporting relationship ($t$ = 3.29, $p$ = .001), Frequency of desire to share continuing bonds expressions ($t$ = 3.54, $p$ = .001) and Meaning-making ($t$ = -2.56, $p$ = .011) predicted anxiety levels. The final model was significant $F(3, 165) = 9.70$, $p$ <.001, and accounted for 15% of the variance in anxiety levels; with Some family members not understanding/supporting relationship ($R^2$ = .06, $p$ = .001), Frequency of desire to share continuing bonds expressions ($\Delta R^2$ = .05, $p$ = .002) and Meaning-making ($\Delta R^2$ = .03, $p$ = .011). Anxiety scores were higher for parents who agreed more that some members of their family did not understand or support their ongoing relationship with their baby, and who reported a greater frequency of wanting to share expressions of their continuing bond with their baby with others. Anxiety scores were lower for those parents who thought they had made more meaning following their baby's death.

Four variables predicted depression levels and accounted for 27.6% of the variance. These were: Frequency held back from sharing to avoid negative response ($t$ = 3.75, $p$ < .001), Meaning-making ($t$ = -4.14, $p$ < .001), Time since death ($t$ = -3.53, $p$ = .001) and Feeling pressure from society to move on ($t$ = 2.32, $p$ = .022). The final model was significant $F(4, 164) = 15.66$, $p$ <.001, with Frequency held back from sharing to avoid negative response ($R^2$ = .12, $p$ < .001), Meaning-making ($\Delta R^2$ = .08, $p$ < .001), Time since death ($\Delta R^2$ = .06, $p$ <.001), and Feeling pressure from society to move on ($\Delta R^2$ = .02, $p$ = .022). Results showed that levels of depression were higher for parents who held back from sharing expressions of continuing bonds to avoid a negative response more frequently, and who felt more pressure from society to move on. Depression scores were lower for parents who thought they had made more meaning following their baby's death, and for those for whom more time had passed since their baby's death.

Desire to talk more freely ($t$ = 2.39, $p$ = .018), Time since death ($t$ = -3.78, $p$ <.001), Avoided talking about relationship with some in case of negative response ($t$ = 2.21, $p$ = .029) and Integration ($t$ = 2.17, $p$ = .031) predicted levels of PTSD. The final model was significant $F(4, 164) = 11.40$, $p$ <.001, and accounted for 21.8% of the variance in PTSD levels; with Desire to talk more freely ($R^2$ = .10, $p$ <.001), Time since death ($\Delta R^2$ = .07, $p$ <.001), Avoided

talking about relationship with some in case of negative response ($\Delta R^2$ = .02, $p$ = .034) and Integration ($\Delta R^2$ = .02, $p$ = .031). PTSD scores were higher for parents who had a greater desire to talk more freely about their relationship with their baby with others, who agreed more strongly that they had avoided talking about their relationship with their baby with some people in case of a negative response, and who perceived their baby to be more integrated into their life. PTSD scores were lower for those parents for whom more time had passed since their baby's death.

Four variables predicted levels of posttraumatic growth and accounted for 37.5% of the variance, these were Meaning-making ($t$ = 6.14, $p$ < .001), Frequency of engagement in legacy building ($t$ = 3.09, $p$ = .002), Frequency of engagement with nature ($t$ = 2.88, $p$ = .005) and Frequency held back from sharing to avoid negative response ($t$ = 2.82, $p$ =.005). The final model was significant $F$(4, 164) = 24.56, $p$ <.001, with Meaning-making ($R^2$ = .18, $p$ <.001), Frequency of engagement in legacy building ($\Delta R^2$ = .12, $p$ < .001), Frequency of engagement with nature ($\Delta R^2$ = .05, $p$ = .001), and Frequency held back from sharing to avoid negative response ($\Delta R^2$ = .03, $p$ = .005). Posttraumatic growth was higher for parents who thought they had made more meaning following their baby's death, engaged more frequently in legacy building activities, engaged more frequently with nature, and who held back from sharing expressions of continuing bonds with others to avoid a negative response more often.

Table 10. Correlations between mental health measures and potential predictors (*N* = 170).

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1.Anxiety | | | | | | | | | | | | | | | | | | |
| 2.Depression | .65* | | | | | | | | | | | | | | | | | |
| 3.PTSD | .66* | .65* | | | | | | | | | | | | | | | | |
| 4.PT growth | .08 | .11 | .27* | | | | | | | | | | | | | | | |
| 5.Level of engagement in continuing bonds (no. of expressions) | .22* | .21* | .22* | .37* | | | | | | | | | | | | | | |
| 6.Attachment | -.11 | -.05 | -.03 | .08 | .30* | | | | | | | | | | | | | |
| 7.Meaning-making | -.16* | -.26* | -.07 | .42* | .07 | .05 | | | | | | | | | | | | |
| 8.Frequency of engagement with nature | .07 | .04 | .06 | .34* | .63* | .16* | .02 | | | | | | | | | | | |
| 9.Integration | .08 | .07 | .19* | .25* | .33* | .51* | .10 | .26* | | | | | | | | | | |
| 10.Frequency of engagement in writing | .13 | .13 | .07 | .16* | .61* | .19* | .02 | .40* | .24* | | | | | | | | | |
| 11.Frequency of engagement in legacy building | .19* | .20* | .20* | .40* | .60* | .07 | .11 | .40* | .16* | .44* | | | | | | | | |
| 12.Frequency of desire to share expressions of continuing bonds | .24* | .17* | .20* | .36* | .69* | .21* | .14 | .44* | .35* | .50* | .54* | | | | | | | |
| 13.Frequency of holding back from sharing to avoid potential negative response | .25* | .34* | .27* | .33* | .37* | .02 | .06 | .28* | .07 | .32* | .32* | .39* | | | | | | |
| 14.Desire to talk more freely about relationship with others | .20* | .26* | .32* | .27* | .31* | .12 | .08 | .31* | .14 | .18* | .24* | .28* | .47* | | | | | |
| 15.Feeling society understands/ supports relationship | -.05 | -.16* | -.07 | .03 | .01 | -.02 | .02 | -.06 | .02 | .13 | .04 | .06 | -.31* | -.34 | | | | |
| 16.Feeling pressure from society to move on | .12 | .30* | .21* | .11 | .16* | .09 | -.09 | .16* | .10 | .08 | .13 | .05 | .36* | .44* | -.70* | | | |

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 17. Some family members not understanding/ supporting relationship | .25* | .21* | .21* | .12 | .13 | -.15 | -.02 | .16* | .03 | .02 | .12 | .05 | .26* | .29* | -.25* | .36* | | |
| 18. Avoided talking about relationship with some people in case of negative response | .15 | .31* | .29* | .16* | .10 | -.04 | -.13 | .16* | .04 | .07 | .18* | .06 | .48* | .45* | -.31* | .43* | .40* | |
| 19. Time since death† | -.15* | -.26* | -.31* | -.18* | -.32* | -.01 | -.08 | -.14 | -.01 | -.01 | -.21* | -.14 | -.12 | -.14 | .09 | -.06 | -.09 | -.10 |

Notes. * =significant at .05; † *n* = 169

Table 11. Summary of multivariate models for Anxiety, Depression, PTSD and Posttraumatic Growth (*n* = 169)

| | *B* | SE *B* | *β* | *p* |
|---|---|---|---|---|
| **Anxiety** | | | | |
| Some family members do not understand/support relationship | 0.49 | 0.15 | .24 | .001 |
| Frequency of desire to share continuing bonds expressions | 1.71 | 0.48 | .26 | .001 |
| Meaning-making | -0.69 | 0.27 | -.19 | .011 |
| **Depression** | | | | |
| Frequency held back from sharing to avoid negative response | 1.38 | 0.37 | .27 | <.001 |
| Meaning-making | -0.90 | 0.22 | -.28 | <.001 |
| Time since death | -0.01 | 0.003 | -.24 | .001 |
| Feeling pressure from society to move on | 0.35 | 0.15 | .17 | .022 |
| **PTSD** | | | | |
| Desire to talk more freely | 1.74 | 0.73 | .19 | .018 |
| Time since death | -0.05 | 0.01 | -.26 | <.001 |
| Avoided talking about relationship with some in case of negative response | 1.52 | 0.70 | .17 | .029 |
| Integration | 2.93 | 1.40 | .15 | .031 |
| **Posttraumatic growth** | | | | |
| Meaning-making | 6.77 | 1.10 | .38 | <.001 |
| Frequency of engagement in legacy building | 5.41 | 1.75 | .22 | .002 |
| Frequency of engagement with nature | 3.73 | 1.29 | .20 | .005 |
| Frequency held back from sharing to avoid negative response | 5.25 | 1.86 | .19 | .005 |

Notes. Variables excluded from the regression models were: **Anxiety**: Level of engagement in continuing bonds (no. of expressions), Frequency of engagement in legacy building, Frequency held back from sharing to avoid negative response, Desire to talk more freely, Time since death; **Depression**: Level of engagement in continuing bonds (no. of expressions), Frequency of engagement in legacy building, Frequency of desire to share continuing bonds expressions, Desire to talk more freely, Feeling society understands/supports relationship, Some family members not understanding/supporting relationship, Avoided talking about relationship with some in case of negative response; **PTSD**: Level of engagement in continuing bonds (no. of expressions), Frequency of engagement in legacy building, Frequency of desire to share continuing bonds expressions, Frequency held back from sharing in case of negative response, Feeling pressure from society to move on, Some family members not understanding/supporting relationship; **Posttraumatic Growth**: Level of engagement in continuing bonds (no. of expressions), Frequency of engagement in writing, Integration, Frequency of desire to share continuing bonds expressions, Desire to talk more freely, Avoided talking about relationship with some in case of negative response, Time since death.

Table 12 summarises the potential protective and risk factors associated with parents' experience of continuing bonds following stillbirth in relation to bereavement adaptation. The majority of continuing bonds related factors were associated with only one mental health measure (i.e. anxiety, depression, PTSD), or posttraumatic growth. However, meaning-making predicted anxiety, depression and posttraumatic growth.

Table 12. Protective and risk factors associated with continuing bonds following stillbirth in relation to bereavement adaptation

| Protective factors | Risk factors |
| --- | --- |
| Time since death (D, PTSD) | A lack of understanding/support for the relationship from some family members (A) |
| Meaning-making (A, D, PTG) | Wanting to share continuing bonds expressions more frequently (A) |
| Engaging with nature (PTG) | Desire to talk more freely about the relationship (PTSD) |
| Legacy building (PTG) | Feeling pressure from society to move on (D) |
| Holding back from sharing more frequently to avoid a negative response from others (PTG) | Holding back from sharing more frequently to avoid a negative response from others (D) |
| | Avoiding talking about the relationship with some people in case of a negative response (PTSD) |
| | Integration with baby (PTSD) |

Notes. A = anxiety, D = depression, PTSD = posttraumatic stress, PTG = posttraumatic growth.

## 3.6 Discussion

Building upon the qualitative findings of Study 1, the current study's inclusion of quantitative measures allowed for further examination of how parents continue to have a relationship with their stillborn baby over time, of parents' experiences of sharing expressions of this relationship with others, and of their perceptions of social support and the social context in which they conduct the relationship. Critically, it also identifies aspects of continuing bonds which are predictive of parents' mental health outcomes and personal growth. The discussion comprises three sections: Expressions of continuing bonds and changes over time, Sharing and social context, and Continuing bonds and coping. These sections correspond to the main research areas into which the research questions were arranged and the results presented.

### 3.6.1 Expressions of continuing bonds and changes over time

Consistent with Study 1 findings, parents expressed their continuing bond with their baby in a plethora of diverse ways, with most parents engaging in 9 out of the 10 different types of continuing bonds expressions in the first year after their baby's death, and 7 out of 10 in the last 12 months. Considering that time since baby's death was wide-ranging, from just over 1 year to 39 years, with a sample mean of over 7 years, this suggests that parents do continue to maintain varied and intricate bonds with their baby for years, even decades, post loss. However, it was also true that the decrease in both the number of expressions engaged in over time, and the frequency with which parents engaged in the various activities and experiences, was statistically significant. These results are reflective of the changes to the relationship observed in Study 1. Study 1 revealed that some parents felt compelled to do as much as they could initially to construct and maintain a meaningful relationship with their baby, to create and evoke mental representations, to materially represent their baby, to express their love, and to forge a social status for their baby, thus validating their baby's existence and confirming his/her importance. However, parents stated that the compulsion to frequently express their relationship in multiple ways lessened over time. In particular, the imperative to materialise the relationship through physical artefacts changed over time.

Generally, the intensity with which parents (particularly mothers) sought to accumulate and engage with material artefacts tended to decrease over time, as connections became more established and possibly internalised. Yet, certain physical reminders (e.g. photographs, jewellery) continued to play an important and prominent role in parents' ongoing lives. Similarly, in the current study the frequency with which parents engaged with physical reminders reduced over time but more than half of parents had frequently displayed or looked at photographs of their baby, and just less than half had frequently carried or worn something associated with their baby in the last year. The need to physically display or represent this relationship frequently in multiple ways may dissipate over time as their baby becomes infused with parents' own personal essence (95.2% of parents felt their baby was part of them), and eventually becomes integrated into their everyday family life.

In the first year post loss parents most commonly reported that they thought about their baby, felt emotional connections to, and communicated with their baby, and these characteristics continued to underpin the relationship over time. These are novel findings which highlight the complex interactive quality, and enduring emotional nature of the ongoing relationship between parent and stillborn baby. The vast majority of parents thought about their baby as a baby, and this may reflect common recollection of the memories created during time spent with their baby. However, 65.3% also reported thinking about their baby at the age he/she would have been if they were still alive and all parents had thought about what their baby would be doing if he/she was still alive in both the first year post loss and the last 12 months, which suggests many parents' proclivity toward constructing an ongoing narrative for their baby as time passes. The majority of parents appeared to perceive a maintenance of the intensity of the bond over time. However, most did perceive some kind of change in their relationship with their baby over time (68.8%), and nearly half believed that the relationship had become stronger over time (47.6%). Therefore, this suggests that some of the changes to the relationship are not related to strength of connection but lie elsewhere. It is possible that parents' perception of change may be due to changes in the type of bond expressed, as some of the more physical and material ties become increasingly

internalised and their baby's essence is absorbed into the parent's own being and everyday existence. Moreover, changes may relate to the evolution and transformation of mental representations of the baby.

Consistent with Study 1 results, more than half of parents (61.2%) had written to or about their baby in the first year post loss. It has been suggested that "writing about or confronting traumatic experiences is beneficial in that it helps the person understand, resolve, and find meaning in the experience" (Pennebaker & Susman, 1988, pp. 331-332). It would appear that initially many parents intuitively sought to express their relationship with their baby in writing. However, as reported in Study 1, the perceived benefits of this practice seem to diminish over time as only 37.9% had written about their relationship in the last 12 months. This constituted the greatest reduction in popularity over time, across all 10 different types of continuing bonds expression (see Table 4). Expressive writing, that is, writing about one's deepest thoughts and feelings pertaining to a traumatic event, has been shown to have therapeutic potential (Pennebaker & Chung, 2011). However, Pennebaker (2013b), the instigator and proponent of the practice, has recommended that expressive writing should ideally be confined to a limited time period in order to produce successful results, as prolonged execution may lead to a maladaptive ruminative state, which could impede development of a clear and coherent narrative. As alluded to in Study 1, it is plausible that some parents may have encountered this, and found themselves repeating or revisiting highly emotionally charged text. It is possible that having recognised writing's weakening, or potentially stymieing effects over time, that some parents ceased the practice. However, it is acknowledged that there could be other reasons for these findings. For instance, parents may face increasing time restrictions due to parenting subsequent children.

As reported in previous studies (Cote-Arsenault, 2003; Cacciatore & Flint 2012a; Murphy & Thomas, 2013), informal rituals played a key role in parents' efforts to construct and maintain a meaningful connection with their baby. Looking at photographs and memory boxes, lighting candles or lanterns and marking their baby's birthday or other special occasion were particularly significant for parents, and remained so over time. Artefacts and mementos,

especially photographs, appear incredibly important to parents following perinatal loss (e.g. Blood & Cacciatore, 2014a; Cacciatore & Flint 2012a), with 89.4% of parents in the current study still engaging with photographs of their baby within the last 12 months. Given the broad range of values for time since death, this engagement can spread across many years in some cases. These results further demonstrate the significant role photographs play in keeping parents' memories of their baby alive, and thereby facilitating their continuing bond over time. For parents of stillborn babies, photographs might be the only physical, visual record of their baby and their unique physical attributes. Moreover, in Study 1, a number of parents reported that they were disappointed with the photographs taken of their baby in hospital, feeling they were inappropriate or did not capture the essence of their baby, and thus did not align with their treasured memories. Therefore, it is imperative that the execution of post mortem photography is sensitive, professional and attuned to the parents' wishes. It may prove beneficial for bereavement midwives to receive specific training relating to the execution and provision of mementos, as they may be best placed, generally having developed an empathetic rapport with parents, to discuss and hopefully meet their expectations in an informed and culturally sensitive way.

### 3.6.2 Sharing and social context

Whilst the majority of parents had shared photographs of their baby with others, it is concerning, given the importance of these reminders to parents, that sharing photographs of their baby most commonly provoked a negative response from others (37.9%), and was the expression that parents were most likely to hold back from sharing for fear of a negative response (66.7%). As the number of parents holding back from sharing photographs in case of a negative response is nearly double that of parents who had actually received a negative response, this may indicate some parents' underlying perception of photographs of their stillborn baby as being potentially socially unacceptable.

These results suggest a perceived social boundary which more than half of parents have been, on occasion, reluctant to transgress. A key finding from Study 1, was a marked discrepancy between, on the one hand, support for,

and validation of parents' development of a relationship with their stillborn baby within the medical environment, manifest in hospital staff responses, and on the other, a dearth of understanding for, or expectation of parents' continuing bond with their baby within wider society, especially over time. Essentially, the current study's findings further demonstrate this divergence. In UK hospitals, parents are offered opportunities to create memories and capture photographic records of their baby and the precious time they spent together. Moreover, post mortem photography of babies and children was relatively common in the 19th century and early 20th century:

> Photographs of infant death /…/ provided proof that the child had been brought into the world, however brief its span of life. The photograph could be shown to friends and family members who were not present at the birth or death to give substance and reality to a life and a person they may never have seen, would never get to know /…/ and provided a particularly poignant and unique record since the child itself played such a vital role in substantiating its own existence. (Linkman, 2011, p.18)

Evidently, these historical benefits are still relevant today for the parents of stillborn babies, who frequently report a lack of validation of their baby's existence and appreciation of the magnitude of their loss. However, a cultural shift toward the "scientisation of death" in modern Western societies has rendered it socially taboo (Frost, Bradley, Levitas, Smith & Garcia, 2007; Walter, 1994), thus shaping current public perceptions of post-mortem photography as being morbid and somewhat macabre (Blood & Cacciatore, 2014a; Cacciatore & Flint, 2012a). Critically, photographic images bring a visibility to stillbirth which is often referred to as an "invisible death" (Cacciatore et al., 2008a), in part due to the site of death being in utero, but also due to the cultural silence which historically surrounds stillbirth and which was reported by parents in Study 1. Moreover, many parents appreciate and treasure photographic images of their stillborn baby (Blood & Cacciatore, 2014a) as they can allow for the establishment and sharing of the baby's identity (Blood & Cacciatore, 2014b) and subsequent incorporation of the baby into the family unit and wider social community (Godel, 2007). However, the

current study highlights that the sharing of images of stillborn babies may not always be well, or compassionately received by others, and parents harbour concerns as to the public's response. In highlighting potential social boundaries and taboos, it enables them to be challenged and eventually eliminated over time through tailored education. Increased awareness of the practice of perinatal bereavement photography is undoubtedly required to better inform wider society of its value. Moreover, the significance of these treasured photographic images to parents, and how they can potentially contribute to coping by facilitating lasting connections between parent and child, should be emphasised in order to enhance understanding and acceptance within wider society, and consequentially start to allay parents' concerns about disclosure.

Parents wanted to share, and actually shared expressions relating to communication with their baby the least. It could be that this type of interaction with their baby, that is, talking to them, like taking photographs, is perceived as less socially permissible (34.1% had held back from sharing in case of a negative response) than other types of expression. However, it could also be due to parents' desire for precious, private intimacy with their baby. Overall, parents were more likely to share expressions of their ongoing relationship with their baby by talking to others, as opposed to physically sharing. This is consistent with Crawley et al.'s (2013) finding that mothers most commonly shared memories of their baby verbally. This result may be due to the fact that the majority of participants in the current study were women, and bereaved mothers in particular have shown a proclivity to talk about their experience of perinatal loss to an empathetic listener (Kavanaugh, 1997; Kavanaugh et al., 2004).

Previous studies have suggested that other parents who have also experienced the loss of a child are often a preferred source of support compared with those who have not (Riches & Dawson, 1998; Segal, Fletcher & Meekison, 1986; Tudehope, Iredell, Rodgers & Gunn, 1986). In contrast to the cited studies, and indeed the tendencies of Study 1 parents, many of whom appeared to share their relationship with their baby predominantly with other bereaved parents, less than half of parents in the current study agreed that

this was the case. Owing to the fact that over half of Study 1 participants were actively involved with the Sands charity, it is feasible that the support group exposed them to more perinatally bereaved parents, and therefore, provided a safe and supportive environment in which to share their ongoing bond with their baby. Recruitment for the current study was considerably broader and not solely UK based, therefore results may more accurately reflect parents' sharing behaviours. It is possible that relevant support groups were not as easily accessible for the current sample.

