Bereaved parents' experiences of post-traumatic growth

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Word count: 20715

Introductory chapter: Thesis overview

Word count: 593

Orientation to the area of study

The death of a child is frequently experienced as traumatic and has the potential to lead to many negative outcomes for parents (e.g. Baddenhorst & Hughes, 2007). Tedeschi and Calhoun (2006) propose that the death of a child poses many psychological challenges, because it is a death which is viewed as ‘unnatural’, i.e. not in the natural order of the world. Tedeschi and Calhoun (2006) suggest that the death of a child can often lead to both greater levels of distress, and eventually personal growth.

Post-traumatic growth refers to positive personal changes in the domains of self-perception, relationships and life philosophy, which are proposed to occur from the struggle to cope with a traumatic event (Tedeschi & Calhoun, 1995). Bonanno (2004) reported that resilience reflects the ability to maintain a stable equilibrium, with no period of pathological symptoms. However, post-traumatic growth proposes that the experiences of the traumatic event lead an individual to evaluate their previously held world assumptions (Janoff-Bulman, 1992; Tedeschi & Calhoun, 1995), which initially leads to increased distress. It is proposed that changes in world views are crucial in order for growth to occur, because it forces individuals to seek meaning and compensate for the incomprehensibility of the event (Engelkemeyer & Marwit, 2008).

Post-traumatic growth has been examined in many populations (Helgeson, Reynolds, & Tomich, 2006) including survivors of violent crimes (Brooks, Lowe, Graham & Robinson, 2016). Linley and Joseph (2004) suggest that the commonality among all events studied in relation to post-traumatic growth, is the struggle with the traumatic experience. They propose that studies of positive personal changes are an important area of research, emphasising that focusing only on the negative outcomes of trauma and adversity can lead to a biased perspective of post-traumatic reactions (Linley & Joseph, 2004). They advocate for the exploration of the potential for both positive and negative outcomes resulting from traumatic experiences (Linley & Joseph, 2004). Furthermore, Calhoun, Tedeschi, Cann, and Hanks,

(2010) have suggested the potential clinical usefulness of understanding the experience of positive changes, and the processes which facilitate these changes.

Overview of thesis chapters

The systematic review (chapter 1) endeavoured to identify peer reviewed journal articles which explored bereaved parents' experiences of post-traumatic growth or positive personal change. Furthermore, the systematic review aimed to synthesise current knowledge in relation to the experience of post-traumatic growth in bereaved parents, and to identify whether any themes emerged in relation to factors that may facilitate or prevent aspects of post-traumatic growth. It was identified that there was a paucity of research exploring the experiences of post-traumatic growth in parents whose baby had died.

The empirical paper (chapter 2) addressed the paucity of research in this area. It undertook the recent Cochrane review recommendations (Koopmans, Wilson, Cacciatore & Flenady, 2013), which highlighted the need for better understandings of post-traumatic growth in parents whose neonatal baby has died. A qualitative methodology was appropriate in order to address this experience. The Stillbirth and Neonatal Death Society kindly supported this research, and facilitated the recruitment of mothers bereaved by neonatal death. Mothers generously provided rich interviews of their experience, detailing the experiences they perceived to be positive personal change and the factors which served as facilitators or barriers to such changes.

The target journal is the European Journal of Psychotraumatology (EJPT); the editor of EJPT has expressed interest in receiving both manuscripts. The chapters comply with the author guidelines for the EJPT (Appendix A); however in line with thesis guidelines, tables and figures have been embedded into the text of the chapters.

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Chapter one: Literature review

What aspects of post-traumatic growth are experienced by bereaved parents?

Word count: 6108

Abstract

Background: The death of a child of any age can be traumatic and can leave bereaved parents experiencing negative outcomes. Recent research has shown the potential utility for understanding more about the development of post-traumatic growth following bereavement.

Objective: This paper sought to identify the aspects of post-traumatic growth experienced by bereaved parents, the factors that may be involved in facilitating or preventing post-traumatic growth and what future research in this area should address.

Methods: A systematic review of peer reviewed articles with a primary focus on positive personal growth in bereaved parents was conducted. Thirteen articles met the inclusion criteria, and were analysed and synthesised according to common and divergent themes.

Results: Bereaved parents were able to experience elements of growth proposed by the post-traumatic growth model. The papers indicated that (i) mothers appeared to experience more growth than fathers, (ii) cultural variation may impact on some participants' experience of growth, and (iii) participants were able to identify growth once some time had passed. Potential facilitators of post-traumatic growth were identified as making meaning, ongoing bonds with the child, being with bereaved families, and family and personal characteristics. Social networks were identified as having the potential to be either a facilitator or a barrier to growth.

Conclusions: In addition to experiencing grief, bereaved parents may also be able to experience aspects of post-traumatic growth, and a variety of factors have been identified as potential facilitators and barriers of these changes. The findings may have implications for service provision (e.g. expert-by-experience services). Furthermore, the findings should be understood in the context of study limitations (e.g. sample representativeness). In order to better understand post-traumatic growth experiences of bereaved parents, future research recommendations are discussed.

Key words: 'personal growth', 'bereavement', 'grief', 'mothers', 'fathers', 'death of a child'

Background

The death of a child can lead to parents experiencing long-term negative psychological responses, such as increased depressive symptoms (Rogers, Floyd, Seltzer & Hong, 2008), anxiety (Buchi et al., 2007) and complicated grief (Zetumer et al., 2015). Bereaved parents have also been found to experience marital difficulties (Rogers et al., 2008) and poorer physical health (Li, Hansen, Mortensen & Olsen, 2002). In a study of bereavement outcomes, Gamino, Sewell and Easterling (2000) highlighted that one of the factors associated with increased experiences of grief was younger age of the deceased. Even if the child is an adult at the time of the death, bereaved parents are likely to experience the death as unnatural and untimely, and are faced with the seemingly incomprehensible task of trying to find some way of continuing to live without their child (Wheeler, 2002).

Bowlby's (1982) influential attachment theory, which was later expanded upon with Murray Parkes (1998) provided important guidance in understanding bereavement; fundamentally proposing that an individual's attachment style will influence the development, maintenance, and crucially in bereavement, the relinquishing of relationships and therefore adaption to bereavement. Many early theories of grief and loss define stages of mourning (e.g. Bowlby, 1982). In an alternative approach to grief theory, Strobe and Schut (1999) proposed the dual process model of bereavement which suggests that individual's oscillate between loss-orientated and restoration-orientated coping with the loss.

Post-traumatic growth proposes that in the struggle to cope with one's trauma, and in addition to experiencing negative outcomes, positive personal changes are possible (Tedeschi & Calhoun, 2004). It is theorised that post-traumatic growth can manifest over five domains: self-perception, relating to others, new possibilities, appreciation of life and existential change (Tedeschi & Calhoun, 2004). Post-traumatic growth has been identified in many populations of individuals who have experienced a traumatic event (Helgeson, Reynolds &

Tomich, 2006). Understanding how individuals experience post-traumatic growth is important in guiding holistic support (Tedeschi & Calhoun, 1995).

Gamino and colleagues (2000) suggested that in addition to understanding the many negative responses to bereavement, it is valuable to understand more about adaptive responses to death. The notion of post-traumatic growth has been applied to bereavement research (Calhoun, Tedeschi, Cann & Hanks, 2010); however Calhoun and colleagues (2010) are keen to emphasise that the identification of growth does not mean that distress is eliminated, and that often, both experiences will co-occur. Michael and Cooper (2013) conducted a systematic review of post-traumatic growth in bereaved populations, which demonstrated that post-traumatic growth is experienced by bereaved individuals. They identified potential mediators in the emergence of growth, which included social support, time since death, religion, and active cognitive coping strategies (Michael & Cooper, 2013).

Objectives

The emerging research for the potential utility of understanding more about post-traumatic growth in bereaved populations was the rationale for this systematic review, which set out to understand:

1. What aspects of post-traumatic growth are experienced by bereaved parents?
2. What factors appear to be associated with facilitating or preventing post-traumatic growth in bereaved parents?
3. What are the gaps in the current understanding of bereaved parents' experiences of post-traumatic growth, and what is required of future research?

Method

Search strategy

Current literature informed the development of a protocol which guided the review (Appendix B). Five electronic academic databases (Web of Science, PsychARTICLES, PsychINFO, CINAL and MEDLINE with full text) were used to retrieve articles in October 2015. The search terms combined ‘growth terms’ (post-traumatic growth, positive growth, benefit finding, stress related growth, positive change, PTG, adjustment, positive adaptation), ‘parent terms’ (parent*, mother*, father*) and ‘death of a child terms’ (neonatal death, bereavement, grief, loss).

Selection of articles

All retrieved articles were screened using the following pre-determined criteria (see Figure 1): Articles were included if they were peer reviewed (excluding theses, reviews, commentaries, conference abstracts, and books), published in English at any time, reporting primary research with a focus on parents’ experience of post-traumatic growth, positive personal change or benefit-finding following the death of their child of any age, including adult children, from any cause of death. Articles were excluded if they included experiences of other family members (e.g. siblings), or if they included miscarriage or stillbirth. Two raters (AW and LH) independently screened all retrieved articles and subsequently discussed and agreed on articles to be included in the review; there was unanimous agreement on papers to be included.

Analysis

A predetermined checklist guided data extraction, which facilitated identification of common themes pertaining to the review questions. Subsequently, included articles were quality assessed using the Mixed Methods Appraisal Tool (Pluye et al., 2011; Table 1).

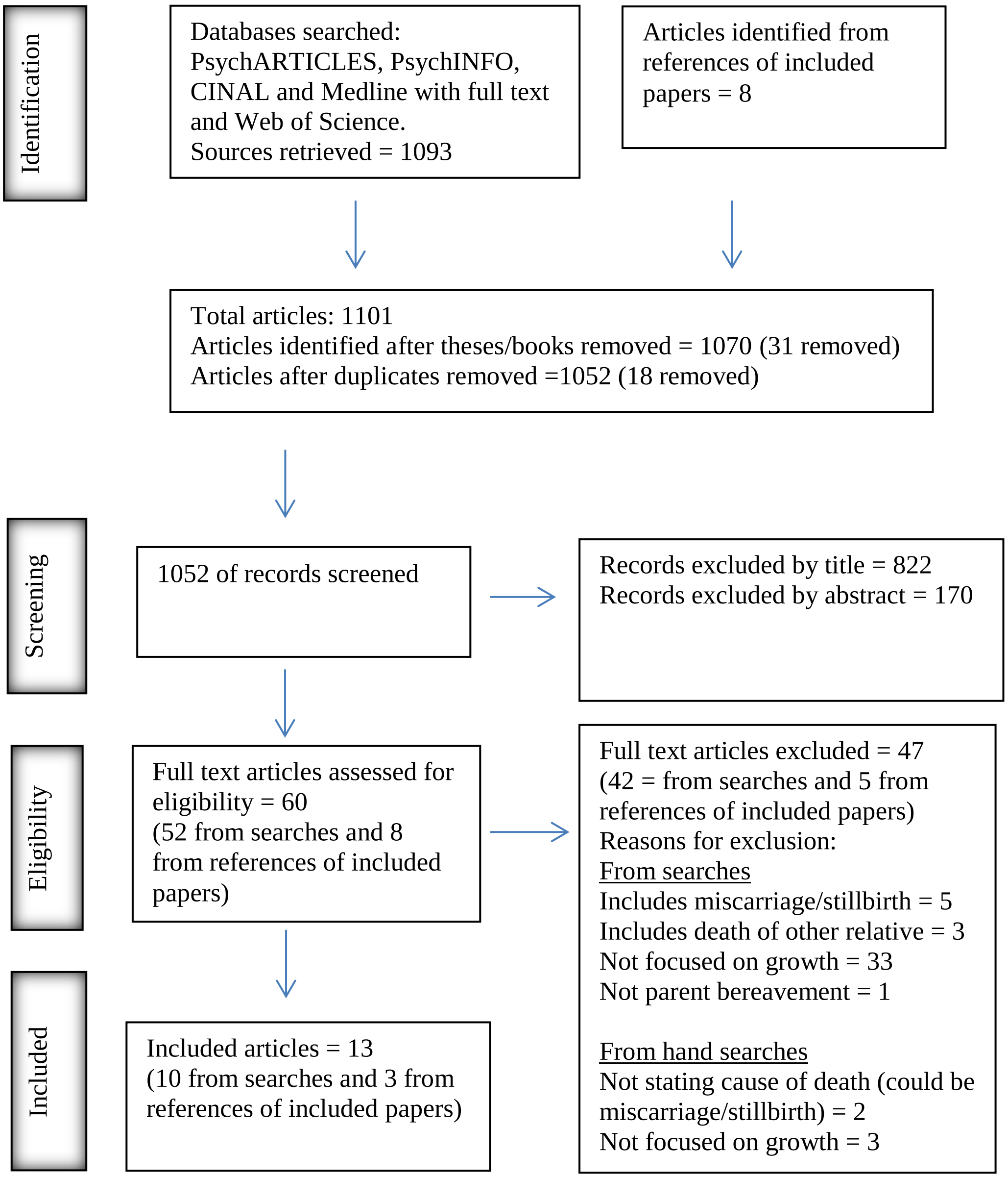

Figure 1: PRISMA diagram to illustrate identification, screening and inclusion of articles

Results

Overview of included papers

Thirteen articles published between July 1997 and October 2015 met the inclusion criteria; a summary of study characteristics is provided in Table 2 and a summary of the aims and findings is provided in Table 3.

Quality appraisal

All studies utilised a cross-sectional design, which does not allow the results to be understood in terms of process of post-traumatic growth, or cause and effect of particular factors. Overall the methods were clearly described, with the exception of Brabant, Forsyth and McFarlane's (1997) study, which provided limited information about their method and analysis. Quantitative studies provided acceptable information regarding the reliability and validity of their chosen measures, and described rationales and procedures for data analysis. In qualitative studies, with the exception of Brabant et al. (1997), the procedures for data analysis were clearly described. However, apart from the study by Reilly, Huws, Hastings and Vaughan (2008), qualitative papers did not comment on their consideration of researchers' influence, either during the data collection or the analysis; this is important as it has the potential to introduce bias. Three mixed method studies were included, two of which were case studies (e.g. Gerrish & Bailey, 2012); however, further information regarding the consideration of combining these methodologies would have been helpful. Participants were typically female and reported being married, Caucasian, and from middle to high socioeconomic background, limiting the generalisability of the data.

