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‘I just needed a space to talk’: an exploration of women’s experiences when needing support for their mental health.

by

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Portfolio for the Professional Doctorate in Counselling Psychology

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Table of Contents

Section 2: Case Study and Process Report – Eating Disorder Treatment using CBT-E

Section 3: Publishable Paper

Acknowledgements

Firstly, it is important to thank and acknowledge all the mothers who came forward and were willing to participate in the study. All the mothers who got in touch showed me how stillbirth comes in many forms, and support needs to be tailored to each individual. I am unable to mention every name who came forward, but the gratitude I feel is immeasurable.

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Finally, to my husband, I would not be at this point if it wasn’t for your love and encouragement.

Declaration

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Preface

This portfolio comprises three pieces of work, each representing a different aspect of my training. The main theme throughout the portfolio is how women seek support and find a space to be heard. The various complexities of the women featured in this portfolio show the variety of life and loss and that just having a place to talk to a professional can be life-changing. It begins with a doctoral research project that explores the experience of support received by mothers who have experienced stillbirth. This is followed by a clinical case study and process report of Enhanced Cognitive-Behavioural Therapy (CBT-E) being used to treat Bulimia Nervosa. Finally, the thesis concludes with a paper submitted to the Journal of Reproductive and Infant Psychology, based on the thesis topic of support experiences following stillbirth.

The pieces of work presented are associated with the provision of support as experienced by women. This is documented by exploring what the experience is like for mothers following stillbirth and how support can be life-changing, as shown in the thesis and process report. Given the development of the 'integrative practitioner', improving understandings of how to provide support post stillbirth and of the treatment experience within an eating disorder is directly applicable to the discipline of counselling psychology. Counselling psychologists are now not just available to offer psychological support but need to be able to manage the physical health and experiences of their clients; this portfolio demonstrates that physical and emotional support is needed in tandem. Although the support needed for stillbirth and eating disorders differs according to the experience, the need to be present and to offer space for some women to talk is what women ultimately need when faced with such challenges.

Section A: Doctoral Research

The research presented in this thesis explores the support experienced by mothers following stillbirth, including those who received very little. Engaging in capturing how bereaved mothers went through various channels and locations to get the support they needed has been enlightening regarding the role psychology currently plays in supporting mothers following stillbirth. It was helpful to know what the mothers interpreted as support; a commonality of having someone there to listen to them and knowing where to get that support came through and could be found in nearly all the interviews. It became clear that receiving guided support was one element that mothers needed, as events usually happen quickly; in most cases, a mother finds out her baby has died, gives birth, spends time with her baby and is then sent home. At this point, she – and, likely, her partner – has to come to terms with the reality of their baby not being alive. It is this experience that requires support and guidance. Some of the mothers interviewed had unequivocal opinions of themselves as parents, mainly if their stillborn was their first child. The bond made through the medium of support during the initial grief period is significant and is evident in how they manage their ongoing grief. Some mothers were supported and could keep memories of their baby with them during the intense period of grief. Others felt so overwhelmed and under-supported that they could not fully bond with their baby due to high levels of anxiety and fear, which left them with longstanding guilt.

This study presents interviews with 14 women from across the UK who experienced stillbirth. The women who chose to share their stories revealed experiences of positive support from places like charities, family, friends and other avenues. The presentation of these support experiences follows a thematic approach, using thematic analysis devised by Clarke and Braun (2013) and taking themes that the researcher has interpreted. In encountering the transcripts multiple times, the reader is offered various views and themes that demonstrate the experiences of looking for, finding and using support. The themes bring together the experience of early support and how that support was experienced by pregnant mothers, which was common in the year following loss. There are four overarching themes in the thematic analysis: (1) The need for connection with my…; (2) A system of support – is it there?; (3) I guess I need to find support myself; and (4) The joy and fear of pregnancy after stillbirth. In presenting this research, I hope that the support experiences of mothers are heard, that there is clarity about what the mothers experienced and that the mental health of this group is valued. Further research is greatly needed.

Section B: Combined Case Study and Process Report

The second part of the portfolio is a client study and process report that shows my work with a young woman diagnosed with Bulimia Nervosa while I was working in an Adult Eating Disorder Service. It details the referral, the client’s formulation and the treatment plan.