Parents reported being most comfortable talking about their relationship with their baby, with their partner and friends. Whilst the majority initially felt comfortable talking to their family about their continuing bond with their baby, a reasonably high percentage (60.0%) of parents felt less comfortable talking to their family over time. This is perhaps similar to the "fading empathy'" reported in Study 1, when some members of support systems are inclined to stop talking about the baby over time, as this is (mistakenly) deemed less upsetting for parents and perceived as healthier for their "recovery". Additionally, it may be expected that close family members, especially the baby's grandparents, would most keenly feel the parents' (i.e. their own child's) anguish following baby's death and have increased concern for their long-term welfare. As a result, parents themselves may try to shield their own family members from further distress. Given the greater intimacy between parents and their family members, it is also plausible that some family members may be more forthright in their views about parents' continued relationship with their baby years post loss. If these views do not align with those of the parent, then parents may feel increasingly uncomfortable and disinclined to talk about their baby with their family. It is interesting to note that twice as many parents felt pressure from their family to move on than from their partner. Remarkably, nearly three quarters of parents said they had avoided talking about their relationship with their baby with some people in case of a negative response. This underscores how complex social interaction can be for many parents, and is redolent of the intricate evaluation process, reported in Study 1, and commonly executed by parents in social situations in order to determine how permissible it is to discuss their baby with others. Moreover, the majority of

parents in the current study would like to talk more freely about their baby, and thought society did not understand or support their ongoing relationship which, arguably, could exacerbate commonly reported feelings of social isolation, disenfranchisement and non-legitimisation of parents' experience (see Burden et al., 2016). Essentially, these results provide a more detailed understanding of the often problematic social landscape in which parents are endeavouring to maintain and express their ongoing relationship with their stillborn baby. Importantly, the next section will reveal how aspects of this social landscape, as experienced by parents, are predictive of bereavement adaptation.

### 3.6.3 Continuing bonds and coping

As anticipated, time since death had an inverse relationship with mental health outcomes in line with the existing literature (Cacciatore et al., 2008a; Crawley et al., 2013; Turton et al., 2001). Perhaps unexpectedly, there was a positive association between PTSD and posttraumatic growth, which may at first glance appear counterintuitive, and is contrary to some previous works. For example, Frazier, Conlon and Glaser, (2001) found that sexual assault survivors who perceived more positive changes in their life post trauma, reported fewer PTSD symptoms. However, the current study's result is consistent with a number of studies assessing meaningful personal growth and mental health (Helgeson, Reynolds & Tomich, 2006; Morris, Shakespeare-Finch, Rieck & Newbery, 2005; Waters, Shallcross & Fivush, 2013), and is relatively common for bereaved populations (Tedeschi & Calhoun, 2008). It has been suggested that ongoing distress might actually fuel posttraumatic growth (Calhoun & Tedeschi, 1998), as greater distress can precipitate re-evaluation of an individual's core beliefs, thus driving efforts to make meaning and affect positive personal change (Waters et al., 2013). The emotional pain of loss also appeared to catalyse personal growth for some parents in Study 1. Inconsistencies in the extant literature may be due in part to the diversity of populations examined, and the wide range of measures used to assess positive growth and mental health outcomes.

Consistent with the findings of Crawley et al. (2013), who reported an association between parents' sharing memories of their baby with others and

mental health outcomes, the current study has provided further evidence to suggest a link between parents' opportunities to share their ongoing relationship with their baby with others, and bereavement adaptation. For the first time, this study has identified that parents who felt a greater desire to share expressions of their continuing bond with their baby with others, those who more often avoided talking to some people in case they responded in a negative way, and those who had a greater desire to talk more freely about their relationship with their baby, had poorer mental health outcomes. It would appear that those parents who did not feel they could satisfy their desire to share their relationship as much as they wished, or who avoided sharing in some instances as they feared a negative response, demonstrated poorer loss adjustment.

This is also consistent with the continuing bonds paradigm that posits sharing mental representations with others as a crucial factor in successful transformation of parents' conceptualisations of their child, a process which can facilitate positive integration of the child into the parent's ongoing life and potentially aid bereavement adaptation (Klass, 1996b). Continuing bonds are not solely intrapsychic processes but 'represent profound, far-reaching and complex social events' (Valentine, 2008, p. 162). Notably, Klass (2006) has postulated that the impact of continuing bonds with the deceased on bereavement adjustment should be analysed within an individual's social context, as maladaptive responses are more likely to emanate from a divergence between a person's internal and social reality, than from any intrapsychic conflict. Indeed, the incongruence of profound parental experience and inadequate societal response has been shown to result in complicated grief, and other negative mental health outcomes including anxiety, depression and posttraumatic stress (Badenhorst, Riches, Turton & Hughes, 2006; Barr & Cacciatore, 2007-2008; Cacciatore, 2013; Hughes & Riches, 2003). As discussed in Study 1, and further supported by the current study's results, if parents who want to express their continuing bond with their baby socially perceive barriers to disclosure and an inability to share their relationship with their baby with others freely, and without concern or fear of

judgement, then it may be inhibiting bereavement adaptation and contributing to poorer outcomes.

Furthermore, a greater frequency of holding back from sharing expressions of continuing bonds in order to avoid a negative response was associated with higher levels of depression, although, it should be noted that this was also linked to higher levels of posttraumatic growth. It is possible that those parents who feel more inhibited with regards to sharing details of their relationship with their baby, owing to a poorer perception of others' potential attitudes toward it and subsequent response, are more likely to report symptoms of depression. As no causation can be inferred from these results, equally, it could be argued that those individuals with increased depressive symptoms may be more socially withdrawn, isolated and reticent (Hall-Lande, Eisenberg, Christenson & Neumark-Sztainer, 2007), and thus more inclined to avoid social interaction. It may be the case that not sharing certain types of expressions with others for fear of a negative response is more self-protective and adaptive, whereas not sharing other types of expressions is more inhibitory and maladaptive. Moreover, as previously discussed, greater distress, possibly aroused by an inability to share as desired and a fear of others' potentially negative response, can serve as a driver for meaning-making and stimulate subsequent posttraumatic growth (Waters et al., 2013). This is certainly an area that warrants more in depth exploration in order to fully understand the potential impact of sharing reticence on mental health.

Bereaved individuals that perceive more available social support have been shown to report less depressive and somatic symptomatology than those who perceive lower levels of social support (Stroebe, Stroebe, Abakoumkin & Schut, 1996), whilst strong family support following stillbirth has been seen to mediate lower levels of anxiety and depression in mothers (Cacciatore et al., 2009). Furthermore, positive social support and support satisfaction have been highlighted as an important protective factor in relation to symptoms of PTSD following infant death and perinatal loss (Christiansen et al., 2013; Horsch et al., 2015). To the researcher's knowledge, this is the first study to examine parents' perceptions of the social context in which they conduct their ongoing relationship with their stillborn baby, and social support for that

enduring bond, in relation to bereavement adaptation. As expected, support and understanding of the continuing bond decreased as the support system became more distant. Significantly, the current study suggests the protective, or buffering effect of strong social support, may be eroded by parents' perceptions of inadequate support and understanding of their relationship with their baby from some individuals, or from society at large. As previously mentioned, more than three quarters of parents agreed that, in general, their personal support systems (i.e. partner, family, and friends) understood and supported their relationship with their baby. However, a number of factors, specifically: sensing societal pressure to move on, some family members not understanding/supporting their relationship with their baby, having a desire to talk more freely about their baby and a greater wish to share continuing bonds expressions, and tending to avoid talking to some people for fear of a negative response, were strongly associated with poorer mental health outcomes. These results are consistent with Study 1 findings and suggest perceived instances of inadequate social support and a social context which fails to fully accommodate parents' ongoing relationship with their baby and their desire to openly express it, may be adversely influencing parents' ability to cope. Moreover, this study further supports previous works (Boerner & Heckhausen, 2003; Klass, 1996b, 2006) that suggest inadequate social support for continuing bonds could potentially impede adaptive integration of the deceased into the bereaved's ongoing life and subsequent bereavement adaptation. Importantly, the current study has identified specific aspects of the social context that could be problematic for the parents of stillborn babies.

In Lovell's (1983) seminal work mentioned in Chapter 1, one mother stated that on leaving hospital and returning to society "she found that people wished to forget and enjoined her to do the same" (p. 760). It would appear that over 30 years later, some parents are encountering a similar societal response. Both Study 1 and the current study have demonstrated that parents are still experiencing pressure from society to "move on", and are struggling to find an accommodating space in which to freely express their ongoing relationship with their baby. Crucially, for the first time, this study provides evidence to suggest that perceived external social attitudes, which are contrary to parents'

internal desire to continue bonds with their baby, are associated with poorer mental health outcomes.

As previously discussed, it has been theorised that bereavement adaptation may be achieved by parents through transformation of mental representations of their child, which when shared with others, facilitates adaptive integration of the child into the parent's life and wider social support systems, and can lead to transformative personal growth (Klass, 1996b). In light of this, the positive correlation between integration and PTSD symptoms in the current study was unexpected. There are a number of possible reasons for this result. Firstly, there may be a certain amount of overlap between the construct of integration and PTSD symptomatology. Parents feeling their baby to be part of their everyday lived experience could be seen to echo common symptoms of PTSD, namely intrusive thoughts and flashbacks. Typically, individuals who suffer from PTSD report intrusive involuntary memory disturbances, which can be highly emotionally charged, together with flashbacks evoking a re-living or re-experiencing of the trauma in the present (Brewin, 2015; Elhers, Hackmann & Michael, 2004; Michael, Ehlers, Halligan & Clark, 2005). It is possible that such intrusive re-experiencing may be interpreted by some parents as feeling their baby to be part of their everyday existence.

Furthermore, integration can be both adaptive and maladaptive. As outlined earlier, parents' experiences of sharing are not always positive, and for many, the opportunities available to them do not match the extent to which parents would like to talk about their relationship with their baby with others. Also, parents most commonly reported holding back from sharing mental representations of their baby with others to avoid a negative response. The complex social landscape in which parents are conducting this relationship, may be adversely affecting the transformation process of parents' mental representations of their baby, thus impeding adaptive re-location of the child for some parents and potentially resulting in problematic connections and maladaptive integration. Finally, it should be noted that this is the first study to attempt to operationalise *adaptive integration*. It may be that the measure utilised (i.e. a composite measure of items *My baby feels part of me, My baby feels part of my everyday life, My baby feels part of our family, I expect to have*

*an ongoing relationship with my baby for the rest of my life*) is too ambiguous, and as a result, it might be capturing both adaptive and maladaptive aspects of integration. Refining this measure in future studies may yield more detailed and enlightening information regarding the potential relationship between integration and PTSD.

In addition to identifying a number of risk factors, this study elucidates key features of the continuing bonds process which are predictive of better mental health and greater posttraumatic growth. Three potentially protective factors were identified: meaning-making, engaging with nature, and legacy building.

**Meaning-making**

As outlined in the introduction to this chapter, previous results relating to individuals' search for meaning and adjustment following traumatic life events, such as bereavement, are mixed. In the current study an increased ability to make meaning, that is, make sense of, and find benefit in their loss, whilst perceiving positive, transformational change to their self-identity, was strongly linked to parents' bereavement adaptation. The more meaning parents perceived themselves to have made as a consequence of their baby's death, the fewer symptoms of anxiety and depression they reported. These results are consistent with a number of previous bereavement studies. Bereaved parents' ability to make sense of their child's death has been shown to be a key predictor in grief severity and bereavement adjustment (Holland, Currier & Neimeyer, 2006; Keesee et al., 2008). Moreover, Lichtenthal et al. (2010) found that bereaved parents who struggled to make sense of, or find any benefits associated with their loss experience, reported more acute normative and maladaptive grief symptoms. Research specifically addressing meaning-making and stillbirth remains sparse. However, search for meaning was highlighted as a significant part of the adjustment process for women following miscarriage (Nikcevic & Nicolaides, 2014), and was also a key predictive factor for current grief acuity in women who had experienced perinatal loss (Uren & Wastell, 2002).

An increase in perceived meaning-made was also associated with greater posttraumatic growth in the current study. A growing array of studies have

shown how experiencing negative life events, such as bereavement, can serve as a catalyst for personal enlightenment and transformational growth (Calhoun & Tedeschi, 1990; Engelkemeyer & Marwit, 2008; Hogan & Schmidt, 2002). Inherent in Tedeschi and Calhoun's (2004) theoretical conceptualisation of posttraumatic growth is the notion that the traumatic event shatters an individual's pre-event belief system, thus precipitating intense cognitive processing which sees reappraisal of the former assumptive world and the construction of new understandings of self and the world; a process which leads to the acquisition of "general wisdom about life, and the development and modification of the individual's life narrative" (p. 12). Undoubtedly, the current study's results are encouraging and support the proposed intricate link between meaning-making and posttraumatic growth.

The current research makes an important contribution to the existing literature base by identifying a strong link between meaning-making and bereavement adaptation following stillbirth. The relationship between meaning-making and coping following perinatal loss most certainly warrants further exploration. It would be beneficial for future studies to deliver insight into the distinct sources which may be stimulating and facilitating meaning-making for perinatally bereaved parents, and why some parents find meaning resolution following traumatic loss, whilst others do not.

**Nature**

Study 1 delivered qualitative evidence to suggest that parents instinctively engage with nature in a variety of ways following stillbirth. Nature enabled parents to develop meaningful connections with their baby via symbolic representations, through place association, and as a channel for communication, whilst natural environments were posited as having therapeutic potential which could facilitate coping. The current study consolidated these findings. Around 70% of parents engaged with nature following their baby's death. Tellingly, engaging with nature in some way that helped was one of few activities that maintained its popularity over time, (increasing by 1.1%), indicating the lasting benefits to parents of this interaction with the natural world. Moreover, it received fewest negative

responses from others when compared with other activities that over half of parents had shared with others. Generally, nature related expressions were also positively perceived as being socially acceptable by the majority of parents. In addition, regression analyses revealed that increased engagement with nature was linked to greater posttraumatic growth. This echoes the findings of Nisbet, Zelenski and Murphy (2011) who reported an association between nature connectedness and autonomy, personal growth, and purpose in life within a sample of business people. To the researcher's knowledge, this is a novel finding for the current population.

Whilst no direct correlation between engagement with nature and meaning-making was observed in the current study, Study 1 data showed that nature provides non-judgemental environments which can accommodate and absorb parents' acute emotional distress, and facilitate interpersonal communication and the meaning-making process, thereby aiding construction of a coherent, meaningful loss narrative. Disclosure and managing emotional distress are fundamental dimensions of the posttraumatic growth model (Tedeschi & Calhoun, 2004). Consequently, in providing an accommodating environment in which parents can engage in unrestricted expression of emotions, and challenging but productive communication with others, it could be argued that nature may facilitate cognitive and narrative processing, thus contributing to positive self-transformation (Pals & McAdams, 2004). Initially, it was thought that the absence of any direct correlation between frequency of engagement in nature and meaning-making in the current study may have been due in part to the use of a composite measure of meaning-making which included three dimensions: sense-making, finding benefit and changes to identity, and that nature may have correlated with only one of these dimensions. Secondary analysis of nature and individual dimensions of meaning-making also found no correlation. However, examining in more detail the individual items of Nature, individual Nature item *Actively engaged with nature in some way that helped me (e.g. walking in nature, being beside the sea) in the last 12 months* did correlate positively with both Meaning-making items related to changes to identity: *I feel I have changed as a person as result of my experience* ($r$ = .16, $p$ <.05) and *I feel like I am a better person as a result of my experience* ($r$ =

.16, $p < .05$) although the strength of correlation was weak. It may be valuable for future studies to focus on possible links between active engagement with nature and identity change. The inclusion of aspects of meaning reconstruction not measured here, such as the realignment of roles and relationships proposed by Kunkel et al. (2014) in their meaning-making typology (used to explore meaning-making in Study 1) may prove valuable.

Clearly, the multifunctional role of nature in facilitating parents' ongoing relationship with their baby, and as a potential aid to bereavement adaptation requires closer examination. The ways in which parents of stillborn babies find nature helpful in coping with the loss of their baby is further explored in Chapter 4 when the researcher argues for the value of developing a nature-based intervention.

**Legacy building**

To date, literature in this field predominantly addresses the personal legacy building behaviours of both adults and children, especially in palliative care settings, be it through creative memory-making, narrative practices (Moxley-Haegert, 2015) or fund-raising for worthy causes (Otis-Green, 2003). In the case of stillbirth, the legacy is being constructed not by the individual themselves prior to death, but by the bereaved parents in memory of their baby. A baby who dies in utero has been denied the opportunity to personally make their mark on the world. Therefore, some parents may feel driven to make their mark for them by means of delivering a positive contribution to society in their baby's honour, for example, in the form of social action, compassion for others or altruistic acts. Approximately half of parents engaged in legacy building following their baby's death, activities conducted in their baby's honour being the most commonly reported. Actively helping other parents affected by stillbirth became slightly more popular over time, with 52.3% reporting that they had assisted other bereaved parents in some way over the last 12 months. These results build upon Murphy's (2013) qualitative findings which showed how parents do perceive positive outcomes from their loss experience, through efforts to improve bereavement care and raise awareness of stillbirth.

Generativity, which involves guiding the next generation, contributing to society and generating new ideas (Huta & Zuroff, 2007) has been shown to be positively associated with well-being (Keyes & Ryff, 1998) and posttraumatic growth (Bellizzi, 2004) in non-bereaved populations. Following bereavement, it has been suggested that providing a service to others, (e.g. bereaved individuals supporting others in a similar position through their loss in honour of the deceased) can facilitate posttraumatic growth (Calhoun & Tedeschi, 2013; Tedeschi et al., 2018). Significantly, the current study provides evidence to support the proposed link between legacy building and positive personal transformation, as parents who engaged in legacy building activities more frequently, recorded higher levels of posttraumatic growth. Legacy building activities can promote meaning (Bernat et al., 2015), therefore, the positive relationship between legacy building and personal growth may be influenced by the meaning and purpose parents derive from engaging in these activities, and are subsequently able to ascribe to their baby's existence. Whilst no direct correlation between frequency of engagement in Legacy Building and the composite measure of Meaning-making was found during secondary analysis, Legacy Building did positively correlate with individual items of Meaning-making related to benefit finding and changes to identity. Frequency of engagement in Legacy Building positively correlated with benefit finding item *As a result of my experience there have been changes to aspects of my life that I see as positive* ($r$ = .18, $p$ <.05) and changes to identity item *I feel like I have changed as a person as a result of my experience* ($r$ = .20, $p$ <.01). Although the correlations are relatively weak, these results together with the results of the regression analyses indicate that further exploration of parents' engagement in legacy building activities following stillbirth and potential links to meaning reconstruction is warranted in future studies.

Legacy building activities can also help parents to maintain lasting connections to their baby, whilst providing opportunities to share their baby's story with others, thereby validating the significance of their baby's existence, affirming social status, and channelling their baby's positive impact on the world through beneficent and philanthropic means. Moreover, social action and altruism could engender a sense of empowerment and mastery (Berzoff, 2011;

Cacciatore, 2007) in parents who feel devoid of control over their own life in the devastating aftermath of their baby's death. Through legacy, parents are able to assume authorship of their baby's ongoing narrative, allowing it to flourish, resonate and inspire, despite his or her physical absence, in a meaningful and enduring way.

### 3.7 Strengths and limitations of Study 2

This study makes a valuable contribution to the theoretical base addressing continuing bonds, and serves to improve understanding of the parent-baby dyad following perinatal loss. It is the first detailed investigation of parents' ongoing relationship with their stillborn baby over time, and its association with mental health outcomes and personal growth. A strength of this study is that it examines a broader range of continuing bonds' expressions and characteristics in relation to mental health outcomes than have other studies in the extant stillbirth literature. Furthermore, it is one of very few works to consider the potential positive outcomes of perinatal loss (see Krosch & Shakespeare-Finch, 2017; Murphy, 2013). It is believed that the inclusion of the PTGI gives a more comprehensive and rounded view of psychosocial outcomes. Regarding the questionnaire design, relatively few additional expressions of continuing bonds were provided by parents in the free text boxes available (Section 2B) demonstrating that the checklist provided was appropriate in capturing the majority of expressions experienced.

Whilst care was taken to design a sensitive and informed questionnaire in consultation with a Sands' liaison officer and an independent parent representative with experience of baby loss, feedback was provided by one participant who voiced concern at the use of certain items. This issue is discussed in further detail in Chapter 4, 4.6 Methodological reflections. The questionnaire was designed for the specific purpose of collecting data for the current study. As this is first stage exploratory analysis of the topic, extensive psychometric testing of the questionnaire was not deemed necessary at this point. However, this pilot questionnaire may benefit from further psychometric testing to enable development for use in future studies. Face validity was used in the current study to determine the validity of constructs such as Attachment

and Integration. Going forward, it is suggested that Principal Component Analysis (PCA) could be employed in order to better categorise parents' expressions of their continuing bonds.

It is acknowledged that not controlling for a number of potential confounding variables is a limitation of this exploratory study. Parents' mental health history was not sought or known and may have affected multiple regression analyses results. Furthermore, during stepwise regression analyses, the predictor variable *Time since baby's death*, which has been shown to predict mental health outcomes following perinatal loss in the extant literature, was not controlled for or partialled out using the hierarchical method. The reason for this decision was due to a lack of existing knowledge about the predictive power of the other predictor variables entered into the regression models. The stepwise method can be particularly useful for first stage exploratory research (Menard, 2002) when there is a large number of potential predictor variables and established theoretical knowledge of the subject under investigation is sparse (Lomax, 2001). Therefore, it was deemed the most appropriate method for the current exploratory study.

Moreover, whilst the number of parents recruited was reasonably large, generalisability may be somewhat limited due to a relatively homogenous sample. The majority of participants being white, well-educated, British women. Generalisations to other sociodemographic backgrounds would be difficult. Future studies would benefit from a more heterogeneous, multi-cultural sample which also captures the experience of a greater number of fathers, with a view to exploring potential cross-cultural or gender differences in the manner in which continuing bonds are expressed, and regarding parents' perceptions of social support for their relationship with their baby, within their specific social context.