Table 1

Quality Analysis

	Screen		Qualitative				Quantitative non randomized				Quantitative descriptive				Mixed methods		
Study reference	Are there clear research questions?	Do the data address the research question?	Are the sources of qualitative data relevant to address the research question?	Is the process for analyzing qualitative data relevant to address the research question?	Is appropriate consideration given to how findings relate to the context?	Is appropriate consideration given to how findings relate to researchers' influence?	Are participants recruited in a way that minimizes selection bias?	Are measurements appropriate regarding the exposure/intervention and outcomes?	In the groups being compared, are the participants comparable, or do researchers take into account the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies?	Is the sampling strategy relevant to address the quantitative research question?	Is the sample representative of the population understudy?	Are measurements appropriate?	Is there an acceptable response rate (60% or above)?	Is the mixed methods research design relevant to address the qualitative and quantitative research questions?	Is the integration of qualitative and quantitative data relevant to address the research question?	Is appropriate consideration given to the limitations associated with this integration?
Bogensperger & Lueger-Schuster (2014)	y	y	y	y	y	n	y	y	y	y					y	y	n
Brabant, Forsyth & McFarlain (1997)	y	y	y	n	n	n											
Buchi et al. (2007)	y	y					y	y	n/a	y							
Engelkemeyer & Marwit (2008)	y	y					y	y	n/a	CT							
Gerrish & Bailey (2012)	y	y	y	y	y	n											
Gerrish, Steed & Neimeyer (2010)	y	y	y	y	y	n					y	n/a	y	n/a	y	y	n
Gerrish, Neimeyer & Bailey (2014)	y	y	y	y	y	n					y	n/a	y	n/a	y	y	y
Jenewein et al. (2008)	y	y					y	y	y	y							
Moore, Cerel & Jobes (2015)	y	y					n	y	y	n							
Parappully, Rosenbaum, Van Den Daele & Nzewi (2002)	y	y	y	y	n	n											
Polatinsky & Esprey (2000)	y	y					y	y	y	y							
Reilly, Huws, Hastings & Vaughan (2008)	y	y	y	y	y	y											
Riley, LaMontagne, Hepworth & Murphy (2007)	y	y					y	y	n/a	CT							

Table 2

Study Characteristics

Authors	Type of study	Country	Ethnicity/ Religion	Sample	Marital status	Type of death	Age of child	Time since death	Measures
Bogensperger & Lueger-Schuster (2014)	Mixed Methods	Austria	Not reported	30 Female (21) Male (9)	Married (66.7%) Divorced (13.3%) Single (6.7%) Other (13.3%)	Illness (50%) Accident (30%) Suicide (16.7%) Homicide (3.3%)	M=10.2 years (yrs) SD=9.4 Range = 4 days-40yrs	M=9.73 yrs SD=7.8 Range=1-26.	Interviews. Post-Traumatic growth Inventory (PTGI). Complicated grief module.
Brabant, Forsyth & McFarlain (1997)	Qualitative	United States of America (USA)	Not reported	14 Female (8) Male (6)	Not reported	Accidents (6) Illness (3) Surgery (1)	Range =1-29yrs Mean=12	Range 1-8yrs Mean=5yrs	Interviews
Buchi et al. (2007)	Quantative	Switzer-land	Not reported	54 Female (27) Male(27)	Married (100%)	Neonatal death	Not reported	Not reported	Munich Grief Scale. PTGI. Pictorial Representation of Illness and Self-Measure (PRISM).Hospital Anxiety and Depression Scale (HADS).
Engelkemeyer & Marwit (2008)	Quantative	USA	Caucasian (97%) Christian (52%) Catholic (27%) Jewish (7%) Other (14%)	111 Gender not reported	Married (72%) Widowed (10%) Divorced (15%) Single (3%)	Homicide (41) Accident (35) Illness (35)	M = 15 yrs SD = 7.5	Range=1-372 months (mths) Mean = 84.3 mths SD=89.9 mths	PTGI. World Assumptions Scale. Revised Grief Experiences Inventory.
Gerrish & Bailey (2012)	Case study	Not reported	Not reported	1 Female	Married	Leukaemia	Not reported	6 yrs	Biographical Grid Method (BGM).
Gerrish, Steed & Neimeyer (2010)	Case studies	Not reported	Caucasian (100%)	2 Females	Married (100%)	Cancer	9 & 22 yrs	7 yrs & 5 yrs	BGM. HGRC.
Gerrish, Neimeyer & Bailey (2014)	Mixed Methods	Not reported	Caucasian (100%)	13 Females	Married (11) Separated (1) Widowed (1)	Cancer	Range 2-35 yrs M=14.8	M=4.5 yrs Range=0.80 -9.3	Interviews. BGM. Hogan Grief Reaction Checklist (HGRC). PTGI.
Jenewein et al. (2008)	Quantative	Switzer-land	Not reported	92 Female (48) Male (44)	Not reported	Neonatal death	Not reported	Not reported	HADS. PTGI. Bayley Scales of Infant Development

Authors	**Type of study**	**Country**	**Ethnicity/ Religion**	**Sample**	**Marital status**	**Type of death**	**Age of child**	**Time since death**	**Measures**
Moore, Cerel & Jobes (2015)	Quantative	USA	Not reported	154 Female (137) Male (17)	Married (65.1%) Divorced (24.3%) Never married (3.3%) Widowed (3.9%) Other (3.3%)	Death by suicide	Not reported	Not reported	PTGI. The Life Orientation Test-Revised (LOT-R). Neuroticism Extraversion Openness Five Factor Inventory. Positive and Negative Affect Schedule. Prolonged grief disorders measure. Ruminative Response Scale. Resilience scale.
Parappully, Rosenbaum, Van Den Daele & Nzewi (2002)	Qualitative	USA	Caucasian (12) Hispanic (2) Afro-American (1) Russian (1)	16 Female (13) Male (3)	Other (12) Divorced (4)	Murder	Range: 7-41 yrs Median: 21 yrs	Range=15 mths-23yrs Median=6 yrs	Semi-structured interviews.
Polatinsky & Esprey (2000)	Quantative	South Africa	Caucasian (100%)	67 Female (49) Male (18)	Married (73%) Divorced (13%) Single (4%) Widowed (10%)	Motor accidents (38%) Suicide (42%) Homicide (11%) Illness (5%) Other (4%)	Not reported	Range = 6mths–8yrs	Contextual information about the death. PTGI
Reilly, Huws, Hastings & Vaughan (2008)	Qualitative	United Kingdom	English (7) Scottish (1) Welsh (1)	9 Female	Not reported	Illness (8) Feeding complication (1)	Range= 23mths-18yrs M=10.64 SD=2.79	M=4.2yrs. Range=10 mths-10yrs SD=2.79	Semi-structured interviews
Riley, LaMontagne, Hepworth & Murphy (2007)	Quantative	USA	Caucasian (92%)	35 Female	Married (90%)	Accident (58%) Neonatal death (12.5%)	M = 12yrs	M = 15.7mths SD=8.4	LOT-R. Dispositional version of the COPE. Inventory of Social Support. HGRC with growth subscale. Inventory of Complicated Grief. PTGI.

Methods used to collect post-traumatic growth data

A variety of methods were used in the included studies to collect data pertaining to post-traumatic growth experienced by bereaved parents. Qualitative studies detailed the use of semi-structured interviews (e.g. Reilly et al., 2008).

Quantative measures predominately used the Post-Traumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), which is a 21-item Likert scale designed to assess post-traumatic growth across five domains (new possibilities, relating to others, personal strength, spiritual change and appreciation of life). The PTGI inventory is widely used in post-traumatic growth research, and has been demonstrated to show good validity and reliability (Tedeschi & Calhoun, 1996). Two studies utilised the Hogan Grief Scale (HGRC; Hogan, Greenfield & Schmidt, 2001), which is a 61-item self-report measure consisting of six factors (despair, panic, blame and anger, detachment, disorganisation and personal growth), designed to measure the multidimensional aspects of bereavement. It has been shown to have good validity and reliability (Hogan et al., 2001).

An alternative method used was the Biographical Grid Method (BGM) (e.g. Gerrish & Bailey, 2012). Based on a social constructionist, repertory grid method, it involves participants identifying personally salient constructs defining “who they were” during a variety of major life events across the lifespan. This approach was used to identify how parents’ self-constructs and overall self-narrative had been affected by their loss.

Table 3

Summary of Findings

Authors	Aims	Findings in relation to personal growth
Bogensperger & Lueger-Schuster (2014)	• To analyse associations between meaning reconstruction, complicated grief and post-traumatic growth (PTG); with special attention to violent and unexpected losses.	• Identified 20 sense making themes and 19 benefit-finding themes; most commonly occurring: personal improvement (46.7%) and changed priorities (43.3%). • No gender differences for PTG, sense making or benefit finding. • Time since death had no significant relationship with PTG. • Negative correlation was found between PTG and complicated grief for bereaved parents of fewer than seven years. • Significant correlation for sense making and PTG and benefit finding and PTG. Study indicates a positive relationship between meaning reconstruction and PTG. • In the cases of traumatic loss, sense making was highly correlated with PTG.
Brabant, Forsyth & McFarlain (1997)	• To explore changes in parents meaning and purpose of life since the death of their child.	• Parents expressed having found new meaning in life through helping others, changes in their values and priorities, and having endured suffering.
Buchi et al. (2007)	• To assess grief and PTG in parents 2-6 years after the death of a premature baby (24-26weeks gestation). • To evaluate Pictorial Representation of Illness and Self-Measure (PRISM) in the assessment of bereavement.	• PTG occurs independently of affective disturbance. • Mothers experienced higher levels of grief but also higher levels of PTG. • Shorter self-baby separation (SBS) scores on PRISM correlated with higher PTG overall and in fathers, but disappeared when grief and gender were controlled. • SBS does not represent greater suffering, if parent has managed to make sense it could represent greater PTG.
Engelkemeyer & Marwit (2008)	• Whether changes in world assumptions are necessary for PTG to occur • To assess whether reported growth would be inversely correlated with grief intensity	• Many parents reported personal growth. • Grief intensity strongly predicted growth scores. • Self-worth strongly predicted growth scores, with a moderate negative correlation for negative beliefs about self-worth and PTG. • Assumptions about the benevolence of the world was not correlated with growth.
Gerrish & Bailey (2012)	• To illustrate BGM method in relation to understanding the complexity of grief responses, including perceptions of growth, in a mother whose child died	• Case study illustrated the complex experience of the mother's grief and growth. • BGM is a useful assessment method for understanding complex grief responses in bereaved parents.
Gerrish, Steed & Neimeyer (2010)	• To develop a revised version of the BGM that could be effectively administered to bereaved mothers, for the purpose of exploring meaning reconstruction processes and PTG.	• Case studies presented detailed examples of how a similar experience can lead to very different outcomes for mothers: one mother presented more complex grief, while the other mother presented with more aspects of PTG.

Authors	Aims	Findings in relation to personal growth
Gerrish, Neimeyer & Bailey (2014)	• To examine the impact of losing a child to cancer on bereaved mothers: 1) self-identify – that is their construal of self, others and world views and 2) means of coping and how these relate to their adaptive or complicated responses to their loss	• All mothers evidenced adaptive and complicated responses; however some showed a higher proportion of one or the other. • Mothers experienced challenges to their views about themselves, others and the world – which instigated highly meaningful changes in their self-identify – emerging from their struggle with grief – lead to substantial personal growth – this was not possible for all mothers. • An ongoing bond with the child was important. • A negative social environment was a barrier to process. • Time to prepare for loss and other children appeared to facilitate growth.
Jenewein et al. (2008)	• To assess the impact of extremely preterm birth on the mental health of parents 2-6 years after delivery • To examine potential differences in PTG between parents whose babies survived or died	• Mothers reported higher PTG than fathers. • PTG appears to be more positively related to bereavement. • Bereaved mothers experienced the value and quality of close relationships more. positively compared to non-bereaved mothers.
Moore, Cerel & Jobes (2015)	• To investigate PTG and what variables contribute to PTG among suicide bereaved parents	• PTG scores were typically in the low-moderate range, and typically lower than those in parents bereaved to other causes. • PTG items most strongly endorsed include: relating to others, spiritual change, appreciation of life. • Resilience inversely predicted PTG scores. • PTG occurs among suicide bereaved parents, but may be complicated by proximity to death and by concurrent brooding unique to answering the question "why".
Parappully, Rosenbaum, Van Den Daele & Nzewi (2002)	• To assess if parents of a murdered child were able to experience a positive outcome resulting from their trauma and to identify associated processes and resources	• Identified four processes (acceptance, finding meaning, personal decision making and reaching out to others in compassion) and six resources (personal qualities, spirituality, and continuing bond with the victim, social support, previous coping experience, and self-care) which appeared to facilitate a positive outcome.
Polatinsky & Esprey (2000)	• To assess whether parents were able to perceive benefit from their trauma, and whether there were any gender differences in perception of benefit • To assess the impact of nature of death, time since death, and age and marital status of parents	• Parents do perceive benefits from experiencing death of their child. • Poor evidence to suggest gender differences in perception of benefits. • Potential relationship between perception of benefit and illness being cause of death. • More benefits identified the longer time had elapsed since death. • Younger and married respondents reported more growth.
Reilly, Huws, Hastings & Vaughan (2008)	• To explore the experiences of mothers after the death of their child with a learning disability.	• Identified five themes: loss, benefit finding, coping, sources of support and medical relationships.
Riley, LaMontagne, Hepworth & Murphy (2007)	• To examine dispositional factors, grief reactions and personal growth in bereaved parents	• More optimistic mothers reported less intense grief reactions and less distress indicative of complicated grief. • Mothers who habitually coped with positive reframing had less intense grief reactions and less complicated grief. • Personal growth was associated with active coping, support seeking and positive reframing.