The disorder had overwhelmed the client’s life and had led to her becoming physically unwell. I used Enhanced Cognitive Behaviour Therapy (CBT-E) as the primary approach in the client’s case. It proved helpful to her to see how her bingeing and purging wasn’t a fixed state and how she could move forward with her life and continue to manage any symptoms that recurred. Methods like an externalisation of the eating disorder (Mountford, Allen, Tchanturia, Eilender, & Schmidt, 2021) were more aligned with my practice style, and I have found using them worthwhile along with the CBT-E approach of thought-challenging. I also tentatively explored compassion-focused therapy to aid the client’s ability to show kindness towards herself. This piece of work seemed to me to be particularly resonant concerning experiences of support when experiencing a severe eating disorder at an age where the effects could be life-changing. Working with this particular client allowed me to use my personality and way of working to be creative and enable the work to be entirely personalised. This allowed her to push the boundaries of the eating disorder by being supported and encouraged, which was a delicate balance. Seeing such a positive change in the client – that she could cease purging and begin to moderate her mood – was a privilege.

This client taught me to trust my intuition and give space to clients who need to talk. This was one point that the client shared as being vital to her, and as I had noted this particular point early on, she felt comfortable to share. Working with my client towards allowing for a valuing of inner compassion and building confidence around her ability to be alone without experiencing the conflict of eating and not eating demonstrated the confusion that an eating disorder brings. Having support with how to manage these thoughts was of great importance to the work and my client. I felt very aligned with my client as she was open to being given support after she decided she could trust me. The eating disorder and lack of confidence did hinder the therapeutic relationship at an early stage in that the client couldn't fully embrace the treatment, but after we had a frank conversation where I demonstrated that I was on her side, the commitment to the treatment improved and her ability to battle the thoughts of her eating disorder became stronger. I was very proud of her for coming so far and encouraged her to continue her personal growth by continuing therapy and maintaining a space to talk with another therapist when she felt ready, as there were other areas of her mental health that needed some support.

Section C: Journal Article

The final element of this portfolio is a publishable article for the *Journal of Reproductive and Infant Psychology*. I intend to position the findings of my study alongside other qualitative explorations of bereavement support experienced by mothers. I initially questioned whether the piece might be better placed within specific pregnancy and birth-orientated journals, such as *BioMed Central (BMC)*, *Maternal Health*, *Neonatology and Perinatology Journal* or *Pregnancy and Childbirth*. However, I chose this journal as it seems particularly open to exploring varied psychological work, including developmental, clinical and social psychology; behavioural medicine; the psychology of women; and health psychology, with a combined medical focus of obstetrics and gynaecology, paediatrics, and paediatric psychiatry. I found the various topics within the journal pertinent to the topic of support after stillbirth as it straddles different elements found within this journal. I also found the balance of medical and psychological approaches practical when exploring the themes within this study, which fed into various aspects of the birth and loss experience and how support can be woven into general care. I would certainly like to share the findings of this study among the community of medical staff who support women through their stillbirth deliveries.

There seem to be real-world implications here that are relevant to the support offered during birth and immediately following stillbirth, which may help inform bereavement midwives and doctors. In submitting my piece to the *Journal of Reproductive and Infant Psychology*, I hope my findings impact the psychological care offered to bereaved mothers. Hopefully, my findings will influence how support is distributed and offered – not just from a charity-based point of view but also in view of a broader psychological spectrum – as the findings demonstrate the need. I experimented with the best way to present the findings clearly and in an accessible way and spent time considering how to streamline this study into a very concise article. I wanted to ensure that the themes were put across as clearly as possible and to factor in the mothers' experiences as faithfully as possible. I have had to focus on the broad domains and be tactful in demonstrating the themes found within them. The exercise has caused me to reflect on the challenges in showing the fullness of the study, but as my research is singular in modality, I was able to make sure the study fits into the journal's publishing guidelines.

Personal Reflections

Counselling psychology encourages practitioners to engage in reflective practice (Lavender, 2003). Reflective practice allows the different aspects of therapy to be examined, be it in sessions or in the practitioner's personal and professional life overall (Strawbridge & Woolfe, 2010). In thinking back over my training to become a counselling psychologist, the journey has been a long, challenging, exciting and humbling process that, linking with this portfolio's common theme, has often caused me to seek support. Support is something that I have previously found very hard to seek and productively to receive. I like to be staunchly independent and this can sometimes be to my detriment. I have sadly had experiences of asking for support only to be belittled or derided for doing so. This led me to feel high levels of self-doubt for many years. It was only through therapy while completing my training that I was finally able to start showing myself compassion, which led to my confidence in my ability to grow.