## 3.8 Summary and conclusions

The passage of time did impact upon certain aspects of parents' relationship with their stillborn baby. The breadth of continuing bonds expressions engaged in, and parents' frequency of engagement, reduced over time. However, a number of informal rituals, namely, looking at photographs and

memory boxes, lighting candles and marking special occasions were of lasting import to parents as they sought to maintain their relationship with their baby over years, if not decades in some instances. Furthermore, parents' mental representations of, emotional attachment to, and communication with their baby remained prevalent over time. Sharing photographs of their baby with others was particularly problematic, as it most commonly triggered a negative response and parents most commonly reported holding back from sharing them. Parents thought that understanding of, and support for their relationship with their baby decreased as social distance increased. Generally, parents' perceptions of social support received from personal support systems were positive. However, this study identifies certain features of social support and the wider social context which are linked to poorer mental health outcomes. Risk factors were identified as: some family members not understanding and supporting parents' relationship with their baby, a greater desire to share continuing bonds expressions with others, feeling pressure from society to move on, a desire to talk more freely about the relationship, avoiding talking with some people in case of a negative response and a sense of integration with baby. Better bereavement adaptation was associated with meaning-making, time since death, engagement with nature, and legacy building. Parents holding back from sharing more frequently to avoid a negative response from others predicted both positive and negative outcomes.

Clearly, parents' desire to express their continuing bond with their stillborn baby is not being adequately accommodated or supported by certain elements of both personal and wider support systems. Of course, it is important to be mindful of the fact that not all parents of stillborn babies continue bonds with their child. However, for those that do, raising awareness in society at large of the potential existence of this relationship and its diverse characteristics, is vital in order to challenge prevailing misperceptions, diminish judgemental, ill-informed responses, and subsequently deliver more consistent, positive, compassionate support, that will allow parents to disclose their relationship more freely, without fear of transgressing social boundaries or invoking negative social responses, which may be detrimental to coping for some parents. Lovell's (1983) aforementioned critique of the clinical response to

stillbirth helped catalyse positive change within the medical arena, it is imperative that these progressive changes in attitude disseminate more widely in society to ensure parents are sensitively and fully supported long term.

Study 1 findings showed that parents of stillborn babies find nature helpful in coping with the loss of their child. The current study has delivered further promising results that indicate the potential benefits of a nature-based intervention for the perinatally bereaved. Results also show that the integration of meaning-making and legacy building activities may increase the efficacy and therapeutic potential of the intervention. Admittedly, the call for meaning-centred interventions for bereaved parents is not a new one (Lichtenthal et al., 2010), however, the fusion of nature, meaning-making and legacy building into a tripartite integrated intervention would constitute an innovative and original approach. Moreover, both nature and legacy building related expressions of continuing bonds appeared to be the most socially acceptable, as perceived by parents. Consequently, it is possible that they can be more easily integrated into parents' ongoing lives, and shared more confidently with others if desired.

More than three quarters of parents considered their relationship with their baby to be an aid to coping. In considering competing grief paradigms, that is, the continuing bonds paradigm (exhibited by parents in this study and prominent in stillbirth management in clinical settings), and the more traditional relinquishing ties model extolling emotional disengagement over time (still evident in Western culture), there was little evidence in the regression analyses results to suggest that engagement in continuing bonds expressions was related to poorer outcomes. In fact, nature and legacy building related expressions positively correlated with posttraumatic growth, which reflects previous findings in the bereavement literature suggesting symbolic connections may be more adaptive (Field et al., 1999). Moreover, virtually all parents described feeling an enduring emotional connection with their baby, which for some, due to the broad range of values reported for time since baby's death, would have lasted for decades, yet mental health outcomes varied widely. Indeed, it appears to be parents' perceptions of the social context and support for their continuing bond, or lack thereof, that is most strongly associated with mental health sequelae and personal growth. These key

findings, together with those from Study 1, are synthesised and further considered in the following chapter.

# Chapter 4 Conclusions and implications

## 4.1 Chapter overview

This chapter summarises the project's main findings and outlines a number of recommendations and implications for care management of stillbirth in light of these findings. The value of developing a nature-based intervention for the perinatally bereaved is explored. Moreover, future research directions and methodological reflections are considered. Finally, a summary of the project's original contribution to the existing knowledge base is presented.

## 4.2 Project overview

Extant literature relating to parent-baby bonds following stillbirth, especially those that continue over time, is sparse, whilst the findings relating to bonds, memory-making and mental health outcomes remain mixed. The focus of the current research was parents who self-identified as experiencing continuing bonds. The primary objectives of this project were to expand upon the existing body of work and explore the ways in which parents experience an ongoing relationship with their stillborn baby long term, and to consider how certain expressions of the relationship and strategies used to facilitate the connection might be related to coping and bereavement adaptation. Intensive interviews allowed parents to express their experience in their own words. Systematic analysis of data led to identification of key themes and sub-themes which formed a conceptual framework of parents' experience of continuing bonds following stillbirth. Subsequently, these themes/concepts were utilised to design an online questionnaire which allowed for further exploration of the ongoing relationship between parent and stillborn baby, and investigation of any association between various aspects of this relationship and bereavement adaptation. The questionnaire covered key areas of interest: parents' engagement in a broad range of continuing bonds expressions and any changes over time; the characteristics of the relationship between parent and baby; the social context in which parents construct and maintain this relationship and their experience of sharing it; meaning-making, and parents' mental health outcomes and potential personal transformation.

## 4.3 Summary of findings and conclusions

A summary of the project's main findings and conclusions is presented below and discussed. Findings are drawn from both studies and are arranged into three sections: Expressions of continuing bonds and changes over time, Sharing and social context, and Continuing bonds and coping. These sections correspond to the three main research areas addressed by the project's research questions. It is acknowledged that some of the findings discussed may be common to other forms of bereavement, however, the researcher is only drawing conclusions in relation to stillbirth.

### Expressions of continuing bonds and changes over time

This project has not only highlighted the broad and diverse range of strategies used by parents to maintain bonds with their child, but has also uncovered key characteristics of the relationship which demonstrate its affective depth and potentially interactive nature. A variety of bonds were identified following analysis of the interview data: material/physical, psychological, emotional, spiritual and social. Parents' connections with their baby were shown to be complex and to have an enduring, pervading influence on parents' ongoing lives. The vast majority of parents reported feeling connected to their baby prior to birth. In line with previous studies, continuing bonds could be private or co-constructed with others (Cote-Arsenault, 2003; Klass, 1996b; Valentive, 2008; Walter, 1996). Study 1 data showed that hospitals and relevant charitable organisations offered parents opportunities to engage in activities that aid development of bonds with their stillborn baby. However, it appeared that outside of these environments few culturally embedded rituals or points of reference were available to parents. As a result, parents found innovative and creative ways to express their relationship with their baby that spanned a broad range of activities and experiences, from designing tattoos and naming stars, to writing poetry and conference speaking.

Analysis of Study 2 questionnaire data revealed that parents' engagement in many continuing bonds expressions tended to decrease over time. However, it was also true that parents maintained varied and intricate bonds with their baby in the years and decades post loss. Typically, parents remained

connected to their baby over time by thinking about or communicating with him/her, and through affective ties. Looking at photographs and memory boxes, lighting candles and marking special occasions were the most commonly reported activities in which parents engaged to help construct and maintain a relationship with their baby as time passed. Many parents sensed their baby's presence and continued to do so over time. Interview data showed that parents often felt this presence through the spontaneous appearance of butterflies or white feathers. Data from both studies demonstrated how using symbolic representations of their baby and engaging with nature were valuable to many parents as they sought to develop a meaningful nexus. Babies could be located internally as an infused part of the self, within the domestic domain as part of the family, or externally in a parallel spiritual realm. Parents conceptualised their child as a baby and as a growing, developing character over time, with data from Study 2 showing that a number of parents did both. Parents continued to care for their child, albeit in a different way to how they parented live children. They nurtured, preserved, honoured and protected their baby's memory. Moreover, legacy building enabled parents to assume authorship of their baby's narrative, developing it in a positive and meaningful way.

Interview data showed that externalising and materialising their baby not only appeared to help parents adjust to their baby's physical absence, but also provided evidence of their baby's existence, whilst facilitating the development and validation of bonds with their baby as they sought to define and share the relationship with others. A reduction over time in parents' tendency to physically represent or materialise their baby in multiple ways was observed in Study 1 and this seemed to correspond with a sense of integration for some parents as their baby became a synthesised and established part of their being and everyday lives. However, certain treasured physical reminders (e.g. photographs, pieces of jewellery) were still a key part of their relationship with their baby in the long term and were used by parents to maintain connections over time. This trend was supported in Study 2 as parents generally engaged less frequently with physical reminders over time, yet half of parents had still frequently displayed or looked at photographs or carried/worn something

associated with their baby within the last 12 months. Whilst the way in which the relationship was expressed changed over time, an overwhelming majority of parents believed the relationship would last their lifetime.

**Sharing and social context**

The findings of this project increase understanding of the often complex social landscape which parents negotiate in the aftermath of their baby's death. Interview data showed how a perceived cultural denial or devaluation of their baby's existence appeared to motivate some parents to seek wider social validation of their child and to assert their baby's social status through sharing with others. However, support for the relationship between parent and baby was mixed. Regarding the social acceptability of various types of continuing bonds expressions/activities, quantitative data revealed that most parents had not experienced a negative response from others when sharing. Moreover, less than half of parents had held back from sharing 27 out of the 28 activities/experiences listed. However, a substantial minority (more than a third of parents) reported that sharing photographs of their baby had provoked a negative response from others. Perhaps unsurprisingly, this was also the activity that parents most commonly held back from sharing.

Parents were most comfortable sharing details of their continuing bond with their baby with their partner, friends and family. Whilst families were generally a good source of support for many parents, over half felt less comfortable talking to their family over time. Critically, although the concept of parents constructing a relationship with their baby was initially socially sanctioned through participation in memory-making activities offered in hospitals, parents in both studies reported that their ongoing relationship was not widely expected or understood by others. Typically, support for the relationship tended to fade over time. Moreover, interview data showed that it could be pathologised as being unhealthy, especially over time. Some parents perceived an increasing pressure to move on or justify their relationship, and often evaluated whether to disclose their ongoing relationship to others, in an effort to avoid judgement and/or negative reactions. As outlined above, most parents did not report holding back from sharing the majority of continuing

bonds expressions, yet nearly three quarters of parents stated they had avoided talking about their relationship with some people for fear of a negative response, and the majority voiced a desire to be able to talk more freely about their baby. This suggests that parents (following any initial period of spontaneous disclosure) are generally discerning and selective when sharing their baby with others, and predominantly share with those who they feel comfortable with and supported by. However, parents do perceive opposition to and a lack of understanding of their ongoing relationship from some outside of their trusted support circle and in society at large, therefore they appear to exercise caution and withhold information about their baby in certain situations.

As outlined above, personal support systems (i.e. partner, family, friends) were mostly supportive of parents' ongoing relationship with their baby, with relationships between partners in particular often strengthened. However, in Study 2 the majority of parents stated that some family members and friends did not support their relationship with their baby. Moreover, interview data showed that a number of parents experienced breakdowns in their relationships with some family members and friends. Study 1 data further showed that restructuring of support systems by parents in order to better accommodate their continuing bond with their baby was not uncommon, with some finding empathetic and validating support from other bereaved parents. Little social expectation of an enduring relationship between parent and stillborn baby, together with an underdeveloped understanding of the nature and potential value of continuing bonds within wider society, appear to be restricting free expression of the relationship for some parents.

**Continuing bonds and coping**

Klass's (1996b) ethnographic study which examined the views of parents of deceased children of various ages who attended a support group, largely inspired the current project and has proved a useful frame of reference for the current findings. Fundamental to Klass's (1996b, 2006) continuing bonds theoretical framework is the relationship between parents' mental representations of their child in their inner and social worlds. Klass (1996b,

2006) suggested that bereavement adaptation is influenced by the degree to which parents' mental representations can be shared with supportive others, and subsequently integrated and validated within their social support systems. Through this process, parents' former relationship with their living child changes but continues, as they adapt to an altered relationship with the deceased. In line with this conceptualisation of continuing bonds, this project has provided evidence of the strategies used by parents of stillborn babies to construct mental representations, both independently and communally with others, and how these representations can be successfully integrated into parents' self-concept, family and ongoing life through positive sharing experiences, which also serve to establish their baby's (sometimes contested) social status. Owing to the homogenous nature of the current sample (i.e. solely comprised of parents of stillborn babies), and the unique characteristics of stillbirth, certain important and distinct aspects of the continuing bonds process following stillbirth have been pinpointed.

Klass (1996b) emphasised parents' need to transform mental representations, from those associated with a living child, to those associated with a deceased child. However, there are subtle differences to be noted in the experience of parents of stillborn babies as their child never lived outside of the uterus, and physical interaction with him/her was so fleeting. As a result, they have relatively few existing mental representations. Consequently, the emphasis for the current population post loss, was on creating and constructing mental representations in order to discover, nurture and develop meaningful ways of connecting with their baby and fostering a relationship with them. This is a novel and important finding as it challenges the commonly held view that parents never really know their stillborn baby (owing to an absence of interaction with a living child outside of the uterus), a view that perpetuates the notion of stillbirth as a less significant loss than other types of bereavement. Constructing mental representations of their baby was key in helping parents develop their baby's character, get to know their child and establish their relationship.

Transformation of mental representations was also evident, and tended to follow this early construction phase. For some parents, sharing their baby's

story with others shaped conceptualisations of their child. For example, in Study 1 one parent's mental representations evolved from baby through childhood and into adulthood over time. Another parent found she was able to think about her baby in more positive ways without feeling overwhelmed by emotional pain. Moreover, Study 2 data showed all parents had thought about what their baby would be doing if they were still alive within the last 12 months. These results demonstrate the fluid and dynamic nature of parents' mental representations and indicate parents' proclivity to develop an ongoing narrative for their baby. It is possible that this transition from construction to transformation of mental representations aligns with some parents' general tendency to shift their focus over time from more external, physical expressions of their relationship with their baby (required to construct connections) to more internal, integrated expressions, which become an established part of their self-concept and everyday lived experience.

A further distinction for those parents who have experienced stillbirth relates to the wider validation of their mental representations of their baby and ongoing relationship with him/her. Owing to the fact that so few people outside of the immediate family meet a stillborn baby, opportunities for collective remembering and consolidation of mental representations are limited. Reported stigma and silence surrounding stillbirth may significantly compromise these opportunities further. Moreover, as demonstrated by one father in Study 1, the birth of a subsequent baby may also impact upon or obfuscate existing mental representations of a stillborn baby, making it difficult to mentally locate or clearly conceptualise the stillborn child. It is possible that these aspects of parents' continuing bonds experience which are relatively specific to stillbirth could be impeding adaptive transformation of mental representations and integration of their baby into their ongoing lives, thus contributing to poor mental health outcomes for parents.

Further evidence of the intersubjective nature of continuing bonds and the importance of the social context has emerged in the current research. Study 1 data demonstrated how opportunities for parents to share their baby's narrative with compassionate and interested others was valuable as it helped to socially validate their child's existence, normalise the relationship and

integrate him or her into their ongoing lives. However, this project has also highlighted inherent difficulties associated with sharing an ongoing relationship with a stillborn baby with others. For many parents the social landscape was a complex one, with the potential for problematic interaction with others. Many parents reported a general lack of understanding of stillbirth within society and some experienced dismissive and unsupportive responses from others to their baby's death. The results of the regression analyses in Study 2 identified a number of factors related to parents' perceptions of the social context in which they experience their continuing bond with their baby, that are predictive of poorer mental health outcomes. Parents who perceived a lack of understanding and support from some family members, who had a greater desire to share and talk more freely about the relationship with their baby, who avoided talking to some people in case of a negative response, and who felt pressure from society to move on had poorer outcomes. A societal failure to adequately support the relationship, or as Klass (2006) suggested, a discrepancy between a parent's internal and social reality, could be adversely affecting parents' ability to cope or adaptively integrate their baby into their lives. In essence, a social context that fails to fully accommodate parents' relationship with their baby may be contributing to poorer outcomes.

Integration is a complex concept. As mentioned above, some parents appeared to successfully integrate their baby into their ongoing lives over time, whilst a few struggled to mentally locate their child in a way that brought them lasting comfort. Moreover, findings relating to integration and coping were mixed. Qualitative data in Study 1 suggested a positive connection between parents' sense of integration with their child and better coping, whereas results of regression analyses in Study 2 showed a positive association between integration and PTSD symptoms. Undoubtedly, this is a concept that requires unpacking and warrants further attention in relation to continuing bonds. The researcher recommends a more refined measure of integration in future studies to disambiguate between adaptive and maladaptive aspects of integration.

Societal expectations not only affected how parents expressed their relationship with their baby but were also felt by parents in relation to grief.

There was a notable tension between the bereavement journey of parents and the expectations of wider society. Parents sensed pressure from society to fully recover from their loss, especially over time. Parents experienced considerable changes to their worldview in order to accommodate their loss and move forward with their baby as a significant part of their ongoing lives. By contrast society tended to rationalise the loss. Essentially, parents' continuing bonds experience was often in opposition to the relinquishing bonds framework seemingly residual in society at large. As a result, parents were at odds with or "out of step with their culture" (Walter, 2018, p. 54). On a domestic level, differences in partners' experience of grief and coping had a destabilising effect on some personal relationships, whilst shared grief strengthened others.

Attig (2004) has suggested that grief is not simply a matter of an emotional reaction to loss that "happens to us", but rather "a matter of what we do with what happens to us" (p. 344). Parents of stillborn babies experience multiple losses that cut across personal, domestic and social spheres. A longed-for future with their baby, friends and family members, their former sense of identity, their place in society and even their voice can be lost at times as they confront tragedy, misperceptions, stigmatisation, marginalisation and silencing. Confronting and adapting to these losses, parents endeavour to create space for their baby and their ongoing relationship. This project highlights how parents instinctively employ multiple and varied coping strategies when faced with their baby's death. Unquestionably, parents' hearts and lives were riven, but the connections to their baby remained resolutely intact. In Study 1 a number of parents alluded to the inherent difficulties of maintaining affective ties with a stillborn baby whose physical presence was so fleeting. However, the relationship was largely portrayed as positive, and many parents derived comfort, strength, support and purpose from their ongoing relationship with their baby. Questionnaire data also showed that the majority of parents believed the relationship had helped them cope with their loss. Whilst it is acknowledged that the experiences of parents who choose not to maintain a relationship with their stillborn baby are not available for comparison, evidence across both studies of positive legacy building in baby's

honour and posttraumatic growth suggests that the relationship makes a valuable contribution to bereavement adaptation. Nevertheless, further investigation is required as a greater sense of integration with their baby, as mentioned above, was linked to increased PTSD symptoms in parents, although this result may been due to methodological issues or conceptual overlap.

The notion of searching for meaning after their baby's death pervaded parents' narratives in Study 1, and successful meaning-making endeavours appeared to provide a profound understanding of their experience and a sense of cognitive calm for some. However, meaning-making was not universal and some parents did not expect to find meaning resolution. Interview data suggested that multiple expressions of parents' continuing bond with their baby (e.g. rituals and legacy building) contributed in some way to the meaning-making process. Moreover, Study 2 regression analyses results showed that meaning-making was strongly associated with better bereavement adaptation. Writing in some form in the initial period post loss was reported by the majority of parents in both studies. Interview data showed that it was perceived as beneficial during that period as it facilitated freedom of expression, cognitive processing of their traumatic experience, and the formation of ties with baby and supportive others. In addition, the findings from both studies demonstrated that parents' engagement with nature was a significant part of their continuing bonds experience and contributed to coping. Nature offered lasting benefits to parents and appeared to be one of the more socially acceptable expressions of their bond with their stillborn baby. Parents used symbols from the natural world as physical representations of their child, sought sanctuary, solace and renewal in blue and green spaces, and some experienced spiritual connections and communication with their child via the natural world. Furthermore, results of regression analyses showed that increased engagement with nature was associated with greater posttraumatic growth.

The implications for care of the findings summarised above, are presented in the following section. A number of key aspects of the continuing bonds experience identified which parents found helpful, or which appeared to be

beneficial to coping, are considered in further detail in relation to short and long-term care management following stillbirth.

## 4.4 Recommendations and implications for care

### 4.4.1 Applied/Clinical

**Informal rituals**

Study 1 revealed that seeing their baby's whole, naked body might be important for some parents, especially mothers. If it is desired, it may be advisable for this to occur soon after birth prior to any deterioration to baby's appearance. It is imperative that parents are given the opportunity to have photographs taken of, and/or with their baby. A potential training deficiency was highlighted in Study 1 regarding the type of photographs captured by hospital staff. Appropriate training should be provided to relevant healthcare professionals as this practice must be thoughtfully approached and should consider cultural sensitivities (Schott et al., 2016). Assigned midwives (or specialist bereavement midwives) may be best positioned to discuss the options with parents, and carry out this valuable task, as they are already invested in parents' emotive experience and have the opportunity to build a compassionate rapport with them. Furthermore, this would protect the parents from having to interact with additional people in the form of an external provider. This recommendation aligns with the NHS's (2019) Long Term Plan, which outlines planned improvements to patient care over the next 10 years, including continuity of carer for women through pregnancy, during birth and into the postnatal period.