Paradox of post-traumatic growth

Despite the primary focus of the included articles being positive growth, many authors also reported parents' experience of ongoing sadness. Reilly et al.'s (2008) participants reported many grief symptoms, including anger and despair after their child's death. They concluded that although the grief persisted, it became easier to manage over time. In addition to reports of growth, Buchi and colleagues (2007) highlighted that 80% of parents still showed signs of grief and 19% indicated ongoing suffering, two to six years after their premature baby died. Gerrish and colleagues (2014) reported that despite mothers being able to recognise personal growth, they also experienced enduring sadness. They reported that all of their participants demonstrated a combination of 'complicated' and 'adaptive' grief (Gerrish et al., 2014).

Grief and post-traumatic growth

Three studies identified the experience of intense grief as an important factor in the development of post-traumatic growth. Buchi et al. (2007) found a positive association between grief and growth scores, when the Hospital Anxiety and Depression Scale scores were controlled. Furthermore, Buchi and colleagues (2007) indicated that bereaved parents in their study had higher grief and higher growth scores. Additionally, Jenewein et al. (2008) found that bereaved parents had higher (but not significantly) PTGI scores overall, when compared to PTGI scores of parents whose pre-term baby survived. In a hierarchical multiple regression analysis, Engelkemeyer and Marwit (2008) found that grief intensity accounted for 4% of the variance of post-traumatic growth scores in their study. Gerrish et al. (2014) reported that women who experience high, but not overwhelming, levels of grief also experienced more growth.

Domains of post-traumatic growth

Bereaved parents in the reviewed papers were able to identify post-traumatic growth changes across the five domains (Calhoun et al., 2010).

Self-perception

In Bogensperger and Lueger-Schuster's (2014) study, personal improvement themes were the most commonly identified; participants reported 'personal growth', 'being more tolerant' and 'developing personal potential'. All of Brabant et al.'s (1997) participants expressed a fundamental change in themselves, particularly in relation to feeling "more sensitive", while Parappully and colleagues' (2002) participants reported becoming more compassionate. Similarly Buchi and colleagues' (2007) participants provided the highest scoring items on the PTGI for 'stronger than I thought I was' and 'knowing I can handle difficulties'. In Moore et al.'s (2015) study, parents did not score as highly on the domain on personal strength on the PTGI (19% endorsed this item), compared to other domains on the inventory. Furthermore, Gerrish and Bailey (2012) used the BGM to illustrate how a mother construed change in the self in relation to being stronger and at the same time more vulnerable.

Changed relationships

'Changed relationships' was the most frequently reported theme of growth. In Brabant et al.'s (1997) study, 10 participants reported an increased desire to help others. Similarly, in a paper of improved methodological quality by Bogensperger and Lueger-Schuster (2014), one third of participants described a desire to help others, especially other bereaved individuals. In Buchi et al.'s (2007) study, high scoring factors on the PTGI for bereaved parents included 'having compassion for others' and 'knowing I can count on people in times of trouble', seemingly indicating that how parents respond to, and offer help, can change. In Jenewein et al.'s (2008) study, bereaved participants scored significantly higher on the PTGI subscale of 'relating to others' compared to any other domain. Similarly, Moore et al.'s (2015) participants most strongly endorsed the 'relating to others' subscale of the PTGI (40%).

New possibilities

Buchi and colleagues (2007) documented that 78% of bereaved mothers and 44% of bereaved fathers reported discovering new priorities related to what is important in life, since the death of their baby. This theme was also identified by Bogensperger and Lueger-Schuster (2014) and Brabant et al.'s (1997) participants reported no longer having such a great focus on work and money, and an increased focus on family life and reduced focus on financial issues. However, parents bereaved by suicide did not score as highly on the domain of new possibilities on the PTGI (18%), compared to other domains on the inventory (Moore et al. 2015).

Appreciation of life

This was one of the least frequently mentioned themes. Eleven participants in Bogensperger and Lueger-Schuster's (2014) study reported a greater appreciation of life. In particular, participants reported having a heightened appreciation of life, living in the moment, and not taking things for granted. One of Brabant et al.'s (1997) participants reported an understanding of how precious life is. Furthermore, Moore and colleagues (2015) participants indicated an increased appreciation for life on the PTGI (33%).

Existential elements

Existential growth refers to changes in how living in the world is viewed and understood; this can encompass changes in religious views, spirituality or meaning of life. In Moore et al.'s (2015) study, parents reported spiritual change on the PTGI (34%). Participants in Brabant et al.'s (1997) paper placed a greater emphasis on turning to religion and feeling more spiritual than before the death.

Similarities and contrasts

Cultural variations

Despite the studies being conducted across many countries, the samples typically reported similar demographics. The only factor that appeared to differentiate the articles in terms of demographic or cultural characteristics was religious beliefs. The studies conducted in America which explored experiences of growth found that participants discussed religion in terms of their personal growth (Brabant et al., 1997; Parappully et al., 2002). A majority (68%) of Parappully and colleagues' (2002) participants specifically mentioned prayer and rituals as an important resource. Similarly Brabant and colleagues' (1997) participants discussed 'finding God' or 'being more spiritual'. Conversely, studies conducted outside of America exploring the experience of growth placed very little or no emphasis on religion contributing to, or being a component of personal growth. Bogensperger and Lueger-Schuster (2014) noted that their participants did not discuss the death of their child in terms of it being 'God's will'; they suggested that this might be a reflection of the prevalence of religious faith in America compared with European countries. Only one study conducted outside of America mentions religion; it reported that women who already had religion in their lives, questioned, but did not change their beliefs, whereas women who did not have religious faith prior to the death of their child, did not turn to religion (Reilly et al., 2008).

Gender differences

Buchi et al. (2007) indicated that bereaved mothers in their study had higher grief scores, but also higher growth scores. Jenewein et al. (2008) reported that mothers experienced more post-traumatic growth than fathers, and that there was a significant interaction between bereavement and gender in the PTGI subscale ‘relating to others’; indicating that bereaved mothers were found to be experiencing the most post-traumatic growth. Furthermore, some mothers reflected on how they felt they were coping differently to their husbands, which made emotion-focused activities difficult (e.g. looking at photographs) (Reilly et al., 2008). However, despite mothers demonstrating higher mean scores on four out of five of the PTGI domains, Polatinsky and Esprey (2000) reported that their study had insufficient evidence of gender differences: they suggested that this may have occurred because all participants were support group members. Similarly, some authors reported that PTGI scores (Engelkemeyer & Marwit, 2008) or reports of benefit-finding (Bogensperger & Lueger-Schuster, 2014) did not differ between mothers and fathers.

Time since death

Brabant et al.’s (1997) study described how only one parent reported feeling like a failure; the authors suggested that this may have been due to this individual experiencing the shortest time since the death of their child. Similarly, Reilly et al. (2008) reported that mothers whose child had died more recently had greater difficulty identifying growth. Polansky and Esprey (2000) reported that time since death was significantly correlated with PTGI scores; in particular with factors of ‘new possibilities’ and ‘relating to others’. Moore and colleagues (2015) suggested that their participants’ scores of growth were lower than expected and proposed that this may have been due to their study including only parents bereaved within the previous two years, and that perhaps that was a barrier for them in measuring growth. Engelkemeyer and Marwit’s (2008) study found that time since death of child was correlated with PTGI scores; furthermore they reported that time since death significantly predicted PTGI scores, and accounted for 8% of the variance.

Nature of death

The mothers in Gerrish et al.’s (2014) study discussed how having the opportunity to prepare for their child’s death from cancer facilitated adaptation. Similarly, Polansky and Esprey (2000) reported that the mean PTGI score was higher for parents whose child died from an illness; however their sample size was too small to determine significance. Furthermore, mothers in Reilly et al.’s (2008) study reported that some perceived positive experiences were related to the mothers’ relief that their child was no longer suffering from illness.

Facilitators and barriers of post-traumatic growth

Cognitive processes

Gerrish and colleagues (2010) presented two case studies which utilised the BGM. They illustrated how one woman had been able to appraise and integrate the experience of her child’s death into her overall identity, which enabled her to accept difficult events and live adaptively. A contrasting case study featured a woman who was unable to re-narrate her assumptions of the world to integrate her child’s death, and continued to experience high levels of distress.

Making sense

Bogensperger and Lueger-Schuster (2014) reported a positive relationship between meaning reconstruction and post-traumatic growth. In total, Bogensperger and Lueger-

Schuster (2014) identified 20 sense-making themes, the most common of which included the purpose of the child's life and death, and biological explanations; they reported that participants often provided multiple sense-making explanations. This was reiterated by Parappully and colleagues' (2002) participants, 93.75% reported the importance of being able to find meaning in their child's murder in order to facilitate growth. Parappully et al.'s (2002) participants reported that finding meaning included drawing on spirituality (e.g. belief in an afterlife) and hypothesising worse things that might have happened.

Continuing bonds

All of the mothers in Gerrish et al.'s (2014) study reported continuing bonds with their children; they highlighted the importance of visiting the cemetery and speaking aloud to their child. Likewise, the participants in Parappully et al.'s (2002) study described how continuing bonds with their child were important in their transformation. Participants described many ways that bonds were continued, including focusing on their continued love for their child, having mementos (e.g. photos) and the perspective that their child would have wanted them to enjoy life again.

Other bereaved families

Parappully et al.'s (2002) participants described how reaching out in compassion and being able to focus their energies on supporting others, in a variety of capacities (e.g. supporting family, forming organisations), was the most common way that facilitated their healing and personal transformation. A similar finding was reported in a paper of improved methodological quality by Reilly and colleagues (2008), who found that participants gained benefit from being with other bereaved mothers, detailing that they were the only people who really understood. Additionally, all the mothers in Reilly et al.'s (2008) study reported involvement with charities or services, and using their experience to support others was helpful.

Social support

The articles demonstrated how the social environment has the potential to be supportive and facilitative of post-traumatic growth (e.g. Gerrish et al., 2014), or unhelpful for bereaved parents (e.g. Gerrish and Bailey, 2012). The latter experience was described by the mothers in Reilly et al.'s (2008) study, who reported developing the ability to mask their emotions, because it did not feel appropriate to talk about their child, despite wanting to. Similarly, the women in Gerrish et al.'s (2014) study detailed the importance of non-judgemental listening. Additionally, in Riley et al.'s (2007) paper, perceived social support was strongly correlated with perceived personal growth. Participants in Parappully et al.'s (2002) study described a range of individuals who provided a source of social support (e.g. friends, family, clergy or professionals).

Family and personal characteristics

Gerrish et al. (2014) reported that the only mother included in their study whose only child had died, was also the only participant to have reported becoming suicidal and having been admitted to a psychiatric hospital. They proposed that having other children may be a protective factor (Gerrish et al., 2014). In Gerrish et al.'s (2010) case study, the participant described how previous difficult life events had helped her to cope with the death of her child; this was echoed by participants in Parappully et al.'s (2002) study. Moore and colleagues (2015) documented that participants who did report new possibilities, were predicted by personality traits of openness to experience, neuroticism and resilience.

Similarly, Riley, LaMontagne, Hepworth and Murphy (2007) reported that more personal growth was associated with dispositional factors such as active coping and support seeking.

Discussion

Thirteen articles were identified following the application of inclusion criteria to the search results. Post-traumatic growth is a relatively recent area of empirical study (Tedeschi & Calhoun, 1995) and conducting research with bereaved parents is a sensitive area; this explains the reasonably small number of articles identified. Prior to conducting the final search, scoping searches established the appropriateness of the search terms and inclusion criteria. Furthermore, the reference lists of all included papers were searched; this generates confidence that the review conclusions are based on a synthesis of all available research.

The findings indicate that bereaved parents included in these studies were able to experience aspects of post-traumatic growth in the domains of changes in self-perception, changed relationships, appreciation of life, changed priorities and existential changes. There appeared to be gender and potentially cultural differences in the experiences of growth. Furthermore, the time since death appeared to be an important consideration associated with growth; however, it was not possible to identify whether the nature of the death impacted on the experience of growth. Additionally, the results suggest multiple factors associated with facilitating or preventing post-traumatic growth including cognitive processes, social networks, other bereaved families, continuing bonds, making sense and personal characteristics.

Previous literature

The findings support the proposals from Tedeschi and Calhoun (1995) that individuals need to experience distress in order to realise post-traumatic growth. However it was not possible to establish whether too much distress can be overwhelming and inhibit the development of post-traumatic growth (Tedeschi & Calhoun, 1995). Included studies identified post-traumatic growth in the domains proposed by Tedeschi and Calhoun (1995) and are consistent with a recent systematic review identifying post-traumatic growth in bereaved populations (Michael & Cooper, 2013). Furthermore, this review supports the importance of models of grief which account for adaption (e.g. Dual Process Model of Bereavement, Stroebe & Schut, 1999).

These findings are consistent with the results of a recent meta-analytic study of post-traumatic growth after a variety of traumatic events (Helgeson et al., 2006), which reported that women typically perceive more benefits from a traumatic event; potentially this is related to how women cope with the experience. The importance of time since death in relation to identifying post-traumatic growth is also supported by Helgeson and colleagues (2006), who identified that benefit-finding was strongly related to less depression and greater positive affect two years after a trauma. Furthermore, this review supports Helgeson et al.'s (2006) findings which documented that it was not possible, based on current evidence, to draw conclusions in relation to the nature of the stressor in understanding benefit-finding. Perhaps this is because understanding how individuals make sense of the experience, is more important than the event itself.

The findings are consistent with the results of a systematic review, in which meaning-making and ongoing bonds were identified as key themes in facilitating post-traumatic growth following bereavement (Michael & Cooper, 2013). The review findings are consistent with literature which describes the potential for social networks to be either facilitative or disenfranchising (Doka, 1999) and a barrier to growth. The finding that dispositional optimism predicted growth (Reilly et al., 2008) was also found by Helgeson et al. (2006).

Evaluation of studies

All of the studies utilised cross sectional designs, therefore causal inferences about the process of post-traumatic growth cannot be made. It was encouraging to see the studies which provided comparisons with a group of parents whose baby had survived (Buchi et al., 2007 and Jenewein et al., 2008); however comparison with a group whose baby did not require neonatal care may have been helpful.

