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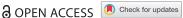
Understanding mothers' experiences of positive changes after neonatal death

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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 from the struggle with a traumatic event. This has not been explored in this context.

Objective: This study sought to understand the experiences of mothers whose neonatal baby had died; in particular, whether mothers were able to experience any positive changes in their lives since the death of their baby. 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 previously. Mothers completed semi-structured, one-to-one interviews. Interview transcripts were analysed using Template Analysis.

Results: Despite ongoing sadness, mothers recognized positive personal changes in their self-perception, relationships and life philosophy which were consistent with the post-traumatic growth model. Mothers also identified facilitators and barriers to these changes which were categorized 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 conscious personal decision to cope with their experience. This is a unique finding which requires further exploration. Facilitators and barriers of growth both occurred as elements within the same five themes, indicating that all identified domains before and after the death have the potential to facilitate or to prevent personal growth. Importantly, these findings indicate that person-centred services, which are responsive to individual needs at all stages, are vital when providing maternity care in the context of loss.

HIGHLIGHTS
• Despite ongoing sadness, mothers recognized positive personal changes in their self-perception, relationships and life philosophy consistent with the post-traumatic growth model.
• All identified domains before and after the death have the potential to either facilitate or prevent personal growth.
• Importantly, these findings indicate that person-centred services, which are responsive to individual needs at all stages, are vital when providing maternity care in the context of loss.

Comprendiendo las experiencias de cambios positivos de las madres después de la muerte neonatal

Antecedentes: la muerte de un bebé neonato tiene el potencial de que los padres experimenten muchos resultados negativos. Contrariamente, el crecimiento postraumático describe cambios personales positivos, que pueden ocurrir al enfrentarse con un evento traumático, no ha sido explorado en este contexto.

Objetivo: Este estudio buscó comprender las experiencias de las madres cuyo bebé recién nacido había muerto, y en particular si las madres podían experimentar algún cambio positivo en sus vidas, desde la muerte de su bebé. El estudio también buscó explorar qué factores pudieron haber facilitado o impedido estos cambios

Método: Se reclutaron diez madres cuyo bebé había muerto en el período neonatal, entre dos y 10 años previos. Las madres completaron entrevistas semiestructuradas, una a una. Las transcripciones de la entrevista se analizaron mediante el análisis de plantillas.

Resultados: A pesar de la tristeza en curso, las madres reconocieron cambios personales positivos, en su autopercepción, relaciones y filosofía de vida que eran consistentes con el modelo de crecimiento postraumático. Las madres también identificaron facilitadores y barreras para estos cambios que se categorizaron en cinco temas: 'Atención centrada en la persona', 'sentido', 'estrategias personales de afrontamiento', 'aprender a vivir con eso' e 'identidad'.

Conclusiones: este estudio identificó que las madres tomaron una decisión personal consciente para sobrellevar su experiencia; este es un hallazgo único que requiere mayor exploración. Los facilitadores y las barreras de crecimiento se presentaron como elementos dentro de los mismos cinco temas, lo que indica que todos los dominios identificados antes y después de la muerte tienen el potencial de facilitar o prevenir el crecimiento personal. Es importante destacar que estos hallazgos indican que los servicios centrados en la persona, que responden a las necesidades individuales en todas las etapas, son vitales cuando se brinda atención de maternidad en el contexto de la pérdida.

了解母亲在新生儿死亡后经历的积极变化

背景： 新生儿的死亡有可能让父母经历许多负面结果。与此相反的，创伤后成长描述了积极的个人变化，这种变化可能源于与创伤事件的斗争。但这种变化尚未在新生儿死亡的情景下被探讨过。

目的： 本研究旨在了解母亲遭遇新生儿死亡后的经历，特别是母亲在婴儿死亡后是否能够体验到任何积极改变。该研究还试图探究哪些因素可能会促进或阻止了这些变化。

方法： 研究招募到10名母亲，在2到10年前经历了新生婴儿死亡。参与研究的母亲们完成了半结构化的一对一访谈。使用模板分析法对访谈记录进行了分析。

结果： 尽管悲伤一直持续，但母亲们在自我认知、人际关系和生活哲学中感受到了积极的个人变化，这与创伤后成长的模式是一致的。这些个人变化可为五个主题：'以人为中心'，'赋予意义'，'个人应对策略'，'学会与之共存'和'身份'。母亲们还提到了促进和障碍这些变化的因素。

结论： 本研究发现，母亲们有意识地做出个人决定来应对自己的经历。这个发现有独特性，还需要进一步探索。在五个成长主题中都发现了促进和阻碍因素，表明所有这些在新生儿去世前后的因素都有可能促进或者阻碍个人成长的发生。重要的是，研究结果表明，在给失去婴儿的母亲提供产妇护理时，关键要在各个阶段提供以人为中心的满足个人需求的服务。

1. Background

1.1. 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, nevertheless in England and Wales one in 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), complex grief (Boelen, 2016), 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).