Owing to so few studies examining continuing bonds following stillbirth, little is known about the experience of conducting a relationship with a stillborn baby, especially long term. It could be helpful to provide some insight to parents into the ways in which they can nurture that relationship, and how it may (or may not) evolve over time. This could be achieved by sharing information with parents derived from other bereaved parents' experience of an ongoing relationship with a stillborn baby, for example, continuing bonds expressions that other parents have found helpful. Provision of information in this way is

similar to psychoeducational interventions which can be beneficial when dealing with certain mental health issues (Donker, Griffiths, Cuijpers & Christensen, 2009). The information could be presented in the form of a booklet provided by health professionals and offered to parents prior to leaving hospital. Parents could then read this information if they thought it was appropriate to their experience. Integrating informal rituals (e.g. engaging with photographs and memory boxes, wearing jewellery associated with baby, lighting candles and marking special occasions) into their ongoing lives may prove useful in creating and maintaining connections with their baby, as these expressions all had lasting import for parents in the current project. The use of symbolic representations from the natural world and associating special places with their baby might also facilitate development of the relationship. Moreover, certain aspects could be incorporated into care packages, for example, including a candle or using nature inspired imagery in memory boxes offered to parents in hospital.

A sense of uncertainty around how best to manage their baby's ashes emerged in some parents' narratives. Again, this insight could be included in the information booklet with suggestions on ways to care for their baby's ashes. It may prove comforting for some parents to have some of the ashes integrated into more portable keepsakes, for example, pieces of jewellery that can be treasured and held close. Moreover, a number of parents in both studies found writing helpful initially. Having a journal or baby book for their stillborn baby in which parents can record memories of their baby and possibly explore their thoughts, feelings and developing relationship with him/her may be a beneficial way of expressing and consolidating their continuing bond. In addition, the process of integrating their baby's narrative into their own life story through the production of structured language could provide clarity and coherence of thought at a time of great uncertainty, which may foster better understanding of their experience and aid parents' personal meaning-making (Boals, 2012; Park & Blumberg, 2002; Pennebaker & Chung, 2011). Whilst parents could be made aware that writing has been employed by other parents as a useful strategy to develop connections with their stillborn baby in the initial post-loss period, additional research is required into writing before it can be

confidently promoted as a therapeutic intervention following stillbirth. (This is further addressed in Future Research Directions, 4.5).

This project has provided evidence that for some parents the imperative to materialise their baby lessened over time. The acquisition of new physical reminders and frequent engagement in multiple ritualised activities became less important as connections with their baby became more established and integrated into their own sense of being. Study 1 interview data showed that some parents experience an initial sense of guilt as these changes to how the relationship is expressed occur. It is important that parents who experience such changes do not feel guilty about not maintaining certain rituals, activities or expressions of their continuing bond. Whilst further examination into the development of parent-baby bonds over time is required, it is tentatively suggested that parents could be made aware that change is not uncommon, and any decline in frequency of engagement in expressions does not equate to a diminishment of love for their baby or weakening of their connection. In fact such changes may be indicative of progression, evolution and consolidation of their relationship with their baby. Ties may change, but ties remain.

**Antenatal classes**

Current interventions in UK hospitals, such as memory-making activities, are triggered post-mortem and only come into play following confirmation of baby's death. However, a number of mothers in Study 1 called for better dissemination of information relating to the possibility of stillbirth as a pregnancy outcome during antenatal classes. Some thought that many other potentially anxiety inducing risk factors and outcomes were addressed during these sessions, for example, Sudden Infant Death Syndrome (which is statistically less likely than stillbirth; Office for National Statistics, 2018) but that stillbirth was not mentioned. This exclusion may be exacerbating the shock and devastation parents report following such an unexpected tragedy. Moreover, reluctance to discuss stillbirth within this arena further contributes to the wider cultural silence perceived by many parents. Provision of information relating to stillbirth in antenatal classes should be further

considered by researchers and health professionals. However, more research addressing this issue is required to fully evaluate the potential benefits and risks to maternal health and wellbeing should this information be given to parents.

**Making decisions**

Interview data showed that most parents highly valued the time spent with their baby and opportunities to engage in memory-making activities. Many parents voiced lingering regret at opportunities missed, and a failure to take full advantage of those precious moments. Disappointment with a paucity of photographs, or the quality of images was particularly common. Some parents acknowledged that a lack of available memory-making opportunities was due to their baby having died some time ago, before improvements made in recent years, but others believed that they were not fully informed of the opportunities available to them in the disorienting aftermath of their baby's death. Some expressed uncertainty about what they were *allowed* to do with their baby. In line with Cacciatore's (2010) intuitive and nuanced patient-centred care, clarity, compassion, sensitivity and patience should be central to health professionals' communication with families to ensure they are afforded an informed choice about interacting with their baby. If parents are initially undecided, all options open to parents should be followed up within the time available, as parents said that this was a difficult and stressful time/environment in which to make decisions. Such vital decision making can be overwhelming and daunting at first, but making the right choice for each individual at that time could prove crucial to any ongoing relationship with their stillborn baby, and their long-term bereavement adaptation. In addition, it should be noted that differences in parental responses during this period were evident in the current project. Some parents were instinctively pro-active and very clear on the activities they wanted to share with their baby, whilst others appeared to require more support and guidance from health professionals during this emotionally turbulent time (Radestad & Christoffersen, 2008).

As suggested by Cacciatore and Flint's (2012b) mindfulness-based bereavement care paradigm ATTEND, which encapsulates the core principles

of patient-centred psychosocial care (Attunement, Trust, Touch, Egalitarianism, Nuance and Death education), professional support needs to be attuned to the individual, and flexible in order to accommodate divergent or changing parental responses and diverse family dynamics. A recent study identified two distinct approaches in stillbirth management in North East UK hospitals, one emphasised patient directed choice and the other profession directed care (Brierley-Jones et al., 2018). It would appear that a combination of these two approaches, or indeed oscillation between the two may be required to ensure optimum, adaptable and accommodating care to those experiencing the trauma of their baby's death.

**Support and inclusivity**

It is critical that fathers' experience of loss following stillbirth is not discounted or subordinated by support systems. Study 1 data showed that fathers were profoundly affected by their baby's death and demonstrated an ongoing emotional attachment to their child over subsequent years and decades. Despite this, support for fathers, particularly informal support, did not appear to be as forthcoming or available to them as it was to mothers. These findings are supported by a recent Sands' survey which reported that nearly a third of male respondents did not receive support following baby loss and two thirds thought it was more socially acceptable for women to talk about perinatal loss than men (Sands, 2019).

Friends and family members need to be mindful of the often acute support needs of fathers as well as mothers. Bereavement support services, such as bereavement counselling, need to be inclusive and available to both parents and also to other family members who may be affected by the loss. Critically, fathers may not always feel comfortable attending baby loss support groups or accessing more traditional forms of support/therapeutic services. Therefore, alternate support strategies/interventions need to be considered, for example, a nature-guided intervention (discussed in the following section). A number of mothers accessed online forums to seek information and support. However, as with support groups, some fathers may perceive these sites to be predominantly populated by, or oriented toward women. The promotion of

father-focussed online forums run by bereaved fathers for bereaved fathers could provide a more comfortable, flexible and easily accessible platform through which to find both informal and formal support as required. Another variant on traditional support services which may be beneficial to fathers is Sands United FC, which organises football teams that provide support to bereaved fathers/family members and promote physical activity whilst also raising vital funds for the stillbirth and neonatal death charity.

Coping with the unexpected death of an individual who has no existing social identity is unique to perinatal loss and, as this project's findings attest, can result in quite distinct consequences for families. As previously discussed, owing to baby's fleeting physical presence, parents of stillborn babies may initially engage in a period of construction and validation of baby's identity and personhood through material representation and sharing. However, as the current research has demonstrated, these processes are not always met with social understanding, approval and support. Therefore, tailored bereavement counselling specific to perinatal loss may be beneficial as more generic approaches may not fully encompass the intrapersonal and interpersonal complexities associated with death in utero. Furthermore, advice leaflets given to parents by health professionals prior to discharge should include information relating to the possibility of divergent grief and coping strategies within partnerships and families. Findings in the extant literature surrounding stillbirth's impact upon relationships are mixed. Similarly, some parents in the current project reported dissonance and tension whereas others alluded to increased support and cohesion. Parents may benefit from a prior awareness of potential variability between partners' bereavement responses, and those of family members and wider social support systems. Better awareness could serve to reduce misperceptions, fractious, judgemental communication and instability, whilst improving the prospects of fortified, reciprocally respectful, nurturing, cohesive relationships that can contribute to parents' positive adjustment following their loss.

### Consciousness-raising

Klass (1996b) identified a general dearth of cultural understanding of continuing bonds following his study of bereaved parents. Over 20 years later, this lack of appreciation of the continuing influence and presence of the dead in some people's ongoing lives seems to persist in wider society. Moreover, for the current population this is coupled with widespread misperceptions of stillbirth. This convergence of ignorance can result in avoidant, inappropriate or inadequate social responses to parents' loss experience and their enduring relationship with their stillborn baby. It is imperative to continue to raise awareness of perinatal loss and continuing bonds so that any ongoing relationship between bereaved parent or family member and stillborn baby can be better understood, normalised and integrated into the cultural framework for understanding death. Whilst efforts have been made in recent years to publicise some of the issues associated with stillbirth, for instance, Sands' Finding the Words campaign promoting open discussion about perinatal loss, Baby Loss Awareness week and the inclusion of storylines depicting baby loss in popular UK soap operas, more needs to be done to ensure widespread exposure. It is strongly recommended that parents are given a platform within mainstream media outlets to communicate their experience in their own words so that their stories reach, and influence, a wider public audience. Educating society in this way could help develop a sensitive and informed language with which to openly address stillbirth and ameliorate social attitudes toward perinatally bereaved parents who maintain a relationship with their baby. As a consequence, it is hoped that social responses would evolve to become more consistently empathetic, compassionate, engaged and supportive, especially over time.

### 4.4.2 Proposing the development of a nature-based intervention

*Those who contemplate the beauty of the earth find reserves of strength that will endure as long as life lasts. There is symbolic as well as actual beauty in the migration of the birds, the ebb and flow of the tides, the folded bud ready for the spring. There is something infinitely healing in the repeated refrains of nature - the assurance that dawn comes after night, and spring after winter.*

(Carson, 1965/2017. p. 98)

Representations of natural environments as both salutogenic and therapeutic are well documented throughout history (see Ward Thompson, 2011). Engagement with green (e.g. gardens, woodlands) and blue spaces (e.g. inland surface water and coastal environments) has been shown to positively influence physical, mental and social well-being in multiple populations (Adevi & Martensson, 2013; Berman et al., 2008; Bratman, Daily, Levy & Gross, 2015; Finlay, Franke, McKay & Sims-Gould, 2015; Hartig, Evans, Jamner, Davis & Garling, 2003; Twohig-Bennett & Jones, 2018; Volker & Kistemann, 2011; Wheeler, White, Stahl-Timmins & Depledge, 2012). Beneficial effects can emanate from a broad spectrum of experiences including viewing images of natural environments (Ulrich et al., 1991), listening to bird sounds (Ratcliffe, Gatersleben & Sowden, 2013,) shinrin-yoku or forest-air bathing (Morita et al., 2007; Park, Tsunetsugu, Kasetani, Kagawa & Miyazaki, 2010) and horticultural activities (Sempik, Rickhuss & Beeston, 2014). Moreover, Mind, the UK based mental health charity, promotes ecotherapy (i.e. an intervention comprising activities in natural outdoor spaces) as an accessible, inclusive and cost-effective way to improve physical and mental health, and wellbeing (Mind, 2013).

Whilst researching stillbirth over the past 6 years, many organic connections between baby loss and the natural world have been observed. Be it parents planting trees in their baby's honour, associating symbols or places in the natural world with their baby, visiting the Sands' memorial garden, walking in natural environments, or having their baby's name written in sand on the Seashore of Remembrance on the other side of the world, there is an abundance of examples of bereaved parents instinctively connecting with

nature in the aftermath of their baby's death. However, nature's potential contribution to bereavement adaptation has received little attention in the academic literature to date. In the current research, engaging with nature was one of the most commonly reported strategies used by parents to help construct and maintain their ongoing relationship with their baby over time. Many parents continued to associate their baby with nature inspired symbols and places in natural environments; places that accommodated private and communal rituals, where their baby could be remembered and new memories forged, and where spiritual and emotional connections between parent and baby could be channelled and reinforced. Nature not only served as an architect of continuing bonds, but was also portrayed as a potentially nurturing and restorative environment. In essence, many parents perceived engagement with the natural world as an aid to short and long-term coping. Furthermore, nature-related activities appeared to be socially acceptable expressions of continuing bonds and were associated with increased posttraumatic growth in parents. Recently, calls have been made for research into newly emerging psychological interventions to support parents' bereavement adaptation following stillbirth (Crispus Jones et al., 2015). In light of the current project's findings, the researcher argues for the value of developing a nature-based therapeutic intervention for perinatally bereaved parents, as it may prove helpful in trying to cope with the loss of their baby. Drawing upon existing literature and the current project's findings, the rationale for such an intervention and the ways in which it may be beneficial to perinatally bereaved parents are further explored below.

Bereaved parents have been shown to exhibit significantly higher levels of depression compared to non-bereaved parents, with the symptoms being prolonged in mothers up to 30 months after the death of their child (Boyle, Vance, Najman, & Thearle, 1996; Vance et al., 1995). Moreover, women who have experienced a stillbirth are at three times the risk of exhibiting depressive symptomatology than women who delivered a live baby (see Huberty et al., 2014), are nearly four times more likely to experience anxiety than controls (Vance et al., 1991), and approximately one in five manifest symptoms of posttraumatic stress disorder (Walling, 2002). In addition to negative mental

health sequelae, and as observed during Study 1, perinatally bereaved parents commonly experience intense and prolonged grief following their baby's death, which can be both mentally and emotionally taxing. As people's lives are intricately interwoven with the lives of their loved ones, when a loved one dies, bereavement demands effortful and constructive action in response (Attig, 2004). Grief work exacts a considerable cognitive and affective toll on the individual; it can be onerous and exhausting to grieve (Stroebe & Schut, 2010; Wada & Park, 2009). Study 1 interview data showed that grief can persist and resurface. Moreover, creating and transforming complex mental representations of the deceased can also be a lengthy and potentially demanding endeavour (Klass, 1996b).

Evidently, stillbirth is an acutely stressful experience that can significantly deplete parents' emotional and cognitive resources, and result in negative mental health outcomes. Parents in the current research appeared to instinctively seek refuge and renewal in natural environments following their baby's death. If engaging with nature is potentially cognitively/affectively restorative and stress reductive, as the dominant theoretical constructs (i.e. Stress Reduction Theory and Attention Restoration Theory) discussed in Chapter 2 suggest, then it would appear to indicate the possible efficacy of a nature-based intervention for the perinatally bereaved. In essence, engaging with nature could provide essential respite and restoration from the often arduous, and sometimes life-long experience of grieving.

In addition, natural environments can encourage physical activity (Hug, Hartig, Hansmann, Seeland & Hornung, 2009), with both green and blue spaces offering the parents in Study 1 opportunities to engage in physical exercise. Following exploratory research into women's perceptions of physical activity and its potential to aid coping following stillbirth, Huberty et al. (2014) proposed that regular physical activity may improve women's mental, physical and emotional states. The authors suggested this could be achieved by: facilitating day-to-day, autonomous management of their grief and intense emotions associated with their baby's death; helping them to cope with negative mental health sequelae (e.g. depressive symptoms); improving general health for any future pregnancies, and as a result, ameliorating their overall quality of life long

term (Huberty, Coleman, Rolfsmeyer & Wu, 2014; Huberty et al., 2014). Physical exercise has been shown to improve the symptoms of depression, anxiety and PTSD in various populations, and in some instances can be equally as effective an intervention as psychotropic medication (Babyak et al., 2000; Blumenthal et al., 1999; Diaz & Motta, 2008; Dunn, Trivedi, Kamper, Clark & Chambliss, 2005; Herring, Lindheimer & O'Connor, 2013; Herring, O'Connor & Dishman, 2010; Herring, Puetz, O'Connor & Dishman, 2012; Mather et al., 2002). Moreover, empirical evidence has shown that individuals practising sports in green spaces, for example, jogging or cycling, reported a greater reduction in stress levels than those who engaged in less strenuous activities (Hansmann, Hug & Seeland, 2007).

A fundamental process for therapeutic practices in nature is the reconnection to nature as a reconnection to self (Jordan, 2009). As discussed elsewhere in this thesis, bereaved mothers in particular may suffer an internalised devaluation of self, including reduced self-esteem (Barr & Cacciatore, 2007-2008; Cacciatore et al., 2013). It could be argued that those parents who have experienced a shattering, deconstruction of former self may find solace and restoration in nature. Extant literature, together with the current project's findings, have also highlighted mothers' (and some fathers') tendency to look beyond their personal coping resources and engage with external support sources (Cacciatore, 2007; Cacciatore et al., 2009). A natural, non-judgemental, nourishing environment may facilitate identity reconstruction, foster internal growth and provide an opportunity for comforting communion with a non-human other. By absorbing extreme emotions and facilitating free expression between partners, as observed in Study 1, it could potentially contribute to meaning-making. Additionally, it is anticipated that feelings of anger and frustration, demonstrated by bereaved fathers post loss (Bohannon, 1990), may be mitigated by the calming influence of nature, whilst their propensity toward activity during bereavement (Avelin, et al., 2013) could possibly be served by outdoor, nature-based therapeutic activities.

The current project's findings demonstrate that parents' engagement with nature following their baby's death was diverse and spanned psychological, physical, social and spiritual dimensions. Equally, nature-based activities were

varied, from walking, hiking, running and cycling, to horticultural activities, to quiet contemplation in traditional deathscapes (e.g. cemeteries) or other blue and green spaces such as seascapes, gardens or countryside. Whilst preliminary findings presented here point to nature as a potentially valuable resource for parents coping with baby loss, the form and characteristics of any intervention need further consideration. Additional qualitative data examining parents' engagement with nature in closer detail was collected from 37 parents during Study 2 for an independent, post-doctoral study in collaboration with the researcher's Director of Studies. It is intended that these data will initially inform and guide development of a nature-based intervention for perinatally bereaved parents. Moreover, integrating strategies to facilitate meaning-making and promote legacy building into a tripartite intervention may prove beneficial as regression analyses results in Study 2 showed that both factors were also linked to better bereavement adaptation. For example, tree planting in honour of their baby is a nature-based physical activity which could also help parents to make a meaningful, long-term, positive contribution to the environment.

Future studies will also need to be mindful of some potential risks detected in the interview data. Death reflected in nature may contribute to the meaning-making process by emphasising the transience of existence (Layne, 2003) but could concurrently compound feelings of loss and failure. An existing affinity between the individual and nature may prove significant in enhancing nature-guided therapy's prospective restorative qualities (Haubenhofer, Elings, Hassink & Hine, 2010). It should also be noted that a therapeutic landscape is not intrinsically salutogenic to all individuals, it is merely a "(potentially therapeutic) landscape setting" (Conradson, 2005, p. 346), a therapeutic landscape experience being influenced by relational interplay between the individual and their broader socio-environmental setting. In essence, some settings can be concomitantly healthy and unhealthy, depending on the feelings and perspectives of those engaging with it (Collins & Kearns, 2007). Whilst the vast majority of evidence from the current research supports the theoretical proposition that evocation of, and engagement with the natural world, could promote continuing bonds and positively contribute to coping

following stillbirth, it is acknowledged that any nature-based intervention may not be appropriate for, or universally beneficial to, all perinatally bereaved parents.

Figure 3 provides an overview of how nature can contribute to coping and bereavement adaptation following baby loss. Essentially, for the first time this project demonstrates nature's significant and multi-functional role. As an architect of continuing bonds, the natural world enabled parents to conceptualise and develop connections with their baby via symbolic representations, through place association, as a channel for communication and spiritual communion, and by providing opportunities for private and communal rituals. Natural settings afforded parents sanctuary from society at times of acute vulnerability, offered a non-judgemental environment when faced with social scrutiny and stigmatisation, promoted a sense of connection and belonging following social ostracism, and accommodated uninhibited expression of emotion which facilitated meaning-making for some. Natural environments also promoted physical activity and fostered renewal and restoration. Moreover, regression analyses results showed that engaging with nature is linked to posttraumatic growth. As such, the current research has provided an original insight into parents' seemingly instinctive engagement with the natural world following stillbirth, and identified the therapeutic potential of nature and its prospective, positive role in bereavement adaptation. Furthermore, the findings strongly indicate that further exploration of nature as an architect of continuing bonds, and nature-based therapy as a complementary intervention for the perinatally bereaved, could prove enlightening and valuable, as parents struggle to restructure an altered existence, socially, psychologically, emotionally and spiritually.