This paradoxical experience presents dilemmas regarding appropriate data collection methods. The PTGI was the most frequently used in the included studies and provided an objective measure which reduces researcher bias. However, it has been criticised for not capturing both aspects of growth (Linley & Joseph, 2004). In contrast, the use of interviews or the BGM have illustrated their utility in capturing the idiosyncratic complexity of the experience of post-traumatic growth. However, these methods have the potential to introduce researcher bias, for example in Brabant et al.'s (1997) paper, "more sensitive" was coded as growth; however, this could be experienced as more or less adaptive.

Mothers are overrepresented in the studies and small sample sizes limited the researchers' abilities to generate significant findings (e.g. Jenewein et al., 2008). Additionally, although the studies were conducted worldwide, the majority of the participants were Caucasian and in the middle brackets of socioeconomic status. Furthermore, almost all of the parents in the included studies were recruited from support groups; consequently participants are individuals who wish to discuss their experience. Therefore, the question remains whether those who do not access support groups are those who experience the least post-traumatic growth (and therefore it is potentially an over-represented phenomenon), or who experience the most post-traumatic growth and thus do not require the support.

Review evaluation

This review benefited from two researchers separately applying the inclusion criteria to all sources retrieved from the database searches and assessing the quality of the included papers. The review was conducted systematically; search terms and inclusion criteria were generated based on extant literature and discussion in supervision. Due to time and resource limitations, it was not possible to include papers not published in English or grey literature, which may have enhanced the review. However, a hand-search of the references of included papers provided reassurance that available studies which met the inclusion criteria were identified. The variety of approaches published within the relatively small sample of papers created some challenges with regard to comparing and contrasting the different epistemological approaches to data collection.

The findings should be viewed in the context of the limitations of the studies and the idiosyncratic experiences of bereaved parents. Every individual will vary in terms of prior mental wellbeing, social support, and subsequent potential for post-traumatic growth. Although there may be indications of growth and potential ways in which this may be facilitated or prevented, these findings cannot be generalised. However, the findings do indicate that further research would be beneficial in order to understand this phenomenon.

Clinical and research implications

Clinicians should be aware of the long-lasting positive and negative changes after the death of a child (Buchi et al., 2007). These findings may help to identify parents who are at greater risk following the death of their child (e.g. limited support networks). The value of being with other bereaved families has the potential to initiate expert-by-experience services (Foot et al., 2014). Furthermore, Calhoun and colleagues (2010) discuss ‘expert companionship’; a model of working with bereaved individuals to facilitate post-traumatic growth. They describe this approach as a clinical stance which includes respect, tolerating oscillating emotions, and appreciation of the paradox.

In order to understand how post-traumatic growth occurs, a longitudinal approach would facilitate an understanding of the process of change. Recruiting from clinical settings would eliminate potential biases that may be occurring from recruiting participants from support groups. There are potential ethical dilemmas in utilising robust research methodologies (e.g. recruiting parents at time of death). However authors have described how parents value talking about their child, even when it is painful (Dyregrov & Dyregrov, 1999) and hope that their participation will help others (Reilly et al., 2008). Furthermore, this review encourages the importance of triangulation of research methods in order to obtain results that may be generalisable, but also to capture the context and nuances of parents' experience (Dyregrov & Dyregrov, 1999). However, future research should be cautious that changes are not assumed to be positive growth.

The question of whether and how gender and culture shapes experiences of post-traumatic growth is an important one. Representativeness of samples (i.e. including more fathers) and cultural differences will be important to address in future studies, particularly as this may inform how to improve support. Understanding parents' previous mental health status would be useful (Gamino et al., 2000; Moore et al., 2015), although methodologically challenging to investigate. It was not possible to establish parental experience of post-traumatic growth with regards to parental relationships, age of the child or the nature of the death (i.e. 'natural' causes such as illness versus accidents, suicide or murder), which future research could address.

Only two articles focused on post-traumatic growth following the death of a neonatal baby and two studies included death of infants in their samples; however these studies were primarily quantative. Given the complex nature of post-traumatic growth and the underrepresentation of parents who have experienced a neonatal death in the literature, future research should explore the post-traumatic growth experiences in this population.

Conclusion

This systematic review synthesises the existing research relating to bereaved parents' experience of post-traumatic growth. The results indicate that in addition to experiencing distress, some bereaved parents are also able to experience positive changes resulting from the struggle with their loss. It would appear that there are gender differences in the experience of growth, with women reporting more growth than men. The review indicates that the process of growth takes time to occur; and that cultural variation - in particular religion - may impact on how growth is experienced. However it was not possible to establish from these studies whether the nature of the death impacted on the experience of growth. The review has identified some of the factors which may facilitate the development of personal growth: These include the importance of supportive networks which include other bereaved parents, continued bonds with the child, and an ability to make sense of the experience. Furthermore, personal and family characteristics may influence the experience of post-traumatic growth in both helpful and unhelpful ways. The findings may have implications for service provision (e.g. development of expert-by-experience groups). However, included papers have limitations which reduce the generalisability of the findings. Future research would benefit from longitudinal, mixed methods research with larger and more diverse samples. However, there is also a need for future research to focus upon more rigorous qualitative research, which in particular explores parental experiences of post-traumatic growth after the death of a baby.

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Chapter two: Empirical research

Understanding mothers' experiences of neonatal death: A focus on positive changes'

Word count: 6405

Abstract

Background: The death of a neonatal baby has the potential for parents to experience many negative outcomes. Post-traumatic growth describes positive personal change, which can occur from the struggle with a traumatic event. Recent literature has indicated the need for exploration of post-traumatic growth in parents whose neonatal baby has died.

Objective: This study sought to understand the experiences of mothers whose neonatal baby had died, and in particular whether mothers were able to experience any changes in their lives, since the death of their baby as positive. The study also sought to explore what factors may have facilitated or prevented these changes.

Method: Ten mothers were recruited whose baby had died in the neonatal period, between two and 10 years ago. Mothers completed semi-structured, one-to-one interviews. Interview transcripts were analysed using Template Analysis.

Results: Despite ongoing sadness, mothers were able to recognise positive personal changes, which were consistent with the post-traumatic growth model. Mothers identified facilitators and barriers to their changes which were categorised into five themes: ‘Person-centred care’, ‘making sense’, ‘personal coping strategies’, ‘learning to live with it’ and ‘identity’.

Conclusions: This study identified that the mothers made a personal decision to cope with their experience; this is a unique finding which requires further exploration. Facilitators and barriers of growth occurred as different dimensions of five themes, indicating that all interactions before and after the death have the potential to either facilitate or prevent personal growth. Furthermore, these findings indicate that person-centred services, which are responsive to individual needs at all stages, are vital when providing maternity care.

Keywords: “post-traumatic growth”, “personal growth”, “perinatal death”, “Qualitative research”, “Template Analysis”

Background

Neonatal death

Neonatal death is defined as the death of a baby in the first 28 days of life (Office of National Statistics (ONS), 2016). Neonatal care has improved over the decades, however in England and Wales, one in every 400 babies died in the neonatal period in 2014 (ONS, 2016). There is evidence that mothers create attachments to their baby even before birth (Yarcheski, Mahon, Yarcheski, Hanks & Cannella, 2009). When a baby dies, bereaved mothers almost always experience grief (Buchi et al., 2007). However, mothers may also experience long-term symptoms of post-traumatic stress disorder (Jind, 2003), anxiety and depression (Vance et al., 1995) and marital problems (Baddenhorst & Hughes, 2007). The death of a baby has wide-reaching effects, including influencing parenting of subsequent children (Warland, O'Leary, McCutcheon & Williamson, 2011) and poorer parental health outcomes (Li, Hansen, Mortensen & Olsen, 2002).

Post-traumatic growth

Recently consideration has been given to the possibility that individuals are able to experience significant personal changes in the aftermath of a traumatic event (Helgeson, Reynolds & Tomich, 2006; Tedeschi & Calhoun, 1995). Post-traumatic growth is proposed to reflect changes across five domains (Taku, Cann, Calhoun & Tedeschi, 2008): 1) Self-perception; the notion of new found personal strength and a changed self-concept, which can be summarised as 'more vulnerable, yet stronger', 2) Changed relationships with others, which can be positive and negative (e.g. greater compassion for others, realising 'true' friends), 3) New possibilities; realising opportunities to do things that individuals may not have done prior to their loss, 4) An appreciation of life and 5) Existential changes (e.g. religious views). This understanding of growth is often condensed into three categories of changes: self-perception, relationships and life philosophy (Tedeschi & Calhoun, 1995).

Bereavement and post-traumatic growth

There is evidence that some individuals experience post-traumatic growth following bereavement (Engelkemeyer & Marwit, 2008; Gamino, Sewell & Easterling, 2000; Michael & Cooper, 2013). Importantly, Calhoun, Tedeschi, Cann and Hanks (2010) emphasise that post-traumatic growth in the context of grief occurs from the struggle with bereavement, and that it would be a gross misinterpretation to suggest that focusing on growth minimises the importance of attending to coexisting negative reactions. Furthermore, they suggest that post-traumatic growth should be viewed as independent of distress associated with loss, and that it would be erroneous to suggest that experience of growth will or should necessarily produce a reduction in psychological distress (Calhoun et al., 2010).

The post-traumatic growth model assumes that individuals hold assumptive world beliefs, determined by factors such as culture and life experiences, which allows them to experience the world as predictable, understandable and meaningful (Calhoun et al., 2010). Bereavement leads individuals to experience distress, but they may also have to review their assumptions; which may at least initially cause further suffering (Calhoun et al., 2010). The post-traumatic growth model postulates that eventual success in rebuilding shattered world views may lead to a more complex understanding about the world. While individuals may be able to recognise personal strength, closeness to others or new possibilities, they may also realise that undesired outcomes cannot always be prevented (Calhoun et al., 2010).

Neonatal death and post-traumatic growth

The experience of neonatal death is likely to shatter an individual’s assumptions about themselves and the world they live in; often mothers create attachments to their baby and have great hopes for their future. Buchi and colleagues (2007) found that while bereaved parents of a premature infant continued to experience grief and anxiety, they also showed evidence of post-traumatic growth (e.g. discovering personal strength, increased compassion for others). However, there are no studies pertaining to the experiences of post-traumatic growth in mothers whose baby died in the neonatal period. A recent Cochrane review identified a need for further research into the area of perinatal death and post-traumatic growth, in order to develop more effective post-loss interventions (Koopmans, Wilson, Cacciatore & Flenady, 2013). A qualitative method is best suited to explore the complex experiences of mothers whose neonatal baby has died.

Objectives

The aim of this research was to generate an understanding of the experiences of mothers whose neonatal baby had died. In particular it was hoped to understand the process of mothers' adjustment, and whether and how any changes in their lives since the death of their baby may be experienced as positive growth. Furthermore this study aimed to explore what factors might facilitate or pose barriers to these changes for these mothers.

Method

Research approval

Approval was obtained from the Liverpool Doctorate of Clinical Psychology (Appendix C) and the Stillbirth and Neonatal Death Society (Sands; Appendix D). Sands were consulted regularly throughout the study development, to ensure that all the materials used were suitable. Ethical approval was obtained from the University of Liverpool Research Ethics Committee (Appendix E).

Design

A qualitative design was used and a purposive sample of women was sought for the research. The inclusion criteria were women of any age (i) who were not currently pregnant, (ii) who lived in the North West of England, (iii) whose baby had died in the neonatal period between two and 10 years ago, and (iv) who felt able to talk about the changes, some of which they had identified as positive, that had occurred in their life since their baby had died.

Recruitment

A protocol for recruitment was developed with Sands (Appendix F) and an advert (Appendix G) for the study was initially placed on regional Sands Facebook pages; the advert was subsequently placed on the national Sands Facebook page. Twenty-four women contacted the researcher, 14 fulfilled the inclusion criteria, and of those 10 were recruited.

Procedure

Mothers interested in participation contacted the researcher and were provided with a participant information sheet (Appendix H), if they met the inclusion criteria. If the mother wanted to participate, a meeting was arranged. During this meeting, informed consent (Appendix I) was gained, mothers also completed a demographics questionnaire (Appendix J) and were informed that they could pause or stop the interview at any time. A topic guide (Appendix K) was utilised during the interview. At the end of each interview, mothers were thanked for sharing their experiences, and provided with a £10 gift voucher and debrief information (Appendix L).

Measures

The participants' demographic information (Appendix J) was recorded. A topic guide, based on extant literature, was developed in order to guide the interviews (Appendix K). Key areas explored were (i) the experience of their baby dying and associated feelings, (ii) ways in which life had changed since their baby died and whether any of these changes were experienced as positive or growth, and (iii) what factors helped or prevented changes being experienced as positive.

Data collection

Semi-structured, one-to-one interviews were conducted with 10 women between July and December 2015. Interviews were carried out at the mothers' homes; they lasted between 55 and 93 minutes (average 70.6 minutes), depending on how much the participant wished to share. Interviews were audio recorded, transcribed verbatim and anonymised.

Analysis

The qualitative data was analysed using Template Analysis (Brooks, McCluskey, Turley, & King, 2015). This method is a style of thematic analysis which is a flexible but structured approach to data analysis, which allows for integration of a priori codes and emerging themes. Template Analysis was viewed as an appropriate choice as it would enable the researcher to refrain from focus on what was already 'known' in terms of the negative outcomes, and instead focus on new insights in relation to potential positive changes. Template Analysis is compatible with different epistemological assumptions (Brooks et al., 2015). This research was based on the stance of subtle-realism (Hammersley, 1992), which acknowledges that the researcher's perspective is influenced by their own position in the world, but retains a belief in phenomena that are independent of the researcher, which can be understood through the process of research. This stance encouraged the use of a priori (top-down) themes and consideration of emergent themes from the experiences of participants (bottom-up themes). The analysis followed the procedures recommended by Brooks et al. (2015):

1. Familiarisation with the data-set by reading transcripts.
2. A computer package (NVIVO 10, 2012) facilitated coding (Appendix M). Preliminary coding was completed utilising a priori themes (Table 1) which were based on extant literature (e.g. Tedeschi & Calhoun, 1995). Codes for emerging themes were added during this process and a new iteration of the coding template was developed for each transcript.
3. Frequently occurring themes were identified and clustered; potential links between the themes were noted. At this point, some themes became redundant and others were redefined (Appendix N). This led to the creation of a final version of the template of themes (Table 2).
4. The final template was applied to every transcript, to ensure that the template accurately reflected the data, and that all relevant themes were captured (Appendix O).