1.2. Post-traumatic growth

Recently consideration has been given to the possibility that individuals are able to experience significant positive personal changes in the aftermath of a traumatic event (Helgeson, Reynolds, & Tomich, 2006; Tedeschi & Calhoun, 1995). Post-traumatic growth is proposed to reflect such 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 summarized as 'more vulnerable, yet stronger'; (2) Changed relationships with others, which can be positive and negative (e.g. greater compassion for others, realizing 'true' friends); (3) New possibilities, realizing 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).

1.3. 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) emphasize 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 minimizes 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 recognize personal strength, closeness to others or new possibilities, they may also realize that undesired outcomes cannot always be prevented (Calhoun et al., 2010).

Bogensperger and Lueger-Schuster (2014) investigated associations between meaning reconstruction, complicated grief and post-traumatic growth in parents, with a particular focus on traumatic bereavement. They found that, in the cases of traumatic loss, sense making was highly correlated with post-traumatic growth (Bogensperger & Lueger-Schuster, 2014).

1.4. 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. Büchi et al. (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. Despite the advances in post-traumatic growth recent in recent years and the quantative measures used to research this field (e.g. Michael & Cooper, 2013), it was important in this novel area to ensure that mothers individual experiences were captured and explored.

1.5. 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.

2. Method

2.1. Research approval

Initial research approval was obtained from the Liverpool Doctorate of Clinical Psychology and the Stillbirth and Neonatal Death Charity (Sands). Sands were involved throughout the study development, to ensure that all materials used were appropriate. Ethical approval was obtained from the University of Liverpool Research Ethics Committee.

2.2. 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.

2.3. Recruitment

A protocol for recruitment was developed with Sands and an advert for the study was initially placed on regional and national Sands Facebook pages. Twenty-four women contacted the researcher, but 10 women who contacted the researcher were excluded as they did not fulfil inclusion criteria either because their baby had been stillborn or that the death of the baby occurred outside of the specified timeframe. Fourteen women fulfilled the inclusion criteria, and 10 of those were recruited

2.4. Procedure

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

2.5. Measures

The participants' demographic information was recorded. A topic guide, based on extant literature, was developed in order to guide the interviews. 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.

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)

2.6. Data collection

Semi-structured, one-to-one interviews were conducted with 10 women. 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 anonymized. All names used in the manuscript are pseudonyms to protect the mothers' identites.

2.7. Analysis

The qualitative data was analysed using Template Analysis (Brooks, McCluskey, Turley, & King, 2015). This method is a flexible but structured approach to data analysis, which allows for integration of a priori codes and emerging themes. 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) Familiarization with the data-set by reading transcripts.
(2) A computer package (NVIVO 10, 2012) facilitated coding. Preliminary coding was completed utilizing a priori themes which were based on extant literature (Table 1). 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 become redundant and others were redefined. 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. The same researcher (AW) conducted the interviews and coded the transcripts. All transcripts were read and discussed by the research team on a regular basis; all stages of the analysis were discussed and refined by the research team. It was collaboratively agreed that the final template accurately reflected the data.

2.8. 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. The researcher was a young woman 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 expected that some women *might* report ongoing distress, despite evidence of growth, but did not presume this to be the case.

3. Results

3.1. 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 educational (high school) attainment qualifications at age 16 and 18. 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. At the time of the interviews, nine of the women had a living child (either an older or younger sibling to the baby who had died). Seven babies died within the perinatal period (first seven days) and three babies died after this time.

4. 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.

5. Themes of post-traumatic growth

5.1. Self-perception

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

5.2. Relationships

All of 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 of 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)

Formal support groups (e.g. Sands) 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)

5.3. 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 participants described new possibilities; some 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)

6. Facilitators and barriers of post-traumatic growth

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

6.1. Person-centred care

Care was experienced as most helpful when it was responsive to individual needs and ongoing difficulties, even many years later. All of 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)

6.1.1. 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 apologizing 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. being given a bed on a maternity ward and therefore being with other mothers and their babies) 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 saving graces, that we'd got to cuddle him, we could make the decisions' (Lynn)

All of the mothers valued spending time with and being able to do things for their baby prior to the baby's 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 of 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 to 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; it is significant that, for most, this was the only help available for their distress. For two women, medication was helpful in the short-term; 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.

6.1.2. Relationships with partner and social network
Two women reported that their partners were coping in different ways (e.g. not discussing experience): one

woman decided to seek support from other sources; 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 most 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. via social media), and most explained this was important because they could really understand each other and empathize. 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. a support group that included parents who has experienced a stillbirth and not a neonatal death), 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)

6.2. Making sense of what happened

All of the women described ongoing reflection 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. about the decision to remove 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)

6.3. Personal coping strategies

Most of the women described making a definite 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 where this had not occurred:

> '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 a depth of self knowledge and a willingness to act on this. They developed 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 emphasized 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)

6.4. *Finding ways of learning to live with it*

The women who had 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 of the women described a continuing bond with their baby and displayed photographs. All of 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 of 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)*

6.5. *Identity*

The women's identity as a mother was as an integrative theme which occurred throughout the interviews. Participants 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 woman 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 (or regain) their identity by having subsequent children, by 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)*

7. Discussion

7.1. *What this study adds*

This is the first study to focus on and provide evidence for mothers' experiences of post-traumatic growth in the context of distress after neonatal death. It adds a unique contribution to an important and understudied area by generating an understanding of some of the potential facilitators and barriers of positive growth. It introduces another potential dimension for how traumatic loss of a neonatal baby may be experienced, instead of focusing on complex grief (Boelen, 2016). This study introduces the possibility that some mothers consciously 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).