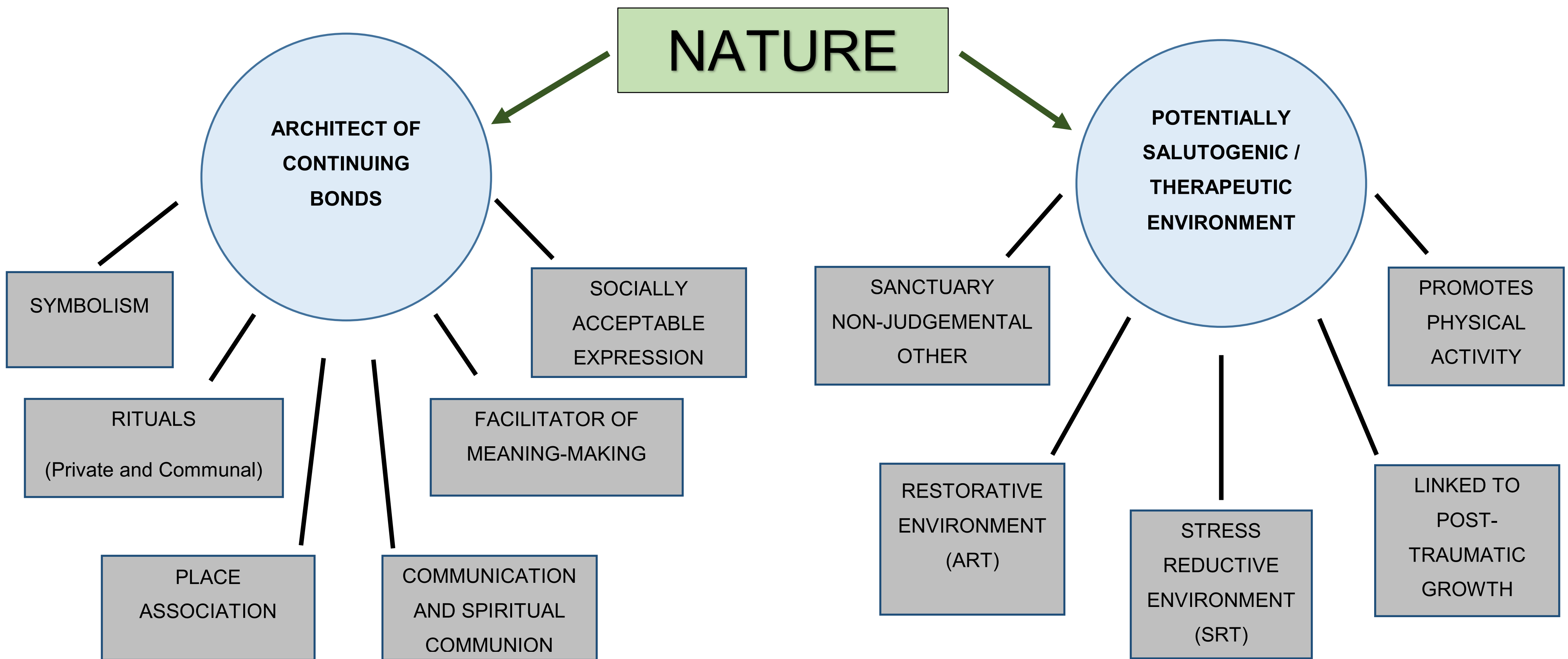


Figure 3. The multi-functional role of nature in coping with stillbirth

## 4.5 Future research directions

As previously mentioned, a key issue identified during this project in relation to parents' successful maintenance of a meaningful connection with their baby, was society's lack of understanding of their loss experience and subsequent ongoing relationship with their baby. Many parents found social pressures to move on, and social judgement of certain aspects or expressions of their continuing bond with their baby, unhelpful and at times inhibiting, especially over time. For example, in Study 1 some parents thought talking about their baby or showing overt emotion years after death was socially stymied or impermissible. Moreover, Study 2 data showed that sharing photographs of their baby was more likely to provoke a negative social response than other expressions of parents' ongoing relationship with their baby. It is imperative to further examine and identify where such social boundaries lie so that they can be highlighted and challenged in order to change public opinion. Negative social responses may be having an adverse impact on parents' relationships with members of their support circles, and also on their ability to positively share their baby with others and integrate him/her into their everyday lives, thus potentially impeding bereavement adaptation. Switching the focus from parents' perceptions of social responses to society itself and its attitudes towards stillbirth and continuing bonds, may prove enlightening and help pinpoint current social boundaries. Identifying what precipitates the uncertainty and discomfort which characterises the inadequate response of some is essential. By exploring social attitudes directly, future studies could gain detailed and valuable insight into the reasons why social responses can be mixed and problematic at times, whilst further examining tensions highlighted during this project between parents' experience and societal expectations of continuing bonds.

Additional research is warranted into the changes experienced by parents over time to their ongoing relationship with their stillborn baby, in order to build upon the current findings and gain a better understanding of the evolution of continuing bonds. This could help health professionals to identify the type of

support parents may require longer term. As suggested in Chapter 2, it might also prove beneficial to expand the debate about differences (often dichotomised by gender) in parental response to stillbirth and continuing bonds, by comparing the experiences of gestational and non-gestational parents in lesbian partnerships.

In addition, searching for, and in some cases, ultimately finding meaning pervaded parents' continuing bonds experience. Meaning resolution appeared to help parents adapt to and integrate their loss into their ongoing lives. As a result, a clearer understanding of what stimulates and facilitates meaning-making (e.g. type of social support available), and why some parents achieve resolution whilst others struggle to do so, would be beneficial to enable the provision of tailored support to parents, and could inform counselling interventions.

The majority of parents who participated in the current research engaged in some form of reflective writing practice following their baby's death. It has been suggested that therapeutic writing can facilitate meaning reconstruction during grief therapy following perinatal loss (Neimeyer, Burke, Mackay & Van Dyke Stringer, 2009). Moreover, creative writing workshops that encouraged participants to explore their personal grief narratives in a supportive environment following miscarriage and perinatal loss, have been found to affect a sense of healing, solace and personal transformation, whilst challenging the social silence surrounding baby loss (Bulger, 2017). However, few empirical studies have considered the potential benefits of writing following stillbirth. Expressive writing interventions have been examined in relation to childbirth and stressful birth experiences (Ayers et al., 2018; Crawley et al., 2018; Horsch et al., 2016) with promising but somewhat mixed results. A randomised controlled trial (RCT), investigating the effectiveness and acceptability of an expressive writing intervention for mothers of very preterm babies, reported that mothers in the intervention group showed reduced posttraumatic and depressive symptoms, and improved mental health status, which were maintained at 6 months follow-up (Horsch et al., 2016). Moreover, a recent systematic review of existing interventions that may prevent PSTD

following childbirth concluded that expressive writing appeared to be the only "convincingly effective" intervention (De Graaff et al., 2018, p. 1). Another RCT evaluating the effect of expressive writing on post-partum women's health found no significant differences between expressive writing, control writing and standard care groups in relation to physical and mental health measured at 1 and 6 months postpartum. However, self-reported levels of stress were rated as significantly reduced by those women who had completed the expressive writing task (Ayers et al., 2018). Critically, whilst most mothers found expressive writing acceptable as an intervention, feasibility was low, predominantly due to the pressures of caring for a newborn baby, and attrition rates were high (Crawley et al., 2018). As it would appear from the current findings that many parents are intuitively writing following their babies death, it is possible that some parents of stillborn babies may be more welcoming of the opportunity to engage with this type of research (than parents of liveborn babies), as it would encourage them to write about their experience, and thus forge deeper connections with their baby. Furthermore, the products of this therapeutic exercise may also be treasured and revisited over time as lasting tethers to their child.

Further exploration of the expressive writing paradigm following stillbirth could prove productive and make a valuable contribution to the growing literature base. Moreover, other types of writing intervention should be considered. For example, Kersting et al. (2013) used a brief internet-based intervention that involved parents (predominantly mothers) who had experienced pregnancy loss taking part in 10 writing exercises over a 5 week period. By requesting that parents focus on difficult memories associated with the loss, reflect on the therapeutic process and outline how they might cope with the loss going forward, the aim of the varied assignments was to enable parents to develop a revised perspective of the loss and the circumstances surrounding it. Results of the RCT showed that the intervention group had significantly reduced symptoms of depression, anxiety, prolonged grief and posttraumatic stress when compared to a control group. Another variant of the therapeutic writing paradigm which could be explored with the current population is a self-

compassion writing intervention. Writing exercises that promote self-compassion, that is self-kindness, common humanity and mindfulness (Neff, 2003) have been shown to reduce negative affect in stigmatised and shame-prone individuals (Johnson & O'Brien, 2013; Sherman, Roper & Kilby, 2019) and may benefit physical health (Wong & Mak, 2016).

The comprehensive nature of this study, together with the wide-ranging nature of the continuing bonds process have highlighted a convergence of numerous theoretical frameworks which would benefit from further examination and integration. For example, psycho-social aspects of continuing bonds, meaning reconstruction and bereavement adaptation, spiritual conceptualisations of continuing bonds, grief theories, the emotional disclosure paradigm, concepts of posttraumatic transformational growth, and nature related theories of stress reduction and cognitive restoration are all relevant to this study of continuing bonds following stillbirth, and have been drawn upon to aid explanation and exploration of parents' relationship with their stillborn baby. Future studies could assess areas of significant overlap within these diverse frameworks and start to construct a more integrated, cohesive and unifying continuing bonds framework to provide further clarity and insight into the complex, pervasive and far-reaching nature of continuing bonds.

As cited at the very start of this thesis, Jolly (2015) poignantly said that "the world of Dead Babies is a quiet and shuttered place". Therefore, it is our responsibility as researchers, through dissemination of our work to dismantle those shutters and shed light upon those once concealed aspects of stillbirth that are of critical import to parents.

## 4.6 Methodological reflections

### 4.6.1 The research process

#### Approach

Continuing bonds following stillbirth is a wide-ranging, complex and sensitive research area which touches upon many aspects of the human condition. As such, I thought its study called for analysis through a prismatic lens best

served by a mixed methods approach. Having adopted a pragmatic stance from the outset, as outlined in Chapter 1, the use of mixed methodology allowed me to apply different perspectives to the research questions in order to provide an holistic and multi-layered insight into the subject. Moreover, there is a dearth of literature that specifically examines the continuing bonds process following stillbirth from a psychological perspective. As a result, it was of critical importance to me, during the first exploratory phase of research, not to make a priori assumptions about the key concepts of parents' experience but to adopt a grounded theory approach (Charmaz, 2006, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1990) in order to determine the salient aspects of parents' relationship with their baby through exploration of the topic in their own words. Personal narratives allow for the sharing and validation of experience, and whilst bereaved parents have reported it being difficult to talk about their experiences, they have demonstrated an eagerness to tell their stories, and to potentially help other families who may be faced with a similar experience (Widger & Picot, 2008). My interaction with parents and direct exposure to their emotive stories was also considered necessary and valuable in deepening understanding of their loss experience.

The aim during the initial qualitative phase (Study 1) was to identify how parents remain connected to their baby, to explore the characteristics of the relationship, and to consider how the relationship might be helping parents to cope. Interpretation of the data highlighted a number of core features of the relationship between parents and their stillborn baby which were taken forward to the second phase of the research programme (Study 2). Quantitative methods were introduced at this stage as they enabled further examination of key aspects of the continuing bonds process with a larger sample, and allowed for statistical analysis of these key aspects in relation to parents' bereavement adaptation. Combining these distinct methods in one research programme in this way not only allowed for triangulation of data, but also facilitated a practical, well-balanced, tailored approach to the research subject that has delivered an extensive, sophisticated and rich understanding of parents' continuing bond with their baby following stillbirth. Furthermore, the use of

mixed methods has produced data that is suitable for a variety of different audiences, this will be key to disseminating the findings as widely as possible in order to contribute to the de-stigmatisation of stillbirth. By offsetting the perceived methodological weaknesses of stand-alone quantitative and qualitative research, for example, omission of the participant's voice and problems with generalisability respectively, I hope the work bridges any disciplinary divides and generates interest in multiple arenas which could spark future inter-disciplinary collaboration on the subject (Creswell & Plano Clark, 2011).

**Study 1**

Interestingly, the interview process itself acted as an expression of parents' continuing bond with their baby. Valentine (2008) has reflected that the research interview can allow the dead to assert their presence, as the bereaved introduces their loved one to the interviewer/audience. This provision of a safe and empathic environment in which to accommodate an introduction may be of particular importance to parents of stillborn babies, as they struggle to maintain their baby's social presence in a broader sense, especially over time, owing to the fact that so few people, if anyone, outside of their immediate family was introduced to or knew their baby (Hughes & Goodall, 2013). Frequently confronted by others' silence and avoidance, or dismissive responses dissuading some from mentioning their baby, a number of parents expressed their gratitude at being afforded the opportunity to talk freely about their baby to an engaged and interested party, without fear of judgement. Essentially, the interview became an "intersubjective space" (Klass & Steffen, 2018a, p. 7) in which continuing bonds flourished, with parent and myself as researcher interacting to evoke baby's presence and co-create and consolidate relational bonds. I felt humbled and privileged to experience parents' relationship with their baby in this way.

Owing to the acutely sensitive and emotive nature of the subject matter, it was not deemed appropriate to regularly break eye contact with parents during face-to-face discussions, or divert attention in order to make comprehensive,

contemporaneous notes. Instead, I drafted brief, memo style notes after each interview. This should be considered by researchers when conducting sensitive research. Note-taking or frequent referral to an interview schedule may not be appropriate as diverting attention away from, at times intense and emotionally charged interactions, could be jarring and be perceived as insensitive or disrespectful.

With reference to use of the term "emergent theme" during Study 1, it is acknowledged that some question the notion of themes "emerging" from the data as it positions the researcher in a passive role which is at odds with the epistemological framework of interpretation and construction within qualitative research (Varpio, Ajjawi, Monrouxe, O'Brien & Rees, 2017). However, I have used the term to denote emergent themes as a product of the researcher's cognitive effort and interpretation of the data.

**Study 2**

During construction of the questionnaire I consulted with a Sands' liaison officer and a parent representative who had personal experience of baby loss, both of whom provided valuable feedback to ensure that the terminology used was sensitive and effective. Due to the sensitive nature of the subject matter and potential emotionality of participants, it was not deemed appropriate to pilot the questionnaire with a large number of parents. One participant from Study 1, who indicated that they would be willing to participate in the follow up study, and who is employed by Sands, piloted the study. As the questionnaire was relatively long, this process also provided an opportunity to gauge whether the task of completing it was potentially too onerous, or emotionally taxing for parents. This proved a valuable exercise and provided perceptive and positive feedback which informed a number of minor modifications to its functionality, such as the addition of a "save and close" function to allow participants to return and complete the questionnaire at a later date, thus mitigating any prolonged or undue emotional distress. Moreover, the pilot resulted in the inclusion of additional questions to better capture the nuances of parents' experience relating to social support for their continuing bond. For example,

originally parents were asked whether their family/friends understood and supported their ongoing relationship with their baby, however, the parent piloting the questionnaire advised that this question did not adequately capture their experience as social support was often mixed, some members of social support systems did understand and support whilst others did not. As a result of this insightful feedback, further questions to determine whether some family members/friends did not understand or support the relationship were included.

Despite efforts to create an informed and sensitive questionnaire, one participant did contact me directly to voice strong concern at the nature of questioning employed in Section 4, which explored the construct of meaning-making. These items were based on those used in previous studies (Currier et al., 2008; Neimeyer et al., 2006) and on emergent themes from Study 1. The inclusion of questions relating to parents' making sense of their experience or feeling like a better person as a result of their experience were highlighted as problematic. The specific use of the term *better person* was perceived as inappropriate as it was thought to implicitly suggest that those parents who did not feel they had become *better* were essentially *worse* people. It was felt that a judgemental tone was inherent in this term that was unhelpful, and which fed into the self-judgement and societal judgement which many parents experience following their baby's death, both of which are explored during this thesis. Moreover, it was argued that in solely asking for further qualitative responses from those parents who felt they had made sense of their experience or had undergone changes to their life for which they were thankful, it was implied that this was the expected and preferred experience, and precluded and in some way demeaned the experience of those parents who felt they had neither made sense of, or found benefit from their experience. Although it was certainly not my intention to cast judgement or overlook alternate experiences, on reflection, I acknowledged that the terminology adopted for future studies would require further consideration, and that the views of those who had alternate experiences to those cited would be explicitly sought, thus ensuring that the complex and varied experiences of parents are fully captured. A response was sent to the participant to explain

the basis for exploring these concepts and for using certain items, and to thank them for their insightful and valuable feedback. Whilst I still consider the reasons for not piloting the questionnaire more extensively to be sound, it may prove beneficial to run a small trial study or convene a focus group with parents to facilitate development of materials for future studies.

The “Prevent Ballot Box Stuffing” option in Qualtrics which ensures participants cannot submit the questionnaire multiple times from the same device was purposefully not used as it may have precluded a second parent within the same household from participating. I acknowledge that by not setting this option there is no way to confirm that an individual did not complete the questionnaire more than once. However, it is thought that the length of the questionnaire and the requirement to complete all questions prior to submission may have discouraged participants from doing so.

Furthermore, the use of self-reported mental health measures is recognised as a limitation of Study 2. The HADS (Zigmond & Snaith, 1983) and IES-R (Horowitz et al., 1979; Weiss & Marmar, 1997) are commonly used, standardised measures of anxiety and depression, and PTSD symptoms respectively. However, they are not diagnostic tools, and were not used for this purpose in the current research, rather they were utilised to measure the presence of symptoms. I accept that the inherently subjective nature of self-reporting is susceptible to responder bias. As a consequence, the results must be viewed with a level of caution.

### 4.6.2 Ethical considerations

Due to the highly sensitive nature of the research area, my primary concern was the recruitment of participants, and their well-being during and after data collection. Seeking the support of Sands, and a number of their support group facilitators was key in trying to ensure that communication between myself and participating parents was informed, sensitive and effective, and that parents’ welfare was prioritised and safeguarded at all times. In addition, I consulted with members of the local primary care trust chaplaincy, who shared their experiences of empathic interaction with perinatally bereaved parents,

providing valuable insight and advice. Parents were advised not to participate if they thought doing so may cause them undue distress. Moreover, relevant support contacts were provided to all parents before and after participation for both studies.

The issue of my welfare as researcher following data collection sessions was a concern raised by my supervision team prior to starting this project. In an effort to address this concern, I arranged supervision sessions with a practising counsellor based at the University of Sunderland, before and after data collection to try to mitigate any potential emotional distress experienced. During the sessions we discussed appropriate measures to take to ensure my ongoing health and wellbeing, and any personal issues which may have arisen as a result of my discussions with bereaved parents. The presence of emotionality in research is discussed further in the reflexivity section below.

### 4.6.3 Reflexivity and the role of the researcher

> Researchers can use grounded theory strategies without endorsing mid-century assumptions of an objective external reality, a passive, neutral observer, or a detached, narrow empiricism. If, instead, we start with the assumption that social reality is multiple, processual, and constructed, then we must take the researcher's position, privileges, perspective, and interactions into account as an inherent part of the research reality. (Charmaz, 2014, p. 13)

The first phase of research was informed by a grounded theory approach, and in line with Charmaz's (2014) position explicated above, I acknowledge the inter-subjectivity of research and that I play an active and influential part in the research process. Therefore, it is important to reflexively consider my role as researcher in the production of knowledge presented in this thesis. Two key aspects have been identified which may have affected interactions between myself and the participants, and my subsequent understanding and interpretation of parents' experience of continuing bonds with their stillborn baby, namely, positionality and emotionality.

**Positionality**

Bourke (2014) suggests that we must be cognisant of positionality and its potential effects on participants and the researcher, accordingly, “we have to acknowledge who we are as individuals, and as members of groups, and as resting in and moving within social positions” (p. 3). Essentially, positionality is thought to be determined by where one stands in relation to “the other” (Merriam et al., 2001) and can influence decisions made during the research process, researcher/participant interactions, and interpretation of outcomes (Bourke, 2014; Foote & Gau Bartell, 2011).

Whilst my status in relation to the participants as parents of stillborn babies (i.e. insider/outsider) was not disclosed prior to interview, a number of parents did ask questions during discussions relating to my motivation for the study which may have been designed to determine whether I had personal experience of stillbirth. When this situation arose, I explained my interest in the subject stemmed from the research interests of my supervision team, as opposed to any personal experience of it. I acknowledge that subsequently, as a result of this disclosure, my perceived “outsider status” may have had some bearing on the few parents who sought further information from me. Whilst it is impossible to know what effect this knowledge may have had on parents during discussions, I had little sense of parents holding back, or feeling hesitant or cautious as to what they felt able or comfortable to discuss. As the findings attest, all parents’ narratives were rich and detailed, which may have been due in part to the relaxed, informal style of the interaction, with emphasis on parent driven discussions as opposed to me assuming the role of formal interviewer with a list of questions I presumed to be important, based on a raft of pre-conceived ideas about the experience of continuing bonds following stillbirth. It is also possible that those who knew that I had not experienced stillbirth myself, may have been further motivated to explain themselves at length and in detail to try to ensure that I was made fully aware of the profound and complex nature of their experience. Moreover, my status as a nonparent may have minimised any predetermined notions or expectations I might have held in relation to a parent’s response to the death of their child. I feel that this

allowed me to be solely focussed on the parents' voices and experiences rather than drawing upon my own relevant or "comparable" experiences of parenthood.

**Emotionality**

Researching sensitive subject areas within the social sciences such as domestic violence, sexual identity and bereavement, including stillbirth, can be distressing and emotive for both participants and researchers (Jones, 2013; Wilcock & Quaid, 2018). However, to date, emotionality in research has received little attention in academic literature. It is possible its omission is due to the guiding principles of traditional scientific philosophies of positivism and post-positivism which privilege detachment, objectivity and emotional neutrality. However, it has been suggested that "emotion is not only to be embraced as part of research practice but that emotion is embedded in the knowledge we produce" (Wilcock & Quaid, 2018, p. 4), and that emotion and reason are not diametric opposites but are inextricably linked during the research process, with both contributing to the dynamic production of knowledge (McLaughlin, 2003). Moreover, wisdom can be conceptualised as balancing multiple components: cognitive, affective, behavioural and reflexive (Bassett, 2005; Kramer, 2000).

When conducting the current research, I was aware of the need to balance and effectively combine emotionality and rationality. Whilst conducting interviews the parent's emotional response was paramount, accordingly, compassionate professionalism and a responsibility for their welfare were prioritised. There is a delicate balance to be found whilst conducting sensitive research in the field. It is imperative to be a genuinely engaged and empathic listener but in order to extract the richness of parents' emotive experience which will drive consciousness-raising and affect change beneficial to those affected by the experience, it is also necessary to remain composed and cognitively alert so as to maintain focus on the subject area and effectively probe salient points raised. It was important to try to spend further time talking to parents after the interview had concluded in order to oversee their return to

emotional stasis. Conducting telephone interviews made this more problematic. Consequently, I would try to carry out any future interviews face to face. In contrast, during transcription, when I considered parents' emotionally charged and poignant accounts in solitude, and whilst immersing myself in the data during analysis, my own emotional response could, and often did emerge. I also experienced a feeling of compunction at having engendered affective reactions in parents during our discussions. Reconciling this sense of guilt with a desire to explore their experience, with a view to raising awareness of stillbirth, was at times difficult to manage.