Reflexivity

The researcher's beliefs have the potential to influence participant recall and data analysis; therefore personal attitudes were reflected on throughout the research in order to reduce bias (Appendix P). The researcher was a young female with no direct experience of childbirth or neonatal death; but a clear awareness of the likelihood for this event to create immense pain and distress, along with the potential for personal growth. The researcher understood the potential for paradoxical experiences, and expected that some women *may* report ongoing distress, despite evidence of growth, but did not presume this to be the case.

Results

Demographic information

All of the women who took part in the study identified as White British and either married or living with a partner. Two women were aged between 18-29, three women were between 30-39 and half of the women indicated being in the 40-49 age category. Seven women held a Degree or Masters Qualification and three women held GCSEs or A-levels. Nine of the women were working and one mother did not specify her occupation. Six women reported having Christian faith and four women indicated that they did not have a religion.

Table 1

A Priori Template

1. Themes of initial distress/pain/grief
1.1. Initially
1.2. Months and years after
2. Themes of PTG
2.1. Self-perception
2.2. Changed relationships
2.2.1. Positive changes
2.2.2. Negative changes
2.3. Changed life philosophy
2.3.1. New possibilities
2.3.2. Appreciation of life
2.3.3. Existential changes
3. Facilitators or barriers of growth
3.1. Relationships/social
3.1.1. Relationship with husband/partner
3.1.2. Others actions/words
3.2. Practical support
3.2.1. Help going back to work
3.2.2. Interactions with services
3.2.3. Charity involvement
3.2.4. Social media
3.3. Children
3.4. Religion
3.5. Anniversaries
3.6. Continuing bonds
3.7. Making sense

Table 2

Final Template

1. Contextual factors
2. Themes of post-traumatic growth
"I think you find a strength you just think you never had… and erm that loads of people do that" (Natalie)
2.1. Self-perception (88/10)
2.2. Relationships (75/10)
2.3. Life philosophy (56/10)
3. Facilitators and barriers of post-traumatic growth
3.1. Person-centred care Including Acknowledgement of my baby's life (42/10) / Being able to talk about my baby (25/8)
"I think it was people not realising that you know, two years afterwards you're still fairly fragile" (Lynn)
3.1.1. How services are experienced
3.1.1.1. Compassionate (19/7)
3.1.1.2. Communication (31/8)
3.1.1.3. Choice and control (29/8)
3.1.1.4. Spending time with baby (23/9)
3.1.1.5. Practical help (19/8)
3.1.1.6. Significant losses (17/7)
3.1.1.7. Going to a counsellor (13/6)
3.1.1.8. Medication(8/6)
3.1.1.9. Subsequent interactions with services (18/6)
3.1.2. Relationship with partner and social networks
3.1.2.1. Relationship with partner (36/9)
3.1.2.2. Support from friends and family (65/10)
3.1.2.3. Being with other bereaved parents (53/10)
3.2. Making sense of what happened
"You're always looking for a reason, always looking for a reason" (Olivia)
3.2.1. Processing the experience (56/10)
3.3. Personal coping strategies
"I think a lot of it is the support you get in those early days and how you decide to deal with it really" (Natalie)
3.3.1. Personal decision to cope (30/8)
3.3.2. Trying to take others perspectives (15/7)
3.3.3. Recognising what you can cope with (self-care) (36/9)
3.3.4. Getting a focus (12/6) - including charity involvement (28/5) / Having another baby (10/5)
3.4. Finding ways of learning to live with it
"It didn't take away my sadness but it just brought more happiness to kind of even it out if that makes sense. Erm, and I think having another focus and again bringing him up very much to know about his big sister is always really important to me" (Debbie)
3.4.1. Children (56/10)
3.4.2. Going back to work (26/8)
3.4.3. Continuing bonds (22/8) / Mementos (14/9)
3.4.4. Importance of time (38/10)
Integrative theme
3.5. Identity (15/8)
"I've not got a child, so I don't know what I should be doing here. Erm, yeah, quite a lot of that so going you know I was off work and you're going, but I don't know what I am doing, I don't have a role sort of thing" (Lynn)

1. Contextual factors

All of the mothers described experiencing intense distress after the death of their baby, and described ongoing experiences of grief and sadness, consistent with existing literature (e.g. Baddenhorst & Hughes, 2007). The results presented will remain within the remit of the research and focus on the experiences of positive personal growth.

2. Themes of post-traumatic growth

2.1. Self-perception

Most of the mothers described experiencing positive changes in self-perception, which included identifying strengths that they did not know they had, feeling more assertive and mature. However, these changes were accompanied by also experiencing negative changes in self-perception; all the women identified with feeling more fragile or vulnerable, or more negative or anxious:

“I think just the fact that we are almost new people … I probably was a bit of a pushover before and now I’m not, I have become very very stubborn, which is not a trait that’s particularly nice for me, [but] it protects me and it protects my family” (Kate)

2.2.Relationships

All the women described changes in perception of themselves in relation to others. Most of the women reported becoming less tolerant of others, especially when it seemed as though others’ problems were trivial in relation to the experience of the death of a baby, or if they felt someone was not contributing to a relationship equally. However, all the mothers described feeling more compassionate towards others experiencing difficulties and having an ability to help others. All of the women explained how relationships had changed in both positive and negative ways since the death of their baby

"I think we both feel let down by our family sides, erm. And other, yeah, I suppose other people kind of come forward and offer help maybe because they have had similar experiences." ... "You see yourselves almost from the outside and realise what support network you've got erm and it means some relationships are so much closer because they are the people that have really been there for you." (Natalie)

Support groups facilitated the development of important new relationships for five of the women. Most of the mothers discussed how already strong couple relationships had become stronger; for most mothers this was attributed to the fact that they had shared an experience that no-one else could understand. However, one mother described how imagining her baby seeing her in an abusive relationship enabled her to leave that relationship. Many of the mothers commented on how their experience had changed their parenting; describing an increased appreciation for, and worry about their existing children:

"I think it's probably changed my parenting, I think I'm a better mum because of losing Abigail." (Debbie)

2.3.Life philosophy

Women who reported being religious prior to the death of their babies described taking comfort from their faith. One mother reported that although her experience had challenged her faith, she had been able to reconcile this. Most of the women discussed having an increased appreciation of life. Many of the mothers described new possibilities; some of the mothers referred to wanting to help improve services, while others described new-found charity involvement:

"I wouldn't be involved in half the things I'm involved in if I hadn't lost Lilly, and I would never have known the existence [of volunteering for charities]." (Rachel)

3. Facilitators and barriers of post-traumatic growth

Facilitators and barriers of growth emerged as different aspects of the same constructs. All the women described their experiences of both positive and negative aspects of the following domains.

3.1.Person-centred care

Care was experienced as most helpful when it was responsive to individual needs and ongoing difficulties, even many years later. All the women spoke about the importance of other people acknowledging their baby's life. Mothers talked about the hurt experienced when people did not look at photographs or talk about their baby:

"It's if we don't talk about Zara it's kind of denying she ever existed and that's all we've got you know. Erm, so if anybody every mentions her, you just like hearing her name." (Natalie)

3.1.1. How services are experienced

Most of the women detailed experiences of different hospitals, and reflected on how compassionate care (e.g. kind and genuine care) had made a big difference. When staff were experienced as rude, dismissive or not apologising for mistakes, this created a barrier for mothers in their ability to move forward. Women described the long-lasting effects of unhelpful experiences (e.g. bed in a maternity ward) and discussed how clear and regular staff communication was important. Mothers valued opportunities to have choice and control both prior to and after the death of the baby:

"so we had him for three days erm, and, in some ways that was very positive and I'll always say that was one of our savings graces, that we'd got to cuddle him, we could make the decisions" (Lynn)

All the mothers valued spending time with and being able to do things for their baby prior to the death (e.g. changing a nappy). After the death, some of the mothers appreciated spending time with their baby: one woman valued the opportunity to bring her baby home after the death. However, some of the mothers found this too difficult and preferred not to see their baby again. All the mothers reported that services helped with creating mementos (e.g. photos, hand/foot prints) which were treasured.

Many mothers explained the importance of practical help from services (e.g. registering the birth and death). One mother described difficulties with the job centre (e.g. being required to sign-on for benefits), which she described as a barrier in being able cope. Most of the women described other significant losses (e.g. miscarriage); these appeared to compound the pain associated with their baby’s death. However, one woman explained how the experience of previous family bereavement informed her decision to seek alternative support.

A small number of women described having the opportunity to talk to a counsellor. Six mothers were offered medication; for most this was the only help available for their distress. For two women medication was helpful in the short-term, and one woman viewed this as a long-term coping strategy. However most of the women reported wanting to talk and not take medication. Furthermore, the women who had had subsequent children, described how - in addition to the fears they were experiencing about having another baby - staff not reading their notes or providing a consistent medical team meant that they had to continually explain their circumstances, which increased their distress.

3.1.2. Relationships with partner and social network

Two women reported that their partners were coping in different ways (e.g. not discussing experience); therefore one woman decided to seek support from other sources, and the other woman struggled to engage with support until she ended the relationship. However, most of the mothers detailed the importance of the couple relationship in supporting each other:

"I think we support each other very well, I think that's a positive, I think Abigail kind of connects us in that way, we have that but no-body else has." (Debbie)

Participants described unhelpful experiences of family and friends who relinquished contact or had strong views about how the mothers should be coping (e.g. an expectation about grieving). Most of the mothers found family and friends supportive when they persisted in maintaining relationships, provided non-judgemental support, continued to talk about the baby and joined in with charitable involvement or events which marked the baby's life.

All of the mothers described their experiences of having contact with other bereaved parents (e.g. social media), and most explained this was important because they could really understand and empathise. The participants also described being able to learn from other bereaved mothers. However, some women explained how support groups did not enable them to meet people with a similar experience (e.g. stillbirth), or provided a context which was experienced as unhelpful:

"The most positive thing to come out of Jessica's death, the friendship I have with [name], because she is the only person who really understands how I feel. … I know how she feels when she was worried about having another baby, I knew how traumatic, I know how it feels when you don't want to have a scan, you don't want to look at the screen and you just know how it is, we don't need to say because we just know. .. I think it helps you up until a certain point and then you get to a point when you just have to step back away from it because you don't need it anymore, and because there are people that 'scab-pick' and that's not good for you." (Karen)

3.2.Making sense of what happened

All of the women described rumination about the events that took place around the time of their baby's death, in order to try and process their experiences. Barriers to being able to make sense of their experience included: issues pertaining to guilt, whether anyone was to blame and not knowing the cause of death. Factors which appeared to be helpful for the women to make sense of their baby's death were: having no regrets (e.g. removing life support), being able to reflect on positive memories of interactions, support and spending time with their baby:

"We could still interact with her, change her nappy, and clean her, things like that. So you know when we look back on the experience, then we feel very honoured and blessed that we had the opportunity to spend six days with her." (Leslie)

3.3.Personal coping strategies

Most of the women described making a personal decision to cope. For some women this occurred due to childcare responsibilities, whereas some women described making this decision after meeting other bereaved parents:

"I kind of never wanted to go down that route [of being anxious and depressed long-term] and I think that's another reason why and where my strong will came in. I had to make things positive for me because I didn't want to end up in that same situation" (Rachel)

A majority of women discussed how it had been helpful to try and take others' perspectives, in relation to others' comments:

"You know people are doing their best and they're not trying to hurt you and they are not going out to hurt you. Yes, they can say things that might sound incredibly erm... hurtful, you

know just thoughtless a lot of the time …. So I think that has helped me sort of manage them and manage my relationships with people." (Lynn)

The mothers discussed developing an understanding of what they were able to cope with and an ongoing need to be able to identify when something was too much for them, and the importance of others understanding this. The women described an awareness of what reignited painful emotions; for some this meant no longer doing certain things (e.g. watching sad films) or attending support groups:

"It became counterproductive it kept, as I got to the point of I don't want to meet any new people, I don't want to read any new stories because it's, I'm just starting to climb out of this pit of despair and I don't want to get dragged back in by somebody that's only just lost their baby" (Mary)

Many mothers discussed how finding something to focus on was helpful; some had become involved with charities to raise money, raise awareness for certain conditions or support bereaved parents. Some of the mothers focused on another pregnancy:

"I wanted to get pregnant again, it was never to replace Beth but you know, we were all ready for a baby and we never got to bring a baby home … I suppose I put a lot of my energy and focus into that." (Leslie)

3.4.Finding ways of learning to live with it

The women who had existing children at the time of their baby's death explained how they needed to carry on living and caring for their children. The women who had subsequent children described how this had not taken away their sadness, but had helped by bringing happiness; however this did not come without difficulty:

"My big want is I will never have a family photograph because there is always somebody missing from it ... it's this constant battle with yourselves, sort of how can I be happy, how can I not be happy. It seems like every time there is a big change you have to wait for things to settle down again" (Lynn)

Returning to work at a pace which was responsive to their needs provided some women an opportunity to establish a routine and some distraction. However, pressure to return to work was experienced as unhelpful:

"It was very difficult for me to go back to work and I went, I'd agreed that I would go in three days a week and the [manager] at the time basically came to see me during that week and said he expected me to be back in full time in the next week, and I just lost the plot" (Karen)

All the women described a continuing bond with their baby and displayed photographs. All the women who had living children referred to their children's brothers or sisters. Some mothers found comfort in believing that their baby was in heaven, whereas other women described keeping their baby's memory alive through charity work. All the mothers explained that a combination of factors had enabled them to experience personal growth and reported that time is an important part of the process.