Basing my thesis on stillbirth happened by accident as I have never been pregnant myself. On listening to a podcast about baby loss, I found I was intrigued by the topic. To be metaphorical, it was like I was looking behind a curtain to a reality I didn't know existed. As I moved through my thesis journey, I came close to giving up and stopping, but the drive to show the interviewed mothers' experiences drove me on, as did the fact that I enjoy the work. On reflection, I felt a strong desire to focus on the topic of support and use it as a theme for my portfolio. My time in the eating disorder service was challenging. It showed me that being a counselling psychologist allows you to be humanistic and approach treatment with the body and the emotional aspect in mind when working with bulimia and other eating disorders. This was similar when researching my thesis, as the mothers had physically given birth but their grief was emotional. Having my awareness broadened in this way – that being a counselling psychologist permits you to hold both the physical and the emotional wellbeing of a client –

was an element I had not envisaged. During my training, I worked with a counselling psychologist within a perinatal setting, which left me driven to work within this area in the future. One element that came from my training and this research was the stance of psychologists when dealing with baby loss. There is little awareness and focus within the NHS setting for baby loss and the anxiety it brings. As it is understandable that grief will follow, the complexities from this research have changed how I look at my work. Looking at how someone presents with anxiety or depression, I spend more time looking at potential losses that can impact the present.

By accomplishing this portfolio of work and the training as a whole, I see it as a defining moment in my professional and personal life. Not only has it cemented my desire to work within the field of counselling psychology, but it has also permitted me to grow into my role as a practitioner psychologist by combining my natural reflexivity with the scientific researcher.

SECTION ONE

DOCTORAL RESEARCH

An Exploration of Mothers’ Experiences of Support following their Baby Being Stillborn

Charlotte Squires

Supervised by Dr Jacqui Farrants

Abstract

Aims: Previous research has documented the medical point of view of stillbirth, with some studies looking at the emotional impact of mothers holding their babies. Others explore the effect of stillbirth on mental health in such outcomes as PTSD, PND, anxiety and depression. Yet, despite recognising the impacts on mothers, there is little detail in this previous research regarding the nature of supportive or unsupportive interactions following stillbirth. This study aimed to explore women's experiences of support following stillbirth.

Method: Semi-structured interviews were undertaken with 14 women who had experienced a stillbirth. The interviews were analysed using Braun and Clark's (2006) method of thematic analysis.

Results: The analysis yielded 17 themes organised into four domains: (1) The need for connection with my…; (2) A system of support – is it there?; (3) I guess I need to find support myself; and (4) The joy and fear of pregnancy after stillbirth. Limitations to receiving support included not wanting to burden others, lack of guidance, fear, and being pregnant again, so talking about the loss was too much. Opportunities to speak openly were rare, but when women could find support, they felt understood and validated. Having the ability to talk in a private and preferably 1:1 space created a very positive reaction in and was a strong desire of the mothers.

Conclusions: The findings are consistent with previous research, suggesting a great need for further infrastructure and research on the specific support required by women and broader members of their networks following stillbirth. They also confirm that social support following stillbirth is immensely valued. There is a potential role for healthcare professionals to work together to offer support and guidance to women and their families in navigating the initial period of grief and aiding them in managing any subsequent pregnancy.

Language Used

When I use the term ‘mother’, it usually refers to the person who is/was pregnant. I use the term because it is the most easily and commonly understood word. In doing so, I appreciate that not all birth parents would define themselves as mothers. When talking about the mothers who were interviewed and their experience, I use ‘mother’ instead of ‘participant’ in the write-up to firmly embed them in the study and use their babies’ names for the same reason.

For ease of reading, I use ‘partner’ rather than ‘spouse or partner’. I use this in the context of heterosexual and same-sex relationships and where couples may or may not be married. I also acknowledge that not all cultures think of spouses as partners. The term ‘husband’ has been used only when the mother used it to describe their relationship, which is personal to them.

Chapter 1: Introduction and Literature Review

1.0 Introduction

Despite being one of the most devastating experiences any family can go through, one in every 250 births ended in a stillbirth (in 2018 in the UK) and the subject is still taboo in broader society. Stillbirth is when a baby dies after 24 weeks of pregnancy but before or during birth. The Office of National Statistics (ONS) tracks the numbers of stillbirths that occur in the UK. The stillbirth rate is defined (by the ONS, 2018) as the number of stillbirths per 1,000 live births and stillbirths. The stillbirth rate reached an all-time low for the third year running in 2019 – 3.9 stillbirths per 1,000 total births (ONS, 2019); this is a 4.9% decrease compared with 2018 (2,689 total stillbirths) (ONS, 2018).