Whilst there is no comparison with the emotional pain experienced by parents and families, conducting such sensitive research can induce complex emotional responses in the researcher, which I believe need to be more widely acknowledged within the research community. We have a duty of care to recognise the potential for emotional toll on researchers, especially those who are immersed within sensitive subject areas for extended periods of time, and to provide support and guidance on how best to manage affective responses. Based upon my own experiences, I would suggest that potentially emotive tasks, (e.g. interviews, transcription, data analysis) are mindfully managed and interspersed with less demanding activities where possible. Limiting my schedule to one interview per day was helpful as it reduced the likelihood of emotional fatigue and allowed time to contemplate and absorb the experience. Taking time out from doctoral research is difficult to achieve but it is imperative that short periods of respite from emotive topics such as bereavement are inserted into the programme. I achieved this by attending more technically based training courses and by spending time in nature to further explore its potentially positive salutogenic and restorative benefits, as outlined during this thesis.

## 4.7 Summary of contribution to knowledge

This section summarises key and novel findings to demonstrate the project's valuable contribution to knowledge. Summaries are provided for each of the project's main research areas: Continuing bonds and changes over time,

Sharing and social context, and Continuing bonds and coping. The section concludes with a bulleted exposition of how the project expands upon the existing knowledge base.

**Continuing bonds and changes over time**

The current research's detailed findings advance understanding of the ways in which parents construct and evoke mental representations of their baby and maintain bonds with them long term. The project highlights the importance of the prenatal period, with formative bonds being constructed during this time when the baby is alive. After their baby's death, seeing the baby's whole, naked body may be important to some parents. Memory-making activities do not solely occur when the baby is present. Memories associated with the baby continue to be made despite the baby's physical absence. Parents most commonly think about, feel emotional connections to and communicate with their baby after their loss. These expressions continue to underpin their relationship with their baby over time. Looking at photographs and memory boxes, wearing jewellery associated with their baby, lighting candles and marking special occasions remain important to parents over time. Collecting mementos may be more common and helpful for mothers than fathers. Moreover, there is uncertainty surrounding long-term plans for their baby's ashes for some parents.

Bonds can change over time. For some parents, changes relate to the manner in which the relationship is experienced, with a general trend seeing external physical/material expressions being supplanted by more internal, integrated expressions. Most parents feel that their baby is part of them. However, many parents continue to engage with important physical reminders of their baby in the years and decades post loss. The number of ways in which parents express their relationship with their baby, and the frequency with which they engage in activities and experiences related to their continuing bond, tend to reduce over time. Some parents may struggle with feelings of guilt as they adapt to this change. For the first time, differences in how parents tend to conceptualise their stillborn baby are identified. Parents more commonly

conceptualise their baby as a baby. However, mental representations also evolve over time as parents construct an ongoing narrative for their child. More than half of parents had thought about their baby at the age they would have been if they had lived, and all parents had thought about what their child would be doing if they were still alive within the last 12 months. The birth of a subsequent child may complicate some parents' mental representations of their stillborn baby and affect their continuing bond with them. The vast majority of parents expect their relationship with their baby to last their lifetime. Parents' enduring emotional ties, ongoing concern for their child and protective instincts, together with multi-modal communication between parent and baby characterise the continuing relationship.

**Sharing and social context**

To the researcher's knowledge, this is the first project to examine parents' perceptions of the social context in which they experience an ongoing relationship with their stillborn baby and social support for that bond, in relation to bereavement adaptation. Engaging with nature and legacy building appear to be the most socially acceptable expressions of continuing bonds. Sharing photographs of their baby appears to be the least socially acceptable activity and parents most commonly hold back from sharing this activity with others. Parents most commonly share their relationship with their baby verbally. Parents appreciate talking about their baby with compassionate, supportive others as it helps them to feel closer and consolidate bonds with their baby. Particularly, parents appreciate others asking about or honouring their baby in some way. Most parents would like to be able to talk more freely about their relationship with their baby.

Parents disclose information about their baby spontaneously, in a protective manner (Charmaz, 1991) and in a confrontive or challenging way. The identification of a third type of disclosure (i.e. confrontive/challenging) is novel and highlights the determination of some parents of stillborn babies to secure acknowledgment of their child and normalise their ongoing relationship. Most parents think that their personal support systems generally support and

understand their relationship with their baby. However, over half of parents think some family members and friends do not support the relationship. Few parents believe the relationship is expected or widely understood in society. Social support for the relationship tends to fade over time with fewer opportunities to share it with others and a growing societal pressure to justify it. Fathers in particular may struggle to find appropriate social support following baby loss. In order to increase general awareness of stillbirth and challenge stigma, some mothers think it may be helpful for antenatal classes to make reference to stillbirth as a possible pregnancy outcome.

**Continuing bonds and coping**

Most parents consider their relationship with their baby to be an enriching experience and an aid to coping. However, some parents also acknowledge the inherent difficulties in constructing and maintaining a relationship with someone whose physical presence was so brief. Grief can be a residual or resurfacing part of parents' long-term experience post loss and for some is inextricably linked to their ongoing love for, and commitment to their stillborn baby. Writing about or to their baby may be helpful to parents in the initial post-loss period. Parents tend to alter their global meaning framework in order to accommodate the loss, whereas others appear to appraise the loss in such a way that enables it to be assimilated into their existing worldview, that is, they trivialise or rationalise the loss. To the researcher's knowledge, this divergence is a novel finding for the current population. Critically, meaning-making is positively associated with bereavement adaptation following stillbirth. For the first time, this project demonstrates how nature plays a multi-functional role in coping with baby loss. Nature as an architect of continuing bonds and as a potentially therapeutic environment may positively contribute to coping. More frequent engagement in both nature-related and legacy building activities are associated with greater posttraumatic growth. A nature-based intervention could be of benefit to perinatally bereaved parents.

Parents' perceptions of inadequate social support for their continuing bond, and social limitations on sharing their relationship are linked to inferior mental

health. Parents' experience of continuing bonds with their baby sometimes puts them at odds with the traditional discourse advocating emotional disengagement from their baby and moving on still prevalent in society. Critically, a social context that fails to fully accommodate their ongoing relationship with their baby may be contributing to poorer outcomes for parents.

The intersubjective nature of continuing bonds and the importance of cultural and social context is central to recent discussions within the field (Klass & Steffen, 2018b). Transforming mental representations by means of sharing them with others is thought to facilitate integration of the deceased child into parents' everyday lives, and potentially aid bereavement adaptation (Klass, 1996b). Any divergence between the bereaved's internal and social reality may adversely affect adjustment to loss (Klass, 2006). This project's empirical evidence makes a significant contribution to knowledge as it highlights how parents of stillborn babies intensively construct mental representations by myriad innovative ways in order to add to their relatively small existing reservoir, thus helping to define and develop a relationship with their baby. Evidence of transformation of mental representations over time also emerged. The project demonstrates how integration of a stillborn baby into perinatally bereaved parents' social world can be problematic due to a complex social landscape. Moreover, for the first time, it identifies specific aspects of parents' ongoing relationship with their baby, and parents' perceptions of the social context in which they experience the relationship that are related to bereavement adaptation.

This project expands upon the existing body of knowledge by:

- Investigating a broader range of continuing bonds expressions, activities and rituals in which parents engage long term, and any changes over time.
- Exploring parents' perceptions of the value of continuing bonds, and how their ongoing relationship may be contributing to coping.
- Analysing the characteristics of the ongoing relationship.

- Examining the social context in which parents experience their ongoing relationship, and opportunities they have to share it with others.
- Identifying aspects of parents' continuing bonds experience that predict mental health and posttraumatic growth.
- Considering the role of nature in bereavement adaptation following stillbirth.

### Concluding thought

The intention of this project was to amplify the voice of parents and allow their experience to educate our wider society in the significant and unique issues surrounding continuing bonds following stillbirth. In keeping with this aim, it is only appropriate that the final message be delivered by a parent of a stillborn baby:

> *…it* [ongoing relationship with baby] *can be a very positive thing and I think that's what I'd want people to know, that… I think people can think that having this sort of relationship can be a sign of disordered grief, or complicated grief, or mental illness, that you're kind of maintaining this relationship with a person who's gone, and actually it's not about that, I'm her mum*, *I will always be her mum, whether she's here or not, and that's a positive thing, not a negative thing, I think that's what I would want people to know…* (Participant 3, Mother)

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# Appendices

## Appendix A Contact Letter

/ / 2015

Dear

My name is Emma Jones and I am a student researcher at the University of Sunderland in my first year of study for a PhD. I am contacting you to see whether you may be willing to help me recruit participants for my research study, called 'Continuing Bonds: Ritual, Meaning-Making and the Therapeutic Potential of Nature Following Stillbirth.'

My study will look at how parents of stillborn babies build and keep bonds with their child. I'm asking parents over 18 whose baby was stillborn at 24 weeks of pregnancy or later if they would like to take part.

In the study, parents will be invited to talk about their ongoing relationship with their baby, how they maintain this relationship (for example, through memories, rituals, activities or honouring their baby's memory) and how this affects their relationship with their baby and their feelings about their baby's death. They can take part in a group discussion or I can speak to them one-to-one if they would prefer.

The overall aim of the study is to provide insight into how parents stay connected with their child. The results will be available to other researchers to help them design more work in this area, and could help inform recommendations and advice about activities and rituals.

I am very aware of how sensitive this area is and I have worked with my supervisory team to consider the ethical issues around this research. The study has been approved by the University of Sunderland's Research Ethics Committee. Parents will remain in complete control of their participation and can withdraw at any time. Parents will be given an information sheet to read before they decide whether to take part. The sheet will:

- Describe the questions that will be asked.
- Advise parents not to take part if they feel they will become distressed.
- Provide links to a number of support helplines.

I will give all participants another sheet at the end of the session that will also include the contacts for support.

Any personal information provided by parents will be kept strictly confidential and parents would not be required to provide their real name during any group discussion. Every participant will be asked to provide an assurance that they will keep the identities of other group members confidential, and that they will not

disclose the nature or content of discussions to any third party. Only the researchers involved in the study will have access to parents' personal details. All information that could potentially identify a participant will be destroyed 1 year after the research study is completed (in approximately 4 years' time).

The results of the study will be written up as part of my thesis and may be submitted for publication in academic journals. No personal information will be included and it will not be possible to trace results back to participants.

If you would like further details on the study before making your decision, please contact me:

Researcher: Emma E. Jones
Email: ba5ejo@research.sunderland.ac.uk
Phone: 07840372001

or my principal supervisor:

Dr. Rosalind Crawley, Reader in Cognitive Psychology, Department of Psychology, University of Sunderland, St. Peter's Way, Sunderland, SR6 0DD.
Email: roz.crawley@sunderland.ac.uk
Phone: 0191 5152522

If you would like to arrange a face-to-face meeting to find out more, we would be happy to arrange that.

If you are willing to help with recruitment, please contact me, Emma Jones, using the contact details shown above. I will then forward full details of the study for your consideration and we can liaise to make the necessary arrangements prior to starting group discussions/interviews in March.

I would like to take this opportunity to thank you for your time, and to stress how grateful I would be for any assistance, information or support you may be able to offer.

Yours sincerely,

Emma E. Jones

PhD Researcher
Department of Psychology
Faculty of Applied Sciences
University of Sunderland
Email: ba5ejo@research.sunderland.ac.uk
Tel: 07840372001

## Appendix B Ethical Approval Certificate (Study 1)

University of Sunderland

RESEARCH ETHICS COMMITTEE

DECISION STATEMENT

**Application Number: 236**

**Project Title: Continuing Bonds: Ritual, Meaning-making and the Therapeutic Potential of Nature Following Stillbirth**

**Chief Investigator: Ros Crawley (DoS)**

**Co workers: Emma E. Jones (PhD student), Dr Lyn Brierley-Jones, Samantha Lomax, Susan Russell**

**Date: 05-01-2015**

**YOUR RESEARCH PROJECT DECISION IS LISTED BELOW**

**APPROVED WITH NO CONDITIONS:** This means you may start the project immediately.

**PRE-CONDITIONS:** This means you must complete the conditions listed below before you start the project. However, you DO NOT have to send any information back to the Committee. The Committee will assume completion of these conditions.

Consent Form
- Include section stating that anonymized quotations may be used in publication(s) of the results

*See also recommendations below*

**COMMITTEE-CONDITIONAL:** This means you must complete the conditions listed below before you start the project. You MUST send the information requested back to the Committee before you start the project. Once the committee has received this information, it will contact you again about its decision.

**REJECTION:** This means the committee does not wish this research to commence. You should not start this research. The Research Ethics Committee will explain why it has reached this view. Please contact the Committee Chair if you have any questions.

## Appendix C Information Sheet

**Information Sheet**

**Continuing Bonds and Coping Following Stillbirth.**

You are invited to take part in this research study which I am conducting as part of my PhD, under the supervision of Dr Rosalind Crawley, who is based within the Psychology Department at the University of Sunderland.

Before you decide whether you would like to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information to find out more, and discuss it with others if you wish. My contact details are provided below if you would like to ask about anything that is not clear.

**What is this research about?**
The aim of the study is to explore whether, and how parents of stillborn babies seek to maintain bonds with their child. We are interested in how any ongoing relationship is expressed, whether it is shared with others, and whether parents feel it has helped them in any way to cope with their loss.

**Can I take part?**
You are eligible to take part in the study if you are 18 years of age or over and your baby was stillborn at 24 weeks of pregnancy or later.

**Do I have to agree to take part?**
No, it is up to you whether you take part or not. If you decide not to take part you do not have to explain why.

**Can I change my mind?**
Yes, taking part in this study is entirely voluntary. If you do take part, you are free to withdraw at any time without giving a reason.

**What does the study involve?**
If you decide to take part, you will be asked to provide some details about yourself, for example, your age, marital status, and the time since your baby/babies died. You will not have to give us any personal information that you do not feel comfortable providing. You will be given the choice of whether to participate in a group discussion with other parents of stillborn babies, or in a one-to-one interview with the researcher. You should be aware that participation in the discussion/interview will involve talking about the events following your baby's death and how you express your continuing bond with your child. The researcher will be responsible for overseeing group discussions and conducting interviews, an administrative assistant may also be present to take notes and provide general support. All interviews/discussions will be

audio-recorded. Only the researcher and supervisors will have access to these recordings which will be destroyed at the end of the study.

**What are the possible risks of taking part?**

You may find being asked to think about and discuss the events following your baby's death and your continuing bond with your child upsetting. If you feel that being asked to think and talk about these sensitive matters will cause you undue distress, we advise you not to take part.

**What are the possible benefits of taking part?**

Some parents have said that although discussing the events following their baby's death can be emotional, they have found comfort and support in sharing their stories with others, and have found benefit in knowing that by participating they may be helping to improve the support provided to other parents of stillborn babies.

**If I take part, will it be confidential?**

Yes, any information you provide will be kept confidential. You do not have to provide your real name during any group discussion. Each participant will have to provide assurances that they will keep the identities of other group members confidential, and will not disclose the nature or content of discussions to any third party. Only the researchers involved in the study will have access to your personal details. Personally identifiable information will be securely destroyed one year after the study is completed, in approximately four years' time.

**What about the results?**

These will be written up as part of my thesis and may be submitted for publication in academic journals in the future. You will be provided with a unique code when the recordings are transcribed to ensure that any quotations published will remain completely anonymous. Your personal information cannot be traced back from the results.

**What if there is a problem or I want independent advice?**

If you have a concern or questions about any aspect of this study, please contact me. If taking part in this study causes you distress or raises issues or concerns, you are advised to speak to your GP. You might also find it useful to contact one of the following organisations:

- Sands, an organisation that offers support to those whose baby dies during pregnancy or after birth: www.uk-sands.org
  helpline: 020 7436 5881 email: helpline@uk-sands.org

- Cruse Bereavement Care: www.cruse.org.uk helpline: 0844 477 9400 email: helpline@cruse.org.uk

- Samaritans: www.samaritans.org helpline: 08457 909090
  email: jo@samaritans.org

**Who has reviewed the study?**

This study has been approved by the University of Sunderland Ethics Committee. If you feel there is something wrong with the study, please contact my PhD supervisor, Dr. Rosalind Crawley (roz.crawley@sunderland.ac.uk) or the Chairperson of the University Research Ethics Committee, Dr EttaEvans (etta.evan@sunderland.ac.uk).

**I would like to take part, what do I do now?**
If you would like to take part, please complete the Consent Form enclosed and return it as an email attachment, or by using the envelope provided. The researcher will then contact you to discuss your participation.

**Contact details**
If you would like further details, if you would like to receive a copy of the study findings, or if you wish to withdraw your data, please contact me or my supervisor:

Researcher (Emma E. Jones): ba5ejo@research.sunderland.ac.uk
Supervisor (Dr. Rosalind Crawley): roz.crawley@sunderland.ac.uk

## Appendix D  Consent Form

**Continuing Bonds and Coping Following Stillbirth.**

**Consent Form**

In order to participate in this study, it is necessary that you give your informed consent. By ticking the consent box, you are indicating that you understand the nature of the study and your role as participant, and that you agree to take part in the research. Please consider the following points before proceeding.

As an informed participant of this study, I understand that:

1. My participation is voluntary and I may end my participation in the study at any time, without penalty.
2. I am aware of what my participation involves.
3. I am aware that any discussions will be audio-recorded. (Only the researcher and supervisors will have access to these recordings which will be destroyed at the end of the study.)
4. I understand that I am required to keep the identities of other participants confidential, and that the content of any discussions must not be disclosed to any third party.
5. I am aware that quotations from any discussions may be published in the researcher's thesis or in academic journals, but that these quotations will remain anonymous.
6. If I have any questions, I will contact Emma Jones or Dr. Rosalind Crawley.

**PLEASE TICK ✓ AS APPROPRIATE:**

1. **I consent to take part in this study** ☐

   **The best way to contact me is:**
   **Name:**
   **Email:**
   **Mobile phone:**
   **Postal address:**

2. **I would prefer to take part in: group discussion** ☐

   **one-to-one interview** ☐ **no preference** ☐

3. **I am happy to be contacted about possible participation in the second phase of this study, which will involve completing a series of online questionnaires** ☐

**WHEN COMPLETED PLEASE RETURN THIS FORM TO THE RESEARCHER**
**THANK YOU**

## Appendix E Personal Details Sheet

### Personal Details

***Please note:*** *These details will remain strictly confidential and will only be viewed by the study's researcher and supervisors. Personal details will be summarised when written up as part of my thesis, or for publication in academic journals in the future. However, your personal information cannot be traced back from the results. All personal data will be stored securely for the duration of the study and will be destroyed one year after the study is completed, in approximately four years' time.*

*Whilst we would appreciate you completing all 12 questions, if there are any questions which you do not feel comfortable answering, please leave them blank.*

1. **Name to be used during discussions: ………………………………………………………….**

(PLEASE TICK AS APPROPRIATE)

2. **Gender: Male** ☐ **Female** ☐

3. **Age: 18-24** ☐ **25-34** ☐ **35-44** ☐ **45-54** ☐ **55-64** ☐ **65+** ☐

4. **Marital Status:**

   **Single** ☐ **Married** ☐ **Separated or Divorced** ☐
   **Living with Partner** ☐ **Partner I don't live with** ☐ **Widowed** ☐

5. **Are you still in a relationship with your baby's other parent? Yes** ☐ **No** ☐

6. **Ethnicity:**

   **Arab** ☐

   **Asian or Asian British – Indian** ☐ **- Pakistani** ☐ **- Bangladeshi** ☐ **- Other Asian background** ☐

   **Black or Black British – Caribbean** ☐ **- African** ☐ **- Other Black background** ☐

   **Chinese** ☐

   **Mixed – White and Black Caribbean** ☐ **Mixed – White and Black African** ☐

   **Mixed – White and Asian** ☐ **Mixed – Other Mixed background** ☐

**White – British** ☐ **White – Irish** ☐ **White – Other White background** ☐

**Any other ethnic origin group** ☐ Please give details…………………………….

7. **Religion:**

   **No formal religion** ☐ **Catholic** ☐ **Church of England** ☐

   **Protestant** ☐

   **Other Christian** ☐ **Buddhist** ☐ **Hindu** ☐

   **Jewish** ☐

   **Sikh** ☐ **Other** ☐ Please give details……………………….

8. **Your highest level of educational qualification:**

   **Postgraduate university degree or postgraduate professional qualification** ☐

   **University or college degree** ☐

   **University or college qualification below a degree (e.g. HND, HNC, City and Guilds Advanced Certificate, Nursing Diploma, Primary School Teaching Diploma)** ☐

   **Upper secondary school qualification (e.g. A levels, Highers)** ☐

   **Lower secondary school qualification (e.g. O levels, CSE's, GCSE's)** ☐

   **Apprenticeship/Trade/Technical or Vocational Training** ☐

   **None of the above** ☐

9. **Gestational age of my baby/babies:**

   **…………………weeks**

   **…………………weeks**

10. **Time since my baby's/babies' death:**

   **............. years ………….. months**

   **………….. years ………….. months**

**11. My baby/babies died:**

**Before labour** ☐ **During labour** ☐

**12. My other children:**

**No other children** ☐

**One or more children** ☐

**Number of children born before my baby's/babies' death** ☐

**Number of children born after my baby's/babies' death** ☐

**Please hand/send this form back to the researcher.**

**Thank you.**

## Appendix F  Interview Schedule

Main topic:

**CONTINUING BONDS or put another way AN ONGOING RELATIONSHIP WITH YOUR BABY**

I'd like to discuss the existence of this relationship, and how you feel and express it…

Possible discussion points:

- Can you tell me about the things you do, or have done in the past, in connection with remembering or thinking about your baby?
    - In hospital –creating memories –anything else that takes place in hospital? Taking baby home? Where are these mementos/artefacts stored now? Are they accessed, how are they used more long term?
    - At home –anything displayed at home? Anything in the garden? Any other objects that help you feel connected to your baby?
    - Any places visited in remembrance or that help you feel close to your baby?
    - Anything created online? Discuss baby with anybody online?
    - Any yearly events or anything to mark anniversary?
    - Charity work, supporting others –how might these activities help you feel closer to your baby?
- What sort of support have you received? From whom? Where? When?
- Anything you would like to do that you feel might make you feel connected to your baby that you haven't done? Why haven't you felt able to do this? Any restrictions felt?
- How do you feel these activities help you stay connected or feel closer to your baby? Why is this important?
- Who participates? Are these expressions/activities shared with others? Who? When? Where?
- Does anybody feel these activities are related to how they have coped? How?
- Is this ongoing relationship understood by those around you? If not, why do you think that might be?
- Do you think the relationship/connection you have with your baby is different in any way than perhaps it might be for someone who's lost an older child or relative?
- You've made references to nature or the natural world whilst we've been talking. Has being in nature, or close to nature made you feel close to your baby in any way? If so, why do you think that is? Could you tell me more about nature and your relationship with your baby?
- Is there anything else you would like to add?