"I think it's just a combination of time and talking with other people" (Mary)

3.5.Identity

The women's' identity was identified as an integrative theme which occurred throughout the interviews. Mothers talked about the importance of being able to do things for their baby, either while in the hospital or after the death of their baby, which appeared to be important in terms of developing a sense of identity as a mother. One mother discussed the importance of being supported to express milk, which was given to her baby in neonatal intensive care unit (NICU):

"They made sure they told me, this is all your milk. That stands out for me as one of the best things I did, that support because it was doing something for her" (Debbie)

Coming home without their baby left the women with a sense of having lost their identity as a mother. Some women had been able to develop their identity by having subsequent children, helping others, or returning to work. As mothers continued to make sense of their experiences and develop continuing bonds with their baby, they began to develop an identity as a mother of a baby who did not survive:

"We've gone from being two adults with no children, to being parents of toddlers, and also a parent to a baby who did not live" (Kate)

Discussion

What this study adds

This is the first study to focus on mothers' experiences of post-traumatic growth after neonatal death, and adds a unique contribution to understanding some of the potential facilitators and barriers of growth. This study introduces the possibility that some mothers make choices in relation to how they cope with their experience. The sample was a small group of women who had sought support from Sands; therefore these women may have had certain characteristics which may have supported the development of these personal coping strategies, for example an internal locus of control (Tedeschi & Calhoun, 1995) or dispositional optimism (Helgeson et al., 2006). This finding raises questions in relation to those women who are not able to develop such coping strategies. Furthermore, there are benefits to developing the ability to recognise what can be coped with; however some self-care strategies could be problematic in the long-term (e.g. avoidance of social events).

This study emphasises that all interactions, even those prior to the death, have the potential to be either a facilitator or a barrier in helping the mother in the long-term. Furthermore, this study highlights the importance of person-centred care for mothers; the complex individual differences that each mother may bring to their experiences require consideration in the provision of her care (e.g. multiple losses, social circumstances).

Extant literature

The findings in relation to experiences of growth in the domains of self-perception, relationships and life philosophy are consistent with post-traumatic growth (Tedeschi & Calhoun, 1995). A couple of the mothers described strengthened faith in existing beliefs, however none of the participants reported new-found religion as an aspect of their growth; a theme which has emerged in American studies where religion is generally more prevalent (Calhoun et al. 2010), indicating potential cultural differences. Tedeschi and Calhoun (1995) cautioned the potential for some individuals who very quickly after an event report many highly positive outcomes. Indeed, these reports could be seen as defensive process where an individual avoids confronting the unbearable pain (Bateman, Brown & Pedder, 2010). However, each of the individuals who participated described both an intense struggle with their pain, and coexisting negative outcomes, alongside their experiences of growth.

The findings are consistent with current literature in relation to the potential processes for facilitating post-traumatic growth, for example, making sense (Michael & Cooper, 2013), rumination (Taku et al., 2008), and charity involvement (Reilly, Huws, Hastings & Vaughan, 2008). Continuing bonds have featured as controversial in the discussion of adjustment following bereavement; some authors suggest that a continuing bond with the deceased has an adaptive role (Klass, 2006). Similarly, for the mothers who participated, having an ongoing bond with their baby was an important aspect of facilitating post-traumatic growth, in line with Michael and Cooper (2013). The indication that support from other bereaved parents is helpful, is consistent with the literature (Reilly et al., 2008); learning from other bereaved mothers could be understood as vicarious learning (Tedeschi & Calhoun, 1995).

Woodroffe (2006) described how the NICU is a place where multiple losses occur (e.g. the “perfect” birth). The importance of person-centred care and the acknowledgement of the baby are consistent with previous literature (Doka, 1999). There has been debate around the guidance in relation to parents being offered to see their baby after death. Baddenhorst and Hughes (2007) suggest that seeing the baby after death is not evidence-based and has the potential to cause post-traumatic stress symptoms for some women. The current findings highlight the importance of care which is sensitive and responsive to individual needs.

Strengths and limitations

The sample were self-selected from the Sands Facebook population and are therefore individuals who wish to discuss their experiences; providing demographic details allowed for ‘situation of the sample’. Therefore, although it was not an aim of the study, the findings have limited transferability. This research does not allow inferences about causal or process factors of growth. However, this study benefitted from a systematic approach, with regular reflection and supervision to monitor the potential for researcher bias. The homogenous sample afforded the opportunity to understand experiences of growth following a neonatal death. Importantly, this study provides a better understanding of the paradox of the experience and the potential for both positive and negative outcomes. The study was developed with Sands, who have extensive experience providing support to bereaved families; providing extra assurance that the study was conducted in an ethical manner. Template Analysis afforded the opportunity to develop a priori codes based on extant literature, but also ensured that emerging themes were identified (Brooks et al. 2015). Furthermore, the stance of subtle realism allowed an insight into the participants’ experience of positive personal changes, while acknowledging the influence of the researcher.

Clinical and wider implications

Person-centred, compassionate and respectful interactions before and after the death of a neonatal baby is vital; interactions will frequently be thought about as mothers attempt to process their experience. These findings develop current understanding regarding identifying those individuals who may require more support (e.g. impact of multiple losses). Having existing or subsequent children may help some mothers; however maternity services need to accommodate individual experiences and fears associated with another pregnancy. Furthermore, returning to work could be helpful for some women. However, employers should be mindful of the long-term impact of neonatal death and the importance of providing individualised support (e.g. graded return), something which is not currently explicit in public health guidance.

Clinical psychology implications

For some mothers, medication may be wanted or needed. The women’s reports of wanting to talk and dissatisfaction with medication being the only option, are an important finding. Combined with evidence from the United States of increased prescribing for bereaved parents following perinatal death (Lacasse & Cacciatore, 2014), it is necessary that services consistently offer holistic approaches which include psychological components. Clinical psychologists could utilise these findings in staff training or facilitating user-led services. Clinical psychologists working with individuals could use narrative approaches to support mothers to ‘thicken the plot’ in relation to her identity as a mother or facilitate sense making and cognitive re-framing of experiences. Furthermore, therapeutic models that support a mother’s intention to cope could include solution focussed approaches. Importantly, the participants all reflected on how they had derived some therapeutic benefit from being able to discuss their experiences, therefore it is possible that the questions and process of these interviews may have clinical applicability. It is important to ensure that identification of growth, has occurred via the struggle with the trauma and that it is not occurring as a defensive denial of the pain (Tedeschi and Calhoun, 1995). Clinical psychologists therefore have an important role in not colluding with an over simplistic view of post-traumatic growth, but rather providing a comprehensive assessment and formulation of the mothers difficulties, pain and struggle with her grief in addition to understanding the potential for growth resulting from the struggle. Furthermore, clinical psychologists possess a combination of clinical and research skills (British Psychological Society, 2010), equipping them with the abilities to conduct further research in this area and improve care.

Future research

Future studies would benefit from exploring the factors associated with mothers' choosing coping strategies. The experiences of post-traumatic growth in relation to stillbirth, miscarriage and abortion would benefit from research attention. Many of the participants reported that their partners were expected to return to work shortly after the death of their baby. Future research would benefit from seeking to understand fathers' experiences and support needs, especially as gender differences following neonatal death are documented (Buchi et al., 2007).

Conclusions

In addition to ongoing sadness, the mothers were able to identify some positive personal changes which resulted from the struggle with their neonatal baby dying. These changes were consistent with the post-traumatic growth model (Tedeschi & Calhoun, 1995). Participants identified facilitators and barriers to positive personal growth; these were identified as different dimensions of five constructs: person-centred care, making sense of what happened, personal coping strategies, learning to live with it and identity. This research contributes a new perspective, that the women who participated reported making a personal decision to cope with their situation and attempted to take others' perspectives, which helped to facilitate their growth. Furthermore, these findings emphasise that all interactions, even prior to the death, have the potential to be either a facilitator or a barrier in helping the mother in the long-term. This evidences the importance of providing person-centred maternity care which accommodates individual needs.

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Appendices

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Word count: 7609

Appendix A: Author Guidelines for European Journal of Psychotraumatology.

This document has been shortened, but the full document can be retrieved from:
http://www.ejpt.net/index.php/ejpt/pages/view/guidelines

Types of papers The Journal welcomes original basic and clinical research articles that consolidate and expand the theoretical and professional basis of the field of traumatic stress (max 6000 words incl. abstract and references, excl. tables/figures).

In exceptional cases the word limit can be exceeded, but in principle this should be avoided. Supplementary material, like large tables, data sets, protocols, videos, questionnaires, non-English versions of the article can be uploaded as supplementary material and will thus also be available online.

Acknowledgements All contributors who do not meet the criteria for authorship should be listed in an acknowledgments section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chairperson who provided only general support. Financial and material support should also be acknowledged.

Ethics and consent When reporting experiments on patients or animals, please indicate whether the procedures followed were approved by your local ethics committee and/or in accordance with the Helsinki Declaration of 1975, as revised in 2008 (http://www.healthscience.net/resources/declaration-of-helsinki/).

Gender Policy Authors must comply with the EJPT gender policy, developed on the basis of recommendations from the European Association of Science Editors (EASE) Gender Policy Committee. All articles submitted to EJPT must:

- report the sex of research subjects
- justify single sex studies
- discriminate between sex and gender (mostly for human research)
- analyse how sex or gender impact the results
- discuss sex and gender issues when relevant

Language All articles should be written in English - British or American as long as consistency is observed.

MANUSCRIPT LAYOUT

Wherever possible, the paper should follow the traditional layout: Title, Biographical details, Abstract, Keywords, Background, Objective, Method, Results, Discussion, Conclusions, References, Tables, Figures.

Title The title should be informative and accurate and at the same time trigger the interest of the reader. A short running head will be derived from the title to appear on each page of the paper.

Abstract Articles must include a structured abstract of 200-300 words providing sufficient information for a reader to be able to decide whether or not to proceed to the full text of the article. The abstract should be structured in the following way (incl. these headings): Background, Objective, Method, Results, Conclusions.

Keywords After the abstract, please give 5-10 key words for readers looking for material by key word searching on Internet. Avoid using the same words as in the title.

Figures Upon acceptance please supply figures/graphics/images in at least 300 dpi. For further information please see Guidelines.

If the figures/graphics/images have been taken from sources not copyrighted by the author, it is the author's sole responsibility to secure the rights from the copyright holder to reproduce those figures/graphs/images for both worldwide print and web publication. All reproduction costs charged by the copyright holder must be borne by the author.

Section headings Please do not number section headings. Use a maximum of three levels of headings made clear by orthographic indicators, i.e. capitals, italics, bold etc.

Quotations Please use double quotation marks. Quotations longer than 40 words should appear in a separate paragraph.

Citation and reference system The *European Journal of Psychotraumatology* applies to the APA system, 6th edition.

Appendix B: Process of systematic review

Question to be answered from systematic review	1. What aspects of post traumatic growth are experienced by bereaved parents? 2. What factors appear to be associated with facilitating or preventing post traumatic growth in bereaved parents 3. Where are there gaps in the current understanding of bereaved parents' experience of post traumatic growth?			
Preparation for searches				
Date	Action taken		Comments	
4.8.15	Met with Shirley Yearwood-Jackson – Psychology librarian to discuss process of searches Conducted scoping searches			
Data base searched	Date of search	Search terms applied	Number of results	Comments
PsychINFO	28.10.15	Growth terms: "ptg" OR "positive growth" OR "benefit finding" OR "stress related growth" OR "positive change" OR "post traumatic growth" OR "adjustment" OR "positive adaption" AND Parents terms: "mother" OR "father" OR "parent" AND Death terms: "loss" OR "grief" OR "bereavement" OR "neonatal death"	113	
PsychARTICLES	28.10.15			
Medline with full text	28.10.15			
CINAL	28.10.15			
Web of Science	28.10.15		980	
Total results retrieved			1093	31 theses and books removed / 18 duplicates removed
Records to be screened – once thesis and book chapters removed			1044	

Inclusion criteria

- Primary focus of paper (or if explorative qualitative research major outcome) to be post traumatic growth/positive personal growth in bereaved parents.
- Papers to be published in English, in a peer reviewed journal, any date of publication

Exclusion criteria

- After some consideration, having completed some interviews and reading. Decision made to exclude experiences of stillbirth/miscarriage. Appears to be a very important, but very different experience to having a child who is born alive and subsequently dies

Selection of papers from retrieved searches

Date	Action taken	Comment	Results remaining
Management of retrieved sources			
28.10.15	Imported all retrieved sources into endnote		
28.10.15	Removed duplicates using function in endnote		
28.10.15	Imported all remaining sources into Excel document for screening		
Screening of sources			
November 2015	Screened titles and coded as excluded if title was irrelevant to research question	Work duplicated by LH for fidelity	

December 2015	Read abstracts and coded as excluded if abstract do not meet inclusion criteria	Work duplicated by LH for fidelity	
December 2015	Read full text papers and excluded if paper did not meet inclusion criteria	Work duplicated by LH for fidelity	
16.12.15	Discussion with LH to make final decision on which full text papers to be included in systematic review		10

Reasons for exclusion

Reason for exclusion	Number of sources excluded	Number of sources remaining
Title		
		1044
Book	3	1041
Not in English/abstract irrelevant	3	1038
Duplicate not identified in endnote	6	1032
Title is nothing to do with child death and/or post traumatic growth – title irrelevant	810	222
Total excluded by title	822	222
Abstract		
Review paper – irrelevant subject	1	221
Not looking at exclusively at parental bereavement	53	166
Not focused on personal/post traumatic growth	116	52
Total excluded by abstract	170	52
Full text		
Not looking exclusively at parental bereavement – 'death of loved one'	1	49
Not looking exclusively at parental bereavement – includes death of spouse	2	47
Not looking exclusively at parental bereavement – included experience of grandparents/aunts etc.	1	46
Evaluation of group – not focused on growth	2	44
Includes miscarriage and/or stillbirth	5	39
Not focused on growth – e.g. focus on pathological responses, distress, return to workplace, religion, care preferences	31	10
Total excluded at full text	42	10

Searching references from included papers

Date	Action	Comment	Results remaining
16.01.16	Searched references of all included papers and identified papers to be considered for inclusion	Identified 8 papers which required consideration for inclusion	8
19.01.16	Applied inclusion criteria to papers to be considered for inclusion	Work duplicated by LH for fidelity	
20.01.16	Discussion with LH to make final decision on which additional papers meet inclusion criteria and should be included in systematic review	Excluded 5 papers on the basis of them not meeting inclusion criteria	3
Reasons for exclusion of identified sources			
Not focused on growth			3
Includes miscarriage and/or stillbirth			2
Final paper numbers			
Papers identified from initial searches			10
Papers identified from references of included papers			3
Total number of papers to be included in SR			13

Data extraction, quality assessment, synthesis and write up

Date	Action	Comment
Data extraction		
	Data extraction of all 13 included papers completed	Decision made to complete data extraction prior to quality assessment, as advised in SR book (Boland, Cherry & Dickson, 2014). Advised that quality assessment prior to extraction, may bias data extraction, but should be considered in synthesis of data and interpretation of outcomes
Quality assessment		
16.02.16	Applied the mixed methods assessment tool to all included articles	Work duplicated by LH for fidelity
17.02.16	Discussion with LH to confirm results of quality assessment	
Synthesis		
19.02.16	Generated a summary of all results from papers	
20.02.16	Generated a one page summary of planned synthesis for supervision	
Write up		
23.01.16 – 4.03.16	Began write up of systematic review	

Appendix C: Study approval from Clinical Psychology Programme

UNIVERSITY OF LIVERPOOL

D.Clin.Psychology Programme
Division of Clinical Psychology
Whelan Building, Quadrangle
Brownlow Hill
LIVERPOOL
L69 3GB

Tel: 0151 794 5530/5534/5877
Fax: 0151 794 5537
www.liv.ac.uk/dclinpsychol

1st September 2014

Amy Waugh
Clinical Psychology Trainee
Doctorate of Clinical Psychology Doctorate Programme
University of Liverpool
L69 3GB

RE: Understanding the factors that facilitate adjustment following neonatal loss
Trainee: Amy Waugh
Supervisors: Gundi Kiemle, Pauline Slade

Dear Amy,

Thank you for your response to the Chair's comments of your research proposal submitted to the D.Clin.Psychol. Research Review Committee (letter dated 27/08/14).