Importantly, this study highlights 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. This study recognizes that support and social relationships can feature as both a potential facilitator of growth and indeed a measure of growth in cases where relationships may have changed. Furthermore, this study emphasizes 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).

The timeframe since the baby's death (2–10 years) was required in order to create a window of potential growth experiences that may have occurred. This was chosen in line with extant literature which states that less than two years and growth is unlikely to be experienced (Calhoun et al., 2010). From the descriptions the mothers provided of the early years, it would appear that growth would be unlikely to occur earlier than two years as this period of distress and sense-making is required to occur before growth

experiences are likely to occur. Furthermore, from the information provided by the mothers during their interviews, and the analysis undertaken, the variety of experiences in relation to time spent with baby before death did not appear to impact on the growth experiences. This appeared to be more associated with mothers feeling in control and having positive interactions or memories wherever possible.

7.2. Present findings in the context of the 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). Some 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.

The findings are consistent with current literature in relation to the potential processes for facilitating post-traumatic growth, for example, continuing bonds, making sense (Michael & Cooper, 2013), rumination (Taku et al., 2008) and charity involvement (Reilly, Huws, Hastings, & Vaughan, 2008). The indication that support from other bereaved parents is helpful is consistent with the literature (Reilly et al., 2008); learning from other bereaved mothers both how to be and how not to be could be understood as vicarious learning (Tedeschi & Calhoun, 1995). The findings are also consistent with the conclusions of Kristensen, Dyregrov, and Dyregrov (2018), which indicated that giving a bereaved person the opportunity to return to the site of the death and be provided with more information can increase sensemaking and cognitive clarity. However they concluded that this can also increase experience of distress and therefore a delicate balance is required when offering support (Kristensen et al., 2018).

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. Furthermore, and in line with the findings of Huh, Kim, Lee, and Chae (2017) which suggest that an individual's attachments styles are important to consider when understanding individual responses to grief, the current findings again

highlight the importance of care which is sensitive and tailored to individual needs.

7.3. Strengths and limitations

The sample were self-selected from the Sands Facebook population and are therefore individuals who wish to discuss their experiences. Therefore, although it was not an aim of the study, the findings cannot be generalized to women who have lost a neonatal baby but who are not in touch with any dedicated support groups. 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 develop an in-depth understanding of the experiences of growth following a neonatal death. The study was designed and developed with Sands, who have extensive experience of providing support to bereaved families, thus 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).

7.4. Clinical and wider implications

Person-centred, compassionate and respectful interactions before and after the death of a neonatal baby is vital; personal and professional interactions will frequently be thought about as mothers attempt to process their experience. Staff understanding the potential long-term significance of what may be small interactions is paramount. 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 attend and respond to individual experiences and fears associated with another pregnancy. Whilst returning to work could be helpful for some women, employers should be mindful of the long-term impact of neonatal death and the importance of providing individualized support (e.g. graded return). This is not currently explicit in public health guidance.

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. It is important to understand the current findings in combination with recent evidence from the USA of increased prescribing for bereaved parents following perinatal death (Lacasse & Cacciatore, 2014) and a recent

review which indicated that antidepressants tend to improve the symptoms of depression more than symptoms of grief (Hensley, 2006). Furthermore, it is necessary that services consistently offer holistic approaches which include psychological components and facilitate client choice when considering interventions (McHugh, Whitton, Peckham, Welge, & Otto, 2013). Psychological professionals and healthcare staff with additional psychological training could utilize these findings to deliver staff training, promote user-led services or work with individuals in order to facilitate sense making and cognitive re-framing of experiences.

7.5. Future research

In the context of the recent addition of Prolonged Grief Disorder to the International Classification of Diseases (ICD-11) (Killikelly & Maercker, 2018), future research may benefit from understanding this concept in addition to increasing understanding of manifestations of post-traumatic growth. It is important to be able to screen and intervene early for individuals who may experience problematic grief trajectories (Djelantik, Smid, Kleber, & Boelen, 2018). Future studies would benefit from exploring how mothers consciously choose coping strategies when going through the process of adjustment following the death of their baby. 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 also benefit from seeking to understand fathers' experiences and support needs, especially as gender differences following neonatal death are documented (Büchi et al., 2007).

8. 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-centre 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 conscious personal decision to cope with their situation, and attempted to take others' perspectives, which helped to facilitate their growth. Significantly, these findings emphasize that all interactions, even prior to the death, in the context of a short and precious life, 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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