## Appendix G Debrief Sheet

# Thank you for taking part in our study

The purpose of the study is to explore how parents of stillborn babies seek to construct and maintain bonds with their child. We are interested in how parents maintain this relationship with their child e.g. through memory, rituals/activities or memorialisation, and how this relationship may be providing solace and helping them to cope. The long-term aim of the study is to provide insight into parents' enduring connection with their child which, it is hoped, will foster a more empathetic, compassionate and supportive response to parents following their loss, and could lead to recommendations being made about the inclusion of certain activities or rituals in care packages in the future.

Undoubtedly, research in this area is currently lacking. Stillbirth has historically been termed a silent loss and the intention of this study is to amplify the voice of parents and allow their experience to educate our wider society in the significant and unique issues surrounding this topic.

If you have a concern or questions about any aspect of this study, please contact me or my supervisor.

**Researcher**: Emma E. Jones Email: ba5ejo@research.sunderland.ac.uk

**Supervisor**: Dr. Rosalind Crawley, Reader in Cognitive Psychology, Department of Psychology, University of Sunderland, St. Peter's Way, Sunderland, SR6 0DD. Email: roz.crawley@sunderland.ac.uk

If taking part in this study causes you distress or raises issues or concerns, you are advised to speak to your GP. You might also find it useful to contact one of the following organisations:

- SANDS, an organisation that offers support to those whose baby dies during pregnancy or after birth: www.uk-sands.org
  helpline: 020 7436 5881 email: helpline@uk-sands.org
- Cruse Bereavement Care: www.cruse.org.uk helpline: 0844 477 9400 email: helpline@cruse.org.uk
- Samaritans: www.samaritans.org helpline: 08457 909090 email: jo@samaritans.org

## What's next?

The second phase of this study will follow up on the important themes raised by you and other parents during our recent discussions and will involve completing a series of online questionnaires. This will enable us to take a closer look at how parents cope long term following the loss of their baby, and provide insight into how the support given to parents can be improved in the future.

If you indicated on the Consent Form that you would like to take part in Phase 2 of the study, we will be contacting you soon to discuss your possible participation.

If you did not indicate on the Consent Form that you would like to take part in Phase 2 but would now like to find out more, please email me and I will send you some further information (Emma E. Jones Email: ba5ejo@research.sunderland.ac.uk).

Please be assured that making enquiries about Phase 2 of the study does not mean that you are required to participate.

## Thank you again for your time and valuable input

## Appendix H  Table Showing Participants' Details

Table H1. Participants' age, gender and time elapsed since baby's death.

| Participant identifier | Age | Gender | Time since baby's death (years:months) |
|---|---|---|---|
| 1 | 45-54 | Female | 7:06 |
| 2 | 35-44 | Female | 5:08 |
| 3 | 35-44 | Female | 6:05 |
| 4 | 25-34 | Female | 0:08 |
| 5 | 35-44 | Female | 3:10 |
| 6 | 45-54 | Male | 22:01 |
| 7 | 35-44 | Male | 4:09 |
| 8 | 35-44 | Female | 10:10 |
| 9 | 35-44 | Female | 2:07 |
| 10 | 35-44 | Female | 4:08 |
| 11 | 35-44 | Female | 13:03 |
| 12 | 35-44 | Male | 7:08 |

## Appendix I Ethical Approval Certificate (Study 2)

**University of Sunderland**

# RESEARCH ETHICS COMMITTEE DECISION STATEMENT

**Application Number: 309**

**Project Title:** Continuing Bonds: Ritual, Meaning-making and the Therapeutic Potential of Nature Following Stillbirth.

**Chief Investigator:** Dr Rosalind Crawley

**Co workers:** Dr Lyn Brierley-Jones, Dr Catherine Kenny, Samantha Lomax, Emma E. Jones (PhD Student)

**Date: 11th August 2016**

**YOUR RESEARCH PROJECT FINAL DECISION IS LISTED BELOW**

| | |
|---|---|
| **APPROVED WITH NO CONDITIONS:** This means you may start the project immediately. | ✓ |
| **PRE-CONDITIONS:** This means you must complete the conditions listed below before you start the project. However, you DO NOT have to send any information back to the Committee. The Committee will assume completion of these conditions. | |
| **COMMITTEE-CONDITIONAL:** This means you complete the conditions listed below and that you MUST send the information requested back to the Committee's officer Mrs. Michelle Marshall at ethics.review@sunderland.ac.uk. Once the committee has received this information, it will contact you again about its decision. You must await the Committee's final decision, before you start the project.<br>• | |
| **REJECTION:** This means the committee does not wish this research to commence. You should not start this research. The Research Ethics Committee will explain why it has reached this view. Please contact the Committee Chair if you have any questions. | |

Signed by the Committee Chair: Dr Etta Evans

## Appendix J  Continuing Bonds and Coping Questionnaire

### Continuing Bonds Following Stillbirth

**<u>Information Sheet</u>**

You are invited to take part in a research study that I am conducting as part of my PhD, under the supervision of Dr Rosalind Crawley. We are based in the Psychology Department at the University of Sunderland, UK.

The following information tells you more about the study. You may want to discuss it with others before deciding whether to take part.

**What is this research about?**

The aim of the study is to explore how parents of stillborn babies maintain an ongoing bond or relationship with their baby. We are interested in how any ongoing relationship is expressed, whether it is shared with others, and whether it affects the way parents think about their baby.

**Can I take part?**

You meet the study requirements for taking part if all of the following apply:

- You are over 18 years old.
- Your baby was stillborn at 24 weeks of pregnancy or later.
- Your baby died more than 1 year ago.
- You feel you have an ongoing relationship with your baby.

**Do I have to take part?**

No, it is up to you whether you take part. If you decide not to, you do not have to explain why.

**Can I change my mind?**

Yes, taking part in this study is entirely voluntary. If you do take part, you are free to leave the study at any time without giving a reason. You can close your web browser at any time during the questionnaire to indicate that you wish to end your participation, any information collected up to that point will not be included in the study, and will be securely deleted. If you complete and submit the questionnaire but wish to withdraw from the study at a later date, please contact me, Emma Jones (ba5ejo@research.sunderland.ac.uk).

**What does the study involve?**

If you decide to take part, you will be asked to fill in a questionnaire. The first section of the questionnaire will ask you for some details about yourself and your baby, for example, your age, marital status, and how long ago your baby died. You will not have to give us any personal information that you do not feel comfortable providing, and we will not ask you for your name, so any information you do provide will remain completely anonymous.

The other sections of the questionnaire will include questions about events relating to your baby's death, how you express your ongoing bond with your baby, and about your feelings since your baby died.

The questionnaire takes around 40 minutes to complete.

Some sections of the questionnaire are not 'mobile-friendly'. We would advise you to access the questionnaire using your personal computer. If you close your web browser before completing the questionnaire, your answers will be automatically saved. You can return to the questionnaire at a later date to complete it providing:

- You use the same computer.
- You do not delete your cookies or internet browsing history.

**What are the possible risks of taking part?**

Thinking about the events relating to your baby's death and your continuing bond with your baby may be upsetting. We advise you not to take part if this could cause you undue distress.

**What are the possible benefits of taking part?**

Some parents have said that although thinking about events relating to their baby's death can be emotional, they have found comfort and support in sharing their stories with others, and have found benefit in knowing that by participating they may be helping to improve the support provided to other parents of stillborn babies. We hope that the study's findings will lead to recommendations being made about the inclusion of certain activities or rituals in care packages in the future.

**If I take part, will my information be confidential?**

Yes, any information you provide will be kept confidential and stored securely. Only the researchers involved in the study will have access to the responses you provide, and this information will be securely destroyed 1 year after the study is completed, in approximately 3 years' time.

**What will happen with the study results?**

These will be written up as part of my PhD thesis and may be published in academic journals or presented at conferences. Results will be completely anonymised. No individual personal information will be reported, so it will not be possible to trace results back to participants. If you would like a summary of the study's results, please contact me, Emma Jones

(ba5ejo@research.sunderland.ac.uk), and this will be emailed to you when we have completed the study.

**What if there is a problem or I want independent support?**

If you have a concern or questions about any aspect of this study, please contact me or my supervisor. If taking part in this study causes you distress or raises issues or concerns, you are advised to speak to your doctor. You might also find it useful to contact one of the following organisations:

- Sands, an organisation that offers support to those whose baby dies before, during, or after birth: www.uk-sands.org helpline: +44 020 7436 5881 email: helpline@uk-sands.org

- MISSFoundation, an international organisation providing support services to families experiencing the death of a child: www.missfoundation.org email: info@missfoundation.org

- Cruse Bereavement Care: www.cruse.org.uk helpline: +44 0844 477 9400 email: helpline@cruse.org.uk

**Who has reviewed the study?**

This study has been approved by the University of Sunderland Ethics Committee. If you feel that certain aspects have not been considered fully, please contact my PhD supervisor, Dr. Rosalind Crawley (roz.crawley@sunderland.ac.uk) or the Chairperson of the University Research Ethics Committee, Dr Etta Evans (etta.evans@sunderland.ac.uk).

**I would like to take part, what do I do now?**

If you would like to take part, please provide your consent below by ticking the box, you will then be directed to the questionnaire to complete.

**Contact details**

Please get in touch with me if you have any questions about the study. If you have any concerns about the study, please contact my supervisor.

Researcher (Emma E. Jones): ba5ejo@research.sunderland.ac.uk

Supervisor (Dr. Rosalind Crawley): roz.crawley@sunderland.ac.uk

## Consent

In order to take part in this study, you need to give your informed consent. By ticking the consent box, you are confirming that you understand what your role as participant involves, and that you agree to take part in the research. Please consider the following points before proceeding.

As an informed participant of this study, I understand that:

1. My participation is voluntary and I may leave the study at any time without having to provide a reason.
2. I will complete a questionnaire as part of the study that will ask about events relating to my baby's death, and my ongoing relationship with my baby.
3. If I have any questions, I can contact Emma Jones or Dr. Rosalind Crawley.

**PLEASE TICK IN THE BOX BELOW TO PROVIDE YOUR CONSENT:**

**I consent to take part in this study** ☐

**PLEASE PROVIDE A CODE NAME IN THE BOX BELOW.** This does not need to be your real name. The code name should be at least 10 characters long and be a combination of letters, numbers and special characters. Please remember this code name as you will need to provide it should you wish to withdraw your responses.

| **Code name:** |
|---|

## Continuing Bonds Questionnaire

## Section 1

**This section is about you and your baby's birth.**

***Please note:*** *These details will remain strictly confidential and will only be viewed by the study's researcher and supervisor. Personal details will be summarised when written up as part of my PhD thesis, and may be recorded in academic journals and conferences in the future. However, your personal information remains anonymous and cannot be traced back from the results. All personal data will be stored securely for the duration of the study and will be destroyed 1 year after the study is completed, in approximately 3 years' time.*

*While we would like you to complete all questions, if there are any questions in Section 1 which you do not feel comfortable answering, please choose the response 'PNA' for Prefer Not to Answer.*

### 1A - About you:

**Age**: (state) PNA

**Gender**: Male Female PNA

**Education**:

Left school before 16 yrs - Left school at 16 yrs - Left school at 17-18 yrs - Degree or further education - Higher Degree or Postgraduate/Professional qualification - PNA

**Marital Status**:

Single – Married – Partner I live with – Partner I don't live with – Separated or Divorced – Widowed - PNA

**Are you still in a relationship with your baby's other parent?** Yes – No - PNA

**Country of residence at the time of your baby's birth**: (state) PNA

**My first language is**: English – Other (state) PNA

**I would describe my ethnic origin as**: (state) PNA

**Religious or Spiritual Orientation**:

No religious or spiritual belief – Catholic – Church of England – Other Christian – Buddhist – Hindu – Sikh – Other formal religion (state) – Other spiritual belief but not an organised religion (please give details) - PNA

**Number of children born before your baby's birth**: (state) PNA

**Number of children born after your baby's birth:** (state) PNA

**If there are any other personal details you feel are relevant, please provide them in the box below.**

## 1B - About your baby's birth:

**Age of baby at birth**: (in weeks) PNA

**Place of birth**: Home – Birth Centre or Midwife-Led Unit – Hospital – Other (state) - PNA

**My baby died**: Before labour –During labour –Not known - PNA

**Time since my baby died**: years months PNA

**Were you given a reason/cause for your baby's death by a health professional?** Yes – No - PNA

**If Yes, please tell us the reason/cause:**

**Were you offered a post mortem?** Yes – No - PNA

**If yes, did you consent to a post mortem?** Yes - No - PNA

**My baby was:** A Single Baby - One of Twins - One of a Multiple Birth - PNA

**Have you experienced more than one stillbirth?** Yes - No - PNA

**If there are any further details about your baby's birth you feel are relevant, or you have experienced more than one stillbirth, please provide this information in the box below.**

| |
|---|
| |

## Section 2A

**This section is about the relationship you have with your baby. Please read each statement, and tell us how much you agree or disagree with it.**

| Item | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Attachment** | | | | | | | |
| I felt attached to my baby before he/she was born | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I felt attached to my baby immediately after he/she was born | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel attached to my baby now | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **Coping** | | | | | | | |
| The ongoing relationship I have with my baby has brought me comfort | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| The ongoing relationship I have with my baby has helped me through the bereavement | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **Time** | | | | | | | |
| The relationship I have with my baby has changed over time | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| The relationship I have with my baby has become stronger over time | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|
| The relationship I have with my baby has become weaker over time | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **Continued Parenting** | | | | | | | |
| I feel an ongoing responsibility toward my baby | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I want to protect my baby's memory | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **Mental Representations** | | | | | | | |
| When I think about my baby now, he/she is as I remember him/her, I still think of him/her as a baby | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| When I think about my baby now, I think of him/her at the age he/she would have been if he/she was alive | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| The mental images I have of my baby have changed over time | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **Integration** | | | | | | | |
| My baby feels part of me | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| My baby feels part of my everyday life | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|
| My baby feels part of our family | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I expect to have an ongoing relationship with my baby for the rest of my life | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

**If you would like to provide any further details about the relationship you have with your baby, please do so in the box below.**

| |
|---|

## Section 2B

**This section is about some of the things you may have done to feel connected to your baby, and how you might have shared your experiences with others.**

**For each of the activities and experiences listed below, we would like you to tell us how often you did this in the first year after your baby died, and how often you have done this in the last 12 months. Please also tell us how you have shared these activities and experiences. Answer N/A for not applicable if you feel an activity or experience does not apply to you. For example, you might answer N/A to the first question because you don't have any photographs of your baby.**

| Item | **In the first year I did this:** | **In the last 12 months I have done this:** | **I have wanted to share this with others** | **I have physically shared this with others (e.g. others were present, or participated or I have shown them objects relating to my baby)** | **I have shared this with others by telling them about it** | **I have tried sharing this with others and some people have responded in a negative way** | **I have held back from sharing this with others in case they responded in a negative way** |
|---|---|---|---|---|---|---|---|
| **Physical Reminders** | | | | | | | |

| Displayed or looked at photos of my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
|---|---|---|---|---|---|---|---|
| Looked at a memory box | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Collected objects that made me think about my baby (e.g. leaves, angels) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Bought or made gifts for my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Carried or worn something I associated with my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Memorialisation** | | | | | | | |
| Visited somewhere in honour of my baby (e.g. altar or memorial garden) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Dedicated something in my baby's honour (e.g. named a star; planted a tree; plaque) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Lit candles or lanterns in remembrance of my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Marked my baby's birthday or other special occasions (e.g. bought cards/presents or had a meal out) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Visited my baby's grave or the site of my baby's ashes | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Attended a memorial service or other remembrance event in memory of my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Symbolism** | | | | | | | |

| Associated certain symbols with my baby (e.g. colours, animals) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
|---|---|---|---|---|---|---|---|
| **Legacy Building** | | | | | | | |
| Done something positive in my baby's honour (e.g. fundraising) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Actively helped other parents affected by stillbirth (e.g. started a support group, acted as a befriender, campaigned for change to care) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Tried new experiences on behalf of my baby (e.g. visited new places) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Communication** | | | | | | | |
| Talked to my baby either in my head or out loud | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Writing** | | | | | | | |
| Written directly to my baby (e.g. a poem, letter) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Written about my baby (e.g. poem, diary, journal) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Sense of Presence** | | | | | | | |
| Had a sensory experience that made me feel my baby's presence (e.g. saw, heard, smelt or felt touch) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Sensed the presence of my baby in another way (e.g. seeing something you associate with your baby like a butterfly landing on you, or seeing a white feather) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |

| Communicated with my baby through a spiritualist | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
|---|---|---|---|---|---|---|---|
| **Mental Representations** | | | | | | | |
| Thought about my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Thought about the time I had with my baby | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Thought about what my baby would be doing now if he/she was alive | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Emotion** | | | | | | | |
| Felt an emotional attachment to my baby (e.g. love or pride) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| **Nature** | | | | | | | |
| Actively engaged with nature or the natural world in some way that made me feel connected to my baby (e.g. visiting a garden; planting flowers/trees; watching a sunrise) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Actively engaged with nature or the natural world in some way that helped me (e.g. walking in nature; being beside the sea) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |
| Associated a symbol from the natural world with my baby (e.g. an animal or flower) | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A | Never-Once-Occasionally-Frequently-N/A |

***NB: Participants who give a positive response to any of the Nature items in section 2B will see the following message inviting them to answer a further 10 open-ended questions relating to nature (EXTERNAL STUDY):***

| As you have told us that engaging with nature has made you feel connected to your baby, or helped you in some way, we would like you to tell us a bit more about your experiences in your own words. If you would be willing to answer a further 10 questions about nature, please provide your email address here and we will send you the necessary information. Thank you. |
|---|

**If there is anything else you have done, or experienced, that has made you feel closer to your baby that is not listed above, please tell us about this below and confirm how often you have done or experienced this since your baby died:**

| Item<br><br>**Please state what you have done or experienced below:** | **In the first year I did this** | **In the last 12 months I have done this** | **I have wanted to share this with others** | **I have physically shared this with others (e.g. others were present, participated or I have shown them objects relating to my baby).** | **I have shared with others by telling them about it** | **I have tried sharing this with others and some people have responded in a negative way** | **I have held back from sharing this with others in case they responded in a negative way** |
|---|---|---|---|---|---|---|---|
| | Never-<br>Once-<br>Occasionally-<br>Frequently-<br>N/A | Never-<br>Once-<br>Occasionally-<br>Frequently-<br>N/A | Never-<br>Once-<br>Occasionally-<br>Frequently-<br>N/A | Never-<br>Once-<br>Occasionally<br>-Frequently-<br>N/A | Never-<br>Once-<br>Occasionally<br>-Frequently-<br>N/A | Never-<br>Once-<br>Occasionally<br>-Frequently-<br>N/A | Never-<br>Once-<br>Occasionally<br>-Frequently-<br>N/A |

**If you would like to provide any further details about the things you have done or experienced that have made you feel closer to your baby, and your experience of sharing with others, please do so in the box below.**

## Section 3

**This section is about how you feel about sharing your relationship with your baby with others.**

**Please read each statement below, and tell us how much you agree or disagree with it in relation to your partner, family, friends, and people outside of your family and friends, e.g. colleagues or society in general. If you don't feel an item is relevant to you, for example, you don't have a partner, then please answer N/A for not applicable.**

| Item | | | | | | | | |
|---|---|---|---|---|---|---|---|---|

| PARTNER | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| My partner understands and supports my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel comfortable talking to my partner about my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel less comfortable talking to my partner about my ongoing relationship with my baby as time goes on | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationship with my partner hasn't changed since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationship with my partner has become stronger since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationship with my partner has | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| become difficult or ended since my baby died | | | | | | | | |
| I have felt pressure from my partner to 'move on' | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my partner thinks my ongoing relationship with my baby is a positive thing | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **FAMILY** | | | | | | | | |
| Overall, my family understand and support my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Some of my family members do not understand and support my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel comfortable talking to my family about my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| I feel less comfortable talking to my family about my ongoing relationship with my baby as time goes on | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|---|
| Overall, my relationships with family members haven't changed since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationships with family members have become stronger since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationships with family members have become difficult or ended since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I have felt pressure from my family to 'move on' | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my family think my ongoing relationship with my baby is a positive thing | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **FRIENDS** | | | | | | | | |
| Overall, my friends understand and support my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Some of my friends do not understand and support my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel comfortable talking to my friends about my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel less comfortable talking to my friends about my ongoing relationship with my baby as time goes on | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationships with my friends haven't changed since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationships with my | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| friends have become stronger since my baby died | | | | | | | | |
| Overall, my relationships with my friends have become difficult or ended since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I have felt pressure from my friends to 'move on' | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my friends think my ongoing relationship with my baby is a positive thing | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **OUTSIDE** | | | | | | | | |
| Overall, people outside of my friends and family understand and support my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Some people outside of my family and friends do not understand and support my ongoing | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| relationship with my baby | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| I feel comfortable talking to people outside of my family and friends about my ongoing relationship with my baby | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel less comfortable talking to people outside of my family and friends about my ongoing relationship with my baby as time goes on | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationships with people outside of my family and friends haven't changed since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, my relationships with people outside of my family and friends have become stronger since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| Overall, my relationships with people outside of my family and friends have become difficult or ended since my baby died | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|---|
| I have felt pressure from people outside of my family and friends to 'move on' | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| Overall, people outside of my family and friends think my ongoing relationship with my baby is a positive thing | N/A | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| | | | | | | | | |

| I have avoided talking about my relationship with my baby with some people in case they reacted in a negative way | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|
| Most of my friends now are other | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| bereaved parents | | | | | | | |
|---|---|---|---|---|---|---|---|
| I share my ongoing relationship with my baby mostly with other bereaved parents | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I would like to talk about my ongoing relationship with my baby more freely with others | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I share my ongoing relationship with my baby with others online (e.g. in forums) | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel society understands and supports my ongoing relationship with my baby | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| I feel pressure from society to 'move on' | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