I can now confirm that your amended proposal (version 2, date 21/07/14) and revised budget (version 3, dated 27/08/14) meet the requirements of the committee and have been approved by the Committee Chair.

Please take this Chairs Action decision as ***final*** approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

Dr Catrin Eames
Vice-Chair D.Clin.Psychol. Research Review Committee.

A member of the Russell Group

Professor John Read	Dr Jim Williams	Dr Joanne Dickson	Dr Laura Golding	Mrs Sue Knight
Programme Director	Clinical Director	Research Director	Academic Director	Programme Co-ordinator
readj@liv.ac.uk	j.r.williams@liv.ac.uk	jdickson@liv.ac.uk	l.golding@liv.ac.uk	sknight@liv.ac.uk

Appendix D: Study approval from the Stillbirth and Neonatal Death Society

Sands
Stillbirth & neonatal death charity

11 February 2015

To Whom It May Concern

Sands support for 'Is it possible for women's lives to change in a positive way after the death of their baby?' (Amy Waugh/Gundi Kiemle)

I write to express Sands' support for the above project.

Sands agreed to support Ms Waugh's work after reviewing her proposal in 2014; we considered it aligned with one of our core aims, to support bereaved parents and ensure they receive the best possible care.

Erica Stewart, our helpline manager and a bereaved parent, and I have worked with Ms Waugh over several months to ensure that parent-facing material is worded sensitively, and that the recruitment process is feasible but addresses any safeguarding issues that we consider could arise. We support researchers in the recruitment of participants for projects such as this quite frequently; we know from our experience in this area and from direct contact with bereaved parents that there is an overwhelming desire to contribute to research into the causes of stillbirth and neonatal death, and the best way to support families after a baby's death.

We have worked with Ms Waugh on the recruitment process and consider that the proposed process will not cause harm to any mother who is alerted to the opportunity to participate or who decides to contact Ms Waugh for further information.

We look forward to working with Amy on this project and hearing about the outcomes of her research.

Yours faithfully,

Laura Price

Laura Price PhD

Research and Information Officer, Sands

Appendix E: University of Liverpool Research Ethics Study approval

RE: ethics amendments RETH000796
Ethics [ethics@liverpool.ac.uk]
Sent:06 March 2015 07:47
To: Waugh, Amy
Cc: Kiemle, Gundi; Slade, Pauline

Dear all,

I am pleased to inform you that the Subcommittee has approved your application for ethical approval for your study. Details and conditions of the approval can be found below.

Reference:	RETH000796
Subcommittee:	Non-invasive procedures
Review type:	Full committee review
Principal Investigator:	Dr Gundi Kiemle
Student Investigator:	Ms Amy Waugh
School/Institute:	Clinical Psychology
Title:	Understanding the factors that facilitate adjustment following neonatal loss
First Reviewer:	Dr Jo Harrold
Date of initial review:	20/01/2015
Date of Approval:	06/03/2015

The application was APPROVED subject to the following conditions:

Conditions

All serious adverse events must be reported to the Subcommittee within 24 hours of their occurrence, via the Research Integrity and Governance Officer (ethics@liv.ac.uk).

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Sub-Committee should be notified. If it is proposed to make an amendment to the research, you should notify the Committee by following the Amendment procedure. If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the Research Integrity and Governance Officer at ethics@liverpool.ac.uk in order to notify them of a change in PI / Supervisor.

Kind regards

Matthew

Matthew Billington
Research Integrity and Governance Officer
Research Support Office
University of Liverpool
Waterhouse Building (2nd Floor, Block C)
3 Brownlow Street
Liverpool
L69 3GL

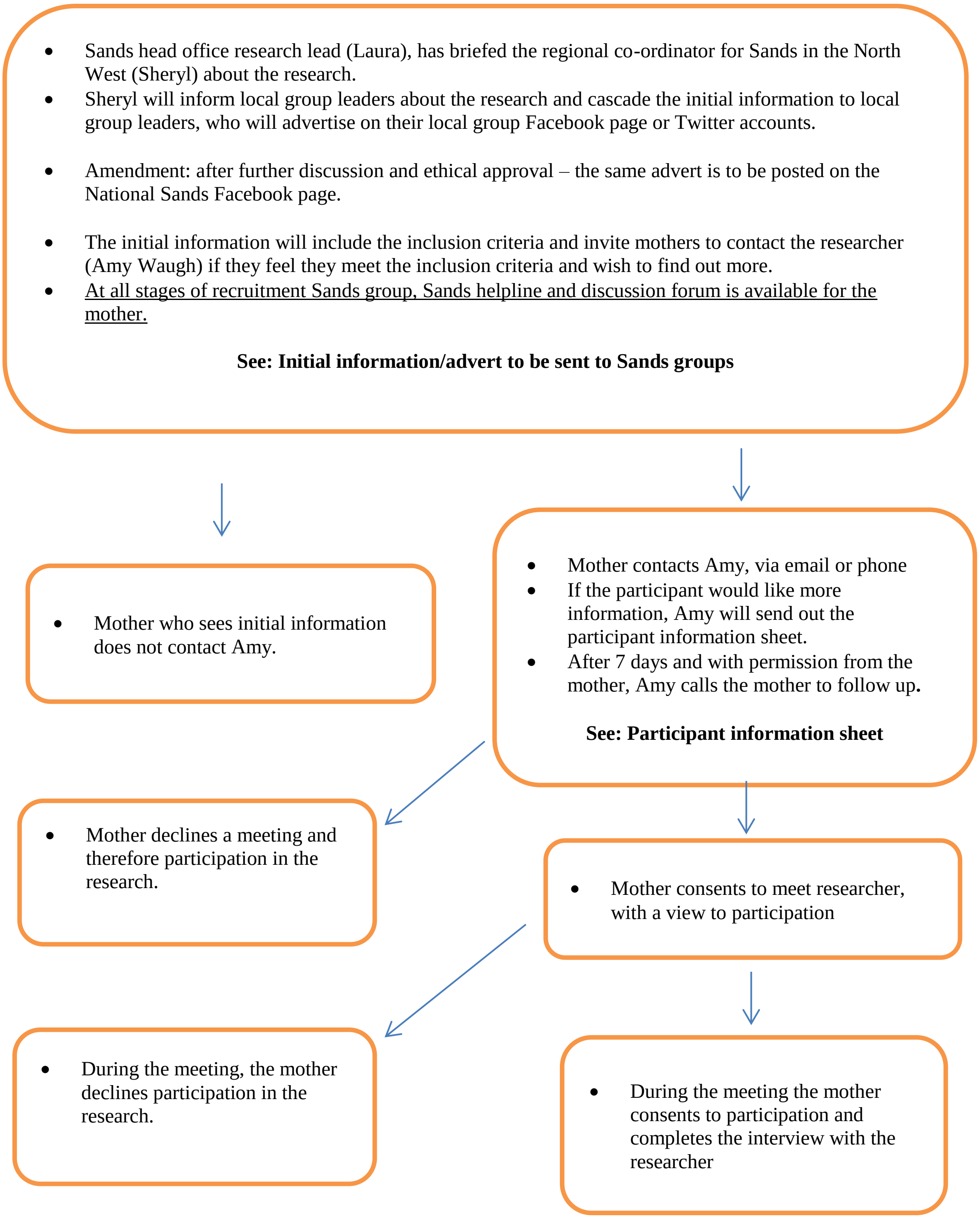
Email: ethics@liverpool.ac.uk
Telephone: 0151 794 8290
Website: Research Integrity & Ethics

Appendix F: Protocol for recruitment

Is it possible for women's lives to change in a positive way after the death of their baby?

Protocol for Recruitment

Date: 4.2.15 (version 3)



- Sands head office research lead (Laura), has briefed the regional co-ordinator for Sands in the North West (Sheryl) about the research.
- Sheryl will inform local group leaders about the research and cascade the initial information to local group leaders, who will advertise on their local group Facebook page or Twitter accounts.

- Amendment: after further discussion and ethical approval – the same advert is to be posted on the National Sands Facebook page.

- The initial information will include the inclusion criteria and invite mothers to contact the researcher (Amy Waugh) if they feel they meet the inclusion criteria and wish to find out more.
- <u>At all stages of recruitment Sands group, Sands helpline and discussion forum is available for the mother.</u>

See: Initial information/advert to be sent to Sands groups

- Mother who sees initial information does not contact Amy.

- Mother contacts Amy, via email or phone
- If the participant would like more information, Amy will send out the participant information sheet.
- After 7 days and with permission from the mother, Amy calls the mother to follow up.

See: Participant information sheet

- Mother declines a meeting and therefore participation in the research.

- Mother consents to meet researcher, with a view to participation

- During the meeting, the mother declines participation in the research.

- During the meeting the mother consents to participation and completes the interview with the researcher

Appendix G: Advert for the study

Research project

Sands has agreed to help a trainee clinical psychologist find bereaved mothers to take part in a research project. Amy Waugh, based at the University of Liverpool, is looking into how mothers' lives change after bereavement.

If you can say yes to all the following questions and would like to find out more about taking part in the study, please contact the Amy using the details below.

- Your baby died in the first 28 days of life
- Your baby died 2—10 years ago
- You are not pregnant
- You can meet Amy in the North West to talk (in English) about your experience
- You feel able to talk about some of the changes that may have happened in your life since your baby died.

Amy's requirements for this study are very specific. If you would like to take part in research but your experience doesn't match with this project, please keep an eye on the UK Sands Facebook page, as we tend to post opportunities for involvement there.

You may not wish to find out any more information, if this is the case, this will not affect the support you receive from Sands.

Contact details for Amy Waugh
Telephone number: 07519 896552
Email address: amy.waugh@liverpool.ac.uk

Appendix H: Participant information sheet

Is it possible for women's lives to change in a positive way after the death of their baby?

Participant Information Sheet

Date: 4.2.15 (version 3)

You are being invited to take part in a research study. Before you decide whether to participate, it is important for you to know why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives or your GP if you wish. You do not have to accept this invitation and you should only agree to take part if you want to. Thank you for reading this information sheet.

What is the purpose of the study?

The death of baby can be a devastating and painful experience. This study will try to gain a better understanding of what helps mothers change over time after their baby has died. In particular we are interested in whether changes may occur after such a tragic event, and if it is possible for some of these changes to be experienced as positive. If this is possible, we would like to find out more about how this happens. It is hoped that the information from this study will help improve the understanding and support provided for mothers whose babies have died.

Why have I been chosen to take part?

Sands, the stillbirth and neonatal death charity, has kindly agreed to help with this research by advertising the study and inviting mothers who feel able to share their personal experience with the researcher, Amy Waugh. For the study, Amy wants to speak to mums whose baby died during the first 28 days of life, between 2 and 10 years ago. Amy will not have access to your medical records; you have been invited to take part following your contact with Sands.

Do I have to take part?

No. Participation in this study is voluntary and deciding not to take part will not affect any support or health services you use or may use in the future.

What will happen if I take part?

If you are interested in taking part, please contact Amy (the researcher), whose contact details are at the end of this sheet. After a conversation on the phone, if you are still willing to take part, Amy will offer you an appointment that is convenient for you. This would usually take place at your home address, however it can take place at the University of Liverpool if you prefer.

When Amy arrives for the interview she will confirm that you have read the information about the study and that you are still happy to take part. If you are, Amy will ask you to sign a consent form and complete a short questionnaire so that we have some general information about you (for example, your age, ethnicity, occupation). If convenient, Amy will complete the interview during this appointment and it is anticipated that this will last around one hour. The interview will be audio recorded. During the interview Amy will ask you about your baby, anything that may have helped you over time and the changes you have noticed in your life since your baby died. If there are any questions you do not feel able to answer, for whatever reason, you can tell Amy that you do not wish to answer.

What will happen if I want to stop taking part?

You can stop taking part in the study at any time without giving an explanation. Once you have had your interview with Amy, you will be able to withdraw your interview from the study up until the point at which it is separated from your personal information (two weeks after the interview). Withdrawing will not affect any support or services you receive now or in the future.

Are there any risks in taking part?

We do not think there will be any risks to taking part, but talking about your baby may bring up some difficult memories and feelings for you. You will be able to stop the interview at any point if you want to take a break. Amy is a trainee clinical psychologist and she will talk to you about who you can speak to for further support. This information will also be provided in writing.

Are there any benefits to taking part?

This research has not been designed to have any therapeutic benefit for mothers and it is unlikely that there will be any direct benefits to you personally for taking part in this research. But it is hoped that the findings from this study will be used to improve the general understanding, knowledge and skills of people who support mothers whose babies have died.

What if I am unhappy or there is a problem?

This study has been approved by the University of Liverpool Research Ethics Committee. If you are unhappy with any aspect of the study you can contact Amy using the details below. Alternatively you can contact (ethics@liverpool.ac.uk).

Reimbursement

If you decide to take part, you will be given a £10 voucher at the end of your interview, for the time and effort you have given to participate in the study.

Will my participation be confidential?

Yes, all answers you give during the meeting will be confidential. They will be added to the information provided by other mothers who take part in the study. It is possible that an anonymised quote from your interview might be used in the final reports, but it will not be possible to trace any of these quotes back to you.

What will happen to the results of the study?

The results of this study will form the basis of a doctoral thesis for the researcher's qualification in Clinical Psychology. The results will be published in a professional publication to increase the knowledge of individuals who support mothers whose baby has died. A summary of the results will be provided to Sands. If you decide to take part, you will be offered a copy of this summary.

Who can I contact if I have further questions?

If you are interested in taking part, or if you wish to ask any questions to help you decide whether or not to take part, you can contact Amy using the following details.

Amy Waugh
Email: amy.waugh@liverpool.ac.uk
Telephone: (07519 896552)

Appendix I: Consent form

UNIVERSITY OF LIVERPOOL

Is it possible for women's lives to change in a positive way after the death of their baby?

Participant Consent Form

Date: 4.2.2015 (version 3)

Title of Research Project:
Is it possible for women's lives to change in a positive way after the death of their baby
Researcher: Amy Waugh (Supervised by Dr Gundi Kiemle and Prof. Pauline Slade)

Please initial box

1. I confirm that I have read the information sheet dated 4.2.15 (version 3) for the above study. I have had the opportunity to consider the information and ask questions, and I have had these answered satisfactorily. ☐

2. I know that my participation is voluntary and that I am free to leave the study at any time without giving any reason. I can choose not to answer one or more of the questions during the interview. ☐

3. I know that, under the Data Protection Act, I can ask for access to the information I have provided at any time and I can ask for the information to be deleted up to two weeks after the date of the interview. ☐

4. I know and agree that my interview will be audio recorded. I am aware that these recordings will be typed up and analysed as part of the study and that my personal details will not be linked to the typed version, and I consent to this use. I understand that the recordings will be destroyed after they have been typed up. ☐

5. I know that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

6. I know and agree that once the interview has taken place, it will be unlinked from my personal information after two weeks and when this happens I no longer be able to withdraw my answers from the study. ☐

7. I know that a summary of the work will be available to participants. Please indicate to the researcher if you would like to receive a copy of this summary ☐

8. I agree to take part in the above study ☐

Participant Name	Date	Signature
Researcher	Date	Signature

Principal Investigator:
Dr Gundi Kiemle
Doctorate in Clinical Psychology
University of Liverpool
0151 794 5534
g.kiemle@liverpool.ac.uk

Student Researcher:
Amy Waugh
Doctorate in Clinical Psychology
University of Liverpool
07519 896552
Amy.Waugh@liverpool.ac.uk

Appendix J: Demographics Questionnaire

Is it possible for women's lives to change in a positive way after the death of their baby?
Demographics Questionnaire
Date: 4.2.15 (version 3)

Thank you for deciding to take part in this research project. In order to understand more about the mothers who have decided to take part, it would be helpful if you could complete the following questions. Please ask if any of the questions are unclear.

Age:
- ☐ 18 – 29
- ☐ 30 – 39
- ☐ 40 – 49
- ☐ 50 – 59
- ☐ 60 – 69
- ☐ 70 – 79

Marital status:
- ☐ Single
- ☐ Cohabiting
- ☐ Married
- ☐ Divorced
- ☐ Separated
- ☐ Other, please specify:

Education level:
- ☐ No qualifications
- ☐ GCSE's
- ☐ A-levels
- ☐ Degree
- ☐ Skills based qualification (e.g. NVQ's)
- ☐ Other, please specify:

Please state your occupation:

Ethnicity:
- ☐ White British
- ☐ White Irish
- ☐ White other, please specify:
- ☐ Black British
- ☐ Black African
- ☐ Black other, please specify:
- ☐ Asian
- ☐ Other, please specify:

Religion:
- ☐ No religion
- ☐ Christian
- ☐ Muslim
- ☐ Jewish
- ☐ Hindu
- ☐ Other, please specific:

Thank you for completing this questionnaire.

Appendix K: Topic guide

Is it possible for women’s lives to change in a positive way after the death of their baby?

Topic Guide

Date: 4.2.15 (version 3)

Hearing from people who have changed following a tragic event, such as the death of a baby, helps us know more about what can happen and how best to support those affected. We would like to hear about your experiences, and what changes may have happened in your life and in yourself since the death of your baby. In particular, we are interested in whether mothers are able to grow and change after such a tragic event. If it is possible to experience some changes as positive, we would like to find out how this happens. We are hoping to speak to up to 12 bereaved mothers in total.

1. Can you tell me about your baby?
   Prompts, if needed:
- When did your baby die?
- What happened?
- How did it happen?
- Where did it happen?
- Who was around/involved (family, services etc.)?

2. Can you tell me about your feelings associated with the loss of your baby?
- Immediately?
- In the following weeks and months?
- In the years following this loss?

3. How has your life changed since (name of baby) died?
- Are there any ways in which you see yourself differently?
- What are your thoughts about how you view yourself now, and the similarities or differences compared with around the time when your baby died?
- How would you describe the ways in which your relationships with others have changed?
- How have your views about the world have changed?
- How might your family/friends describe the changes in you?

4. Although (name of baby)’s death was very difficult, how do you feel you have grown and developed since then?
   Prompt, if needed:
- What about any positive developments?

5. What sort of things (people, events, experiences) have been important in bringing about any positive changes after (name of baby)’s death?
- Family/relationships / new friends?
- Existing / subsequent children?
- What may be helpful now?

6. What sort of things (people events experiences), if any, got in the way of making any positive changes after (name of baby)’s death?

7. Looking back, what may be stopping or may have stopped you seeing any changes as positive?
- Anything that blocked/delayed your grieving process?
- What was really unhelpful when you were trying to cope – initially or later?
- What might have helped more – either initially or later on?

Appendix L: Debrief sheet

Is it possible for women's lives to change in a positive way after the death of their baby?

Participant Debrief Information

Date: 4.2.15 (version 3)

Dear (name of participant),

Thank you for taking part in this research study. Talking about the death of a baby can be difficult, and your generosity and willingness to participate in this study are greatly appreciated. It is hoped that the information provided by all the women in this study will improve our understanding of how people's lives change following the death of their baby soon after birth. We hope that this information will be used to improve the care and support provided for other women whose babies have died.

It is possible that our meeting may have raised some difficult memories and emotions for you. If you would like to speak to someone, contact:

Sands, the stillbirth and neonatal death charity
Helpline: 020 7436 5881 (Monday to Friday: 9.30am – 5.30pm and Tuesday and Thursday evenings: 6pm – 10pm); for more information see www.uk-sands.org

Your GP
If you feel you need further support, you can ask your GP for a referral for 1:1 counselling or psychological therapy within your local NHS services.

The Samaritans:
The helpline is open 24 hours a day, 365 days of the year. The Samaritans provide a confidential listening service for anybody who is feeling upset or worried. Their volunteers will listen to you, and help you talk about how you feeling if you wish.
Telephone: 08457 90 90 90 or for more information see www.samaritans.org

If you have any complaints, concerns or questions about this research, please contact, Amy Waugh (researcher) on amy.waugh@liverpool.ac.uk or (07519 896552).
Alternatively, you could contact the Liverpool University research ethics committee (ethics@liverpool.ac.uk)

Appendix M: Examples of coding in NVIVO

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Appendix N: Example of clustering codes

Name of initial code Numbers in brackets are (number of references to code/number of transcripts reference appears in)	Ideas for clustering / code labelling	Description	Comments	Final code
4. Prior to death of baby	Prior to death of baby			
4.1. Context of pregnancy (12/8)	Description of pregnancy	What was happening at the time of the pregnancy – relationships/problems with conceiving / Whether first pregnancy / Found out there was a problem during pregnancy or not	A variety of experiences – not sure any connections… and limited relevance to question - remove	n/a – removed
4.2. During pregnancy (7/5)				n/a - removed
4.3. Description of the birth (11/10)	Description of birth	Description of the birth	A variety of experiences – not sure any connections… and limited relevance to question - remove	n/a - removed
4.4. Time in nicu (23/7)	Time in NICU	Description of experience of being in NICU	**Link to communication factors** e.g. language used/approach when breaking bad news/explanations of equipment and also something about others parents in NICU	Person-centred care
4.5. Spending time with baby (13/6)	Spending time with baby	Descriptions of spending time with baby	**Links to role/identity as a mother – but mostly experience of services?** –being able to do things for baby – wipe eyes/express breast milk to be used to nourish baby, being able to have cuddles and let family see baby was important vs. painful experience of not be able to touch baby	Person-centred care
4.6. Finding out something was wrong with my baby (14/8)	Finding out something was wrong with my baby	Description of finding out that baby was unwell and would not survive	A variety of experiences – not sure any connections… and limited relevance to question - remove	n/a - removed
4.7. Finding out the baby would not survive (6/6)				
4.8. Making the decision to let baby go (6/4)	Coping mechanisms and control over the situation in NICU	Description of the way mothers described coping with their experience at the time and how they reflected on these experiences	Does this link to no regrets? / processing of experience?	Making sense of what happened
Name of initial code Numbers in brackets are (number of references to code/number of transcripts reference appears in)	Ideas for clustering / code labelling	Description	Comments	Final code

5. After the death of baby	After the death of baby			
5.1. Death of baby (12/9)	Death of baby	Description of experience of death of baby	A variety of experiences – not sure any connections… and limited relevance to question - remove	n/a removed
5.2. Spending time with baby – after death (14/7)	Spending time with baby after death	Description of mothers experiences of spending time with their baby after the death.	Link to role/identity as a mother? – being able to do something for baby But also a very personal decision Something about choice in seeing baby again after death – some mothers offered/some chose not to and some didn't have a choice..	Person-centred care

Name of code Numbers in brackets are (number of references to code/number of transcripts reference appears in)	Ideas for code to be used in final coding template	Description	Comments	Final code
5.3. New possibilities (9/6)	New possibilities	Description of things that mothers view as possible in life now/have done since the death of baby – that would not have done otherwise	**Call this section "New Life Philosophy"?**	Life philosophy
5.4. Existential changes (12/5)	Existential changes	Changes in religious views/spirituality or the meaning of life and death – which have changed since death of baby		
5.5. Changes in life priorities (15/5)	Changes in life priorities	Changes in life priorities which have resulted from the death baby		
5.6. Changes in relation to appreciation of life (10/4) / Appreciating others in my life more (7/4)	Appreciation of life and others	Changes in appreciation of life or other in life – which has resulted from experience of baby dying		

Appendix O: Spread of themes across participants

	Lynn	Kate	Karen	Michelle	Debbie	Mary	Rachel	Oliva	Leslie	Natalie
4. **Contextual factors**	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5. **Themes of post-traumatic growth**										
5.1. Self-perception (88/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5.2. Relationships (75/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5.3. Life philosophy (56/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6. **Facilitators and barriers of post-traumatic growth**										
6.1. **Person-centred care Including Acknowledgement of my baby's life (42/10) / Being able to talk about my baby (25/8)**	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6.1.1. How services are experienced										
6.1.1.1. Compassionate (19/7)		✓	✓	✓		✓		✓	✓	✓
6.1.1.2. Communication (31/8)	✓	✓	✓	✓	✓	✓		✓	✓	
6.1.1.3. Choice and control (29/8)	✓	✓	✓		✓	✓	✓	✓	✓	
6.1.1.4. Spending time with baby (23/9)	✓	✓	✓	✓	✓	✓	✓	✓		✓
6.1.1.5. Practical help (19/8)	✓	✓	✓	✓	✓	✓	✓		✓	
6.1.1.6. Going to a counsellor (13/6)		✓			✓	✓	✓	✓		✓
6.1.1.7. Medication(8/6)	✓	✓	✓	✓		✓	✓			
6.1.1.8. Subsequent interactions with services (18/6)	✓	✓		✓	✓		✓		✓	
6.1.2. Relationship with partner and social networks										
6.1.2.1. Relationship with partner (36/9)	✓	✓	✓	✓	✓		✓	✓	✓	✓

	Lynn	Kate	Karen	Michelle	Debbie	Mary	Rachel	Oliva	Leslie	Natalie
6.1.2.2. Support from friends and family (65/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6.1.2.3. Being with other bereaved parents (53/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6.2. **Making sense of what happened**										
6.2.1. Processing the experience (56/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6.3. **Personal coping strategies**										
6.3.1. Personal decision to cope (30/8)	✓		✓	✓		✓	✓	✓	✓	✓
6.3.2. Trying to take others perspectives (15/7)	✓	✓	✓		✓	✓		✓		✓
6.3.3. Recognising what you can cope with (self-care) (36/9)	✓	✓	✓	✓	✓	✓	✓	✓		✓
6.3.4. Getting a focus (12/6) - including charity involvement (28/5) / Having another baby (10/5)	✓		✓		✓	✓	✓	✓	✓	✓
6.4. **Finding ways of learning to live with it**										
6.4.1. Children (56/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6.4.2. Going back to work (26/8)	✓		✓	✓	✓	✓		✓	✓	✓
6.4.3. Continuing bonds (22/8) / Mementos (14/9)	✓	✓		✓	✓	✓	✓	✓	✓	✓
6.4.4. Importance of time (38/10)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Integrative theme										
6.5. **Identity (15/8)**	✓	✓		✓	✓	✓		✓	✓	✓

Appendix P: Excerpts from reflective diary

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