**If you would like to provide any further details about how you feel about sharing your relationship with your baby with others, please do so in the box below.**

## Section 4

**This section is about some of the things you may have done since your baby's death.**

**Please read each statement below, and tell us how much you agree or disagree with it.**

| Item | | | | | | | |
|---|---|---|---|---|---|---|---|
| **I have tried to look for answers as to why my baby died** | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

| Item | | | | | | | |
|---|---|---|---|---|---|---|---|
| **I have been able to make some sense of my loss** | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

**If you feel you have been able to make some sense of your loss, please explain how you feel you have done this in the box below.**

| |
|---|
| |

| Item | | | | | | | |
|---|---|---|---|---|---|---|---|
| **As a result of my experience, there have been changes to aspects of my life that I see as positive** | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

**If you feel there have been changes to aspects of your life that you're thankful for, please tell us about this in the box below.**

| |
|---|
| |

| Item | | | | | | | |
|---|---|---|---|---|---|---|---|
| **I feel I have changed as a person as a result of my experience** | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |
| **I feel like I am a better person as a result of my experience** | Strongly Agree | Agree | Slightly Agree | Neither Agree nor Disagree | Slightly Disagree | Disagree | Strongly Disagree |

**If you would like to provide any further details about who you are as a person following the death of your baby, please do so in the box below.**

| |
|---|
| |

## Section 5A

**This section is about how you feel about your life.**

**For each of the statements below, please choose the response that best reflects how you have felt DURING THE PAST MONTH.**

**I still enjoy the things I used to enjoy**
Definitely as much
Not quite so much
Only a little
Hardly at all

**I can laugh and see the funny side of things**
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

**I feel cheerful**
Not at all
Not often
Sometimes
Most of the time

**I feel as if I am slowed down**
Nearly all the time
Very often
Sometimes
Not at all

**I have lost interest in my appearance**
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

**I look forward with enjoyment to things**
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

**I can enjoy a good book, radio or television programme**
Often
Sometimes
Not often
Very seldom

**I feel tense or wound up**
Most of the time
A lot of the time
From time to time, occasionally
Not at all

**I get a sort of frightened feeling as if something awful is about to happen**
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

**Worrying thoughts go through my mind**
A great deal of the time
A lot of the time
From time to time, but not too often
Not at all

**I can sit at ease and feel relaxed**
Definitely
Usually
Not often
Not at all

**I get a sort of frightened feeling like butterflies in the stomach**
Not at all
Occasionally
Quite often
Very often

**I feel restless as if I have to be on the move**
Very much indeed
Quite a lot
Not very much
Not at all

**I get sudden feelings of panic**
Very often indeed
Quite often
Not very often
Not at all

## Section 5B

**Below is a list of things people sometimes experience after major life events. Please read each item, and then tell us how much you have been affected by these things DURING THE PAST MONTH with respect to your baby's death.**

| Item | | | | | |
|---|---|---|---|---|---|
| **Any reminder brought back feelings about it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I had trouble staying asleep.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **Other things kept making me think about it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I felt irritable and angry**. | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I avoided letting myself get upset when I thought about it or was reminded of it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I thought about it when I didn't mean to.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |

| | | | | | |
|---|---|---|---|---|---|
| **I felt as if it hadn't happened or wasn't real.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I stayed away from reminders of it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **Pictures about it popped into my mind.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I was jumpy and easily startled.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I tried not to think about it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I was aware that I still had a lot of feelings about it, but I didn't deal with them.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **My feelings about it were kind of numb.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I found myself acting or feeling like I was back at that time.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I had trouble falling asleep.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I had waves of strong feelings about it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I tried to remove it** | Not at all | A little bit | Moderately | Quite a bit | Extremely |

| | | | | | |
|---|---|---|---|---|---|
| **from my memory.** | | | | | |
| **I had trouble concentrating.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I had dreams about it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I felt watchful and on-guard.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |
| **I tried not to talk about it.** | Not at all | A little bit | Moderately | Quite a bit | Extremely |

## Section 5C

**For each of the statements below, please tell us the degree to which you have experienced a change in that aspect of your life as a result of your baby's death.**

| Item | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | |
| **Knowing that I can count on people.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **A sense of closeness with others.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **A willingness to express my emotions in** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |

| | | | | | | |
|---|---|---|---|---|---|---|
| **times of trouble.** | | | | | | |
| **Having compassion for others.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **Putting effort into my relationships.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I learned a great deal about how wonderful people are.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I accept needing others.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| | | | | | | |
| **I developed new interests.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I established a new path for my life.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I'm able to do better things with my life.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **New opportunities are available which wouldn't have been otherwise.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I'm more likely to try to change things which need changing.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| | | | | | | |
| **A feeling of self-reliance.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |

| **Knowing I *can* handle difficulties.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
|---|---|---|---|---|---|---|
| **Being able to accept the way things work out.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I discovered that I'm stronger than I thought I was.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| | | | | | | |
| **A better understanding of spiritual matters.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **I have a stronger religious faith.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| | | | | | | |
| **My priorities about what is important in life.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **An appreciation for the value of my own life.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |
| **Appreciating each day.** | No change | Changed to a very small degree | Changed to a small degree | Changed to a moderate degree | Changed to a great degree | Changed to a very great degree |

University of Sunderland

## Thank you for taking part in our study

## Your contribution to our research is highly valued

The purpose of the study is to explore how parents of stillborn babies seek to build and maintain bonds with their baby. We are interested in how parents maintain this relationship, and how it might be providing solace and help. The long-term aim of the study is to provide insight into parents' ongoing connection with their baby which, it is hoped, will foster a more empathetic, compassionate and supportive response to parents following their loss, and could lead to recommendations being made about the inclusion of certain activities or rituals in care packages in the future.

**Please note:** If taking part in this study has caused you distress or has raised issues or concerns, you are advised to speak to your doctor. You might also find it helpful to contact one of the following organisations:

- Sands, an organisation that offers support to those whose baby dies before, during, or after birth: www.uk-sands.org helpline: +44 020 7436 5881 email: helpline@uk-sands.org

- MISSFoundation, an international organisation providing support services to families experiencing the death of a child: www.missfoundation.org email: info@missfoundation.org

- Cruse Bereavement Care: www.cruse.org.uk helpline: +44 0844 477 9400 email: helpline@cruse.org.uk

## Appendix K Breakdown of Data Showing Parents' Engagement in Continuing Bonds Expressions Over Time

Table K1. Percentage of parents engaging in continuing bonds expressions and frequency over time.

| | | 1st Yr | | | Last Yr | | |
|---|---|---|---|---|---|---|---|
| | | Once | Occ | Freq | Once | Occ | Freq |
| Physical Reminders | Displayed or looked at photos of baby | 1.8 | 16.5 | 75.9 | 5.3 | 30.0 | 54.1 |
| | Looked at a memory box | 7.6 | 28.8 | 56.5 | 21.2 | 49.4 | 11.2 |
| | Collected objects that made me think about baby | 4.1 | 31.8 | 40.6 | 10.6 | 35.9 | 26.5 |
| | Bought or made gifts for baby | 4.1 | 32.4 | 34.7 | 12.4 | 34.7 | 18.8 |
| | Carried or worn something associated with baby | 1.8 | 15.9 | 62.9 | 3.5 | 22.4 | 49.4 |
| Memorialisation | Visited somewhere in honour of baby | 5.9 | 21.2 | 57.1 | 10.0 | 35.3 | 32.9 |
| | Dedicated something in baby's honour | 27.6 | 18.8 | 20.0 | 15.9 | 18.2 | 11.2 |
| | Lit candles or lanterns in remembrance of baby | 6.5 | 32.9 | 51.8 | 12.9 | 42.4 | 32.4 |
| | Marked baby's birthday or other special occasions | 17.6 | 11.8 | 60.6 | 18.8 | 17.1 | 54.1 |
| | Visited baby's grave/site of ashes | 3.5 | 10.6 | 64.1 | 7.1 | 27.1 | 41.2 |
| | Attended memorial service or other remembrance event in memory of baby | 33.5 | 18.2 | 18.8 | 23.5 | 19.4 | 8.2 |
| Symbolism | Associated certain symbols with baby | 1.8 | 20.0 | 54.1 | 1.8 | 31.8 | 41.2 |
| Legacy Building | Done something positive in baby's honour | 23.5 | 22.9 | 21.8 | 26.5 | 21.8 | 15.9 |
| | Actively helped other parents affected by stillbirth | 8.8 | 20.6 | 18.8 | 8.8 | 20.0 | 23.5 |
| | Tried new experiences on behalf of baby | 8.2 | 19.4 | 7.1 | 6.5 | 19.4 | 4.1 |
| Communication | Talked to baby either in my head or out loud | 0.6 | 17.6 | 75.3 | 4.1 | 37.1 | 50.0 |
| Writing | Written directly to baby | 16.5 | 17.6 | 23.5 | 9.4 | 18.8 | 4.1 |
| | Written about baby | 9.4 | 21.2 | 34.1 | 7.6 | 27.1 | 8.8 |

| | | 1st Yr | | | Last Yr | | |
|---|---|---|---|---|---|---|---|
| | | Once | Occ | Freq | Once | Occ | Freq |
| Sense of Presence | Had a sensory experience that made me feel baby's presence | 6.5 | 27.6 | 21.8 | 7.1 | 27.1 | 9.4 |
| | Sensed the presence of baby in another way | 7.6 | 22.9 | 37.6 | 7.1 | 35.3 | 24.7 |
| | Communicated with baby through a spiritualist | 6.5 | 3.5 | 1.8 | 6.5 | 2.4 | 1.2 |
| Mental Representations | Thought about baby | 0.0 | 1.8 | 98.2 | 0.0 | 9.4 | 90.6 |
| | Thought about the time I had with baby | 0.6 | 5.9 | 92.9 | 2.3 | 21.8 | 75.3 |
| | Thought about what baby would be doing if he/she was alive | 0.0 | 7.6 | 92.4 | 1.8 | 22.3 | 75.9 |
| Emotion | Felt an emotional attachment to baby | 0.6 | 4.7 | 94.1 | 0.6 | 7.6 | 90.6 |
| Nature | Engaged with nature in some way that made me feel connected to baby | 8.2 | 26.5 | 36.5 | 7.6 | 33.5 | 25.9 |
| | Engaged with nature in some way that helped me | 2.4 | 29.4 | 41.2 | 5.3 | 35.9 | 32.9 |
| | Associated a symbol from nature with baby | 4.7 | 15.9 | 46.5 | 3.5 | 21.2 | 41.2 |

Notes. 1st Yr = the first year following baby's death; Last Yr = the last 12 months; Occ = Occasionally; Freq = Frequently. Data for participants who responded Never or Not Applicable are not shown.

## Appendix L Breakdown of Data Showing Parents' Sharing Behaviours Over Time

Table L1. Percentage of parents who wanted to share and shared continuing bonds expressions and the frequency with which they did so.

| | | Wanted to Share | | | Shared Physically | | | Shared by Telling | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Once | Occ | Freq | Once | Occ | Freq | Once | Occ | Freq |
| Physical | Displayed or looked at photos of baby | 6.1 | 51.8 | 31.7 | 10.9 | 55.8 | 21.2 | 3.6 | 47.3 | 32.7 |
| | Looked at a memory box | 13.2 | 43.4 | 8.2 | 18.6 | 35.4 | 4.3 | 7.5 | 50.3 | 10.7 |
| | Collected objects that made me think about baby | 5.6 | 41.9 | 20.0 | 5.7 | 45.9 | 15.1 | 4.4 | 48.1 | 13.9 |
| | Bought or made gifts for baby | 5.8 | 36.8 | 20.6 | 9.2 | 37.9 | 15.7 | 5.3 | 46.0 | 16.0 |
| | Carried or worn something associated with baby | 2.5 | 39.9 | 27.2 | 3.9 | 47.1 | 20.0 | 4.5 | 43.3 | 22.3 |
| Memorial | Visited somewhere in honour of baby | 5.7 | 57.9 | 17.0 | 6.4 | 58.6 | 10.2 | 5.6 | 55.6 | 20.0 |
| | Dedicated something in baby's honour | 12.9 | 40.8 | 15.0 | 13.8 | 37.2 | 13.8 | 11.4 | 41.6 | 14.8 |
| | Lit candles or lanterns in remembrance of baby | 5.5 | 51.8 | 25.0 | 11.1 | 49.4 | 17.9 | 9.3 | 51.2 | 17.9 |
| | Marked baby's birthday or other special occasions | 6.7 | 38.4 | 40.2 | 10.5 | 38.3 | 32.7 | 5.5 | 43.3 | 33.5 |
| | Visited baby's grave/site of ashes | 4.2 | 54.2 | 20.1 | 6.9 | 54.5 | 15.2 | 4.3 | 58.9 | 16.3 |
| | Attended memorial service or similar | 16.2 | 37.3 | 10.6 | 21.7 | 33.6 | 4.9 | 15.0 | 37.9 | 7.9 |
| Symbolism | Associated certain symbols with baby | 4.5 | 35.5 | 25.8 | 4.6 | 35.5 | 18.4 | 6.5 | 38.1 | 18.7 |
| Legacy | Done something positive in baby's honour | 13.3 | 31.3 | 31.3 | 14.0 | 29.4 | 25.2 | 15.6 | 30.6 | 29.3 |
| | Actively helped other parents affected by stillbirth | 3.1 | 29.5 | 29.5 | 4.7 | 24.4 | 25.2 | 3.8 | 33.6 | 25.2 |
| | Tried new experiences on behalf of baby | 3.1 | 24.4 | 5.5 | 1.6 | 26.0 | 1.6 | 2.4 | 29.0 | 3.2 |
| Comm | Talked to baby either in my head or out loud | 3.7 | 26.3 | 7.4 | 5.2 | 19.6 | 4.6 | 7.5 | 24.8 | 6.2 |

| | | Wanted to Share | | | Shared Physically | | | Shared by Telling | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Once | Occ | Freq | Once | Occ | Freq | Once | Occ | Freq |
| Writing | Written directly to baby | 12.5 | 17.4 | 5.6 | 13.4 | 14.9 | 2.2 | 10.1 | 22.5 | 2.9 |
| | Written about baby | 11.5 | 26.4 | 12.2 | 9.4 | 23.0 | 5.8 | 13.4 | 26.8 | 7.7 |
| SoP | Had a sensory experience that made me feel baby's presence | 13.4 | 29.1 | 4.5 | 7.1 | 30.2 | 2.4 | 9.9 | 29.8 | 6.1 |
| | Sensed the presence of baby in another way | 6.1 | 38.8 | 12.9 | 5.7 | 32.9 | 10.0 | 4.9 | 38.2 | 12.5 |
| | Communicated with baby through a spiritualist | 3.8 | 13.5 | 5.8 | 6.1 | 11.2 | 4.1 | 6.2 | 13.4 | 4.1 |
| Mental | Thought about baby | 2.5 | 44.8 | 42.3 | 4.0 | 53.0 | 21.5 | 3.8 | 55.0 | 24.4 |
| | Thought about the time I had with baby | 3.1 | 45.4 | 35.0 | 3.4 | 52.4 | 15.9 | 3.8 | 59.7 | 15.7 |
| | Thought about what baby would be doing if he/she still alive | 4.2 | 44.2 | 34.5 | 3.4 | 48.3 | 16.3 | 6.2 | 52.8 | 16.1 |
| Emotion | Felt emotional attachment to baby | 2.4 | 30.5 | 54.2 | 4.7 | 44.3 | 28.9 | 5.5 | 45.4 | 30.1 |
| Nature | Engaged with nature in some way that made me feel connected to baby | 6.9 | 45.1 | 11.8 | 7.9 | 44.3 | 6.4 | 5.6 | 45.8 | 6.9 |
| | Engaged with nature in some way that helped me | 5.3 | 41.7 | 13.2 | 6.8 | 38.8 | 8.8 | 4.7 | 40.3 | 7.4 |
| | Associated a symbol from nature with baby | 1.4 | 37.9 | 17.9 | 5.0 | 34.5 | 14.4 | 2.8 | 38.0 | 14.8 |

Notes. Occ = Occasionally; Freq = Frequently. Data for participants who responded Never or Not Applicable are not shown.

Table L2. Percentage of parents who shared expressions and had a negative response and who held back from sharing to avoid a negative response, and the frequency of these behaviours.

| | | Tried sharing and had negative response | | | Held back from sharing to avoid negative response | | |
|---|---|---|---|---|---|---|---|
| | | Once | Occ | Freq | Once | Occ | Freq |
| Physical | Displayed or looked at photos of baby | 13.9 | 23.4 | 0.6 | 3.8 | 39.6 | 23.3 |
| | Looked at a memory box | 7.4 | 4.1 | 0.0 | 5.4 | 24.5 | 14.3 |
| | Collected objects that made me think about baby | 6.5 | 11.0 | 0.0 | 4.0 | 27.2 | 7.9 |
| | Bought or made gifts for baby | 4.8 | 9.0 | 0.7 | 2.8 | 22.9 | 6.9 |
| | Carried or worn something associated with baby | 7.3 | 5.3 | 0.7 | 5.4 | 22.3 | 8.8 |
| Memorial | Visited somewhere in honour of baby | 5.9 | 11.1 | 0.7 | 5.4 | 25.5 | 7.4 |
| | Dedicated something in baby's honour | 7.2 | 5.8 | 0.7 | 5.0 | 18.6 | 5.0 |
| | Lit candles or lanterns in remembrance of baby | 5.8 | 7.8 | 1.3 | 1.9 | 20.5 | 6.4 |
| | Marked baby's birthday or other special occasions | 6.4 | 10.2 | 1.9 | 2.6 | 25.8 | 6.5 |
| | Visited baby's grave/site of ashes | 7.4 | 9.6 | 1.5 | 3.7 | 20.1 | 7.5 |
| | Attended memorial service or similar | 4.6 | 8.4 | 1.5 | 3.8 | 18.9 | 5.3 |
| Symbolism | Associated certain symbols with baby | 7.5 | 8.2 | 0.0 | 0.7 | 21.1 | 6.8 |
| Legacy | Done something positive in baby's honour | 3.6 | 11.7 | 0.7 | 3.7 | 17.9 | 5.2 |
| | Actively helped other parents affected by stillbirth | 4.1 | 13.1 | 0.8 | 2.5 | 18.0 | 5.7 |
| | Tried new experiences on behalf of baby | 0.8 | 5.0 | 0.0 | 0.9 | 10.3 | 1.7 |
| Comm | Talked to baby either in my head or out loud | 4.7 | 4.0 | 0.0 | 0.7 | 14.7 | 18.7 |
| Writing | Written directly to baby | 1.5 | 1.5 | 0.0 | 0.7 | 11.6 | 8.7 |
| | Written about baby | 0.0 | 3.6 | 0.7 | 1.5 | 15.3 | 5.1 |

| | | Tried sharing and had negative response | | | Held back from sharing to avoid negative response | | |
|---|---|---|---|---|---|---|---|
| | | Once | Occ | Freq | Once | Occ | Freq |
| SoP | Had a sensory experience that made me feel baby's presence | 3.1 | 4.7 | 1.6 | 1.6 | 16.3 | 14.0 |
| | Sensed the presence of baby in another way | 1.5 | 5.2 | 1.5 | 2.2 | 19.1 | 8.1 |
| | Communicated with baby through a spiritualist | 2.2 | 4.3 | 1.1 | 2.2 | 10.1 | 2.2 |
| Mental | Thought about baby | 6.0 | 17.2 | 1.3 | 2.6 | 29.4 | 15.0 |
| | Thought about the time I had with baby | 8.1 | 10.8 | 0.7 | 3.3 | 25.8 | 13.2 |
| | Thought about what baby would be doing if he/she still alive | 5.4 | 12.8 | 1.3 | 2.0 | 26.5 | 15.2 |
| Emotion | Felt emotional attachment to baby | 5.3 | 15.1 | 0.7 | 2.6 | 25.0 | 12.8 |
| Nature | Engaged with nature in some way that made me feel connected to baby | 1.5 | 5.2 | 0.0 | 2.2 | 16.1 | 5.8 |
| | Engaged with nature in some way that helped me | 1.4 | 5.0 | 0.0 | 1.4 | 16.7 | 5.6 |
| | Associated a symbol from nature with baby | 1.5 | 5.8 | 0.0 | 0.0 | 17.9 | 4.3 |

Notes. Occ = Occasionally; Freq = Frequently. Data for participants who responded Never or Not Applicable are not shown.