Recently, Stowe et al. (2021) found that between April 2019 and June 2020 there were 2,825 stillbirths, with the highest percentage of stillbirths being reported in London, compared with the other three English regions (South of England, Midlands and East of England, and North of England). In 2020 overall, ONS reported 2,429 stillbirths compared with 2,522 stillbirths in 2019, with the stillbirth rate remaining at 3.9 per 1,000 births. In the most recent statistics, there were 618 stillbirths between January and March 2021 – just three fewer than over the same period in 2020 (ONS, 2021) – while at the peak of the second wave of the COVID-19 pandemic, there were 226 stillbirths in January 2021, compared with 207 the previous year. As a result, the stillbirth rate increased from 3.9 in 2020 to 4.2 in 2021, peaking in January 2021. It is important to note the variations in the statistics given by the ONS and Stowe et al. (2021). Even though the two sources are reporting on the same topic, the quoted date ranges vary. Therefore, the data needs to be handled carefully if comparisons are to be made in future studies, such as the use of the per 1,000 birth vs total stillbirth number, as these numbers vary when the analysis is explored.

These statistics build a picture of the number of parents who have experienced stillbirth and who will have needed support not just in the first year but after the initial grief period. Since the conception of this thesis in 2018, there have been 8,258 stillbirths up to the most recent data in March 2021. These 8,258 families may have spent the days after their stillbirth looking for support. Some will have been successful – finding support from close family and circles of friends or charities, which would lead them to begin their journey to try for another baby or navigate their grief. However, not everyone can access support, and there are people within that 8,258 who will have struggled to find help. The statistics highlight that stillbirth is a common occurrence that results in families requiring support, yet research suggests families have reported not finding the support they need quickly, which this study will explore. Further studies on how lockdown and COVID-19 impacted stillbirth rates will be helpful, like that of Khalil et al. (2020), which explored how COVID-19 affected women who had a stillbirth and were asymptomatic of the virus.

Support is defined and understood in this thesis as any action or relationship that positively benefits a person (Finfgeld-Connett, 2005). Cacciatore, Schnebly and Froen (2009) suggest that various factors influence the delivery of support, that is, assessing the need and providing the support. However, one crucial aspect of support is its existence being recognised by the person needing it. Conversely, Bolger, Zuckerman and Kessler (2000) suggest that people may be unable to stipulate what was supportive to them in times of need. However, given the limitations in defining social support, I am also using the mothers' perceptions of support, which are sourced from the interviews. These views are subjective, and the study recognises that this small study will not accurately express every mother's experience.

Before the 1970s, the attitude towards stillbirth had been to remove the baby immediately after birth (Davenport, 2010) and prevent mothers from seeing their baby (Üstündağ-Budak, Larkin, Harris, & Blissett, 2015). Attitudes have since changed, and now there are supporting bodies, such as the Stillbirth and Neonatal Death Society (Sands), that have developed guidelines on how medical professionals can help parents who experience stillbirth (Sands, Hunter, Schott, Henley, & Kohner, 2016). However, Cockburn (2007) found that healthcare teams have noted that, although these guidelines are helpful, their content is based on an intuitive approach, which can be misunderstood as interpretation is highly subjective, and found that there is a need for more research-based evidence of how to aid parents during this challenging time. Also, it seems there is still a stigma attached to stillbirth, and general recognition of stillbirth and its emotional effects remain somewhat negative in medical literature and society (Brierley-Jones, Crawley, Lomax, & Ayers, 2014; Lisy, Peters, Riitano, Jordan, & Aromataris, 2016).

Stillbirth research has been conducted for over 50 years, and the focus has expanding. Current research around stillbirth focuses on why and how stillbirth occurs, and what could have gone wrong during the pregnancy. Literature on stillbirth is supplied from predominantly health-based perspectives, such as the nursing and midwifery fields. Focus is also on the burial/cremation of the baby and the initial grief reactions from various points of view, e.g., fathers, healthcare professionals and other family members (Swart, 2020), rather than a psychologically focused point of view. Filling this gap in psychological-based (especially counselling psychology) viewpoints through more in-depth research could help to develop a greater focus on this area.

A small study by Rogers, Spink, Magrill, Burgess, and Agius (2015) conducted research with the charity Petals (which offers counselling to parents following perinatal bereavement or trauma during pregnancy or birth) to evaluate the effect of counselling interventions following the death of a baby or traumatic birth. At the time of writing their study, there was a scarcity of research evaluating the usefulness of psychological interventions following baby loss. However, there was usefulness to this study as it found that offering free specialised counselling for parents suffering perinatal loss appeared to be associated with an improvement in psychological outcomes. The study was fair in size (107 participants) and an exploration of this rarely studied area, it highlighted in 2015 that having a space for parents to be supported in their grief improved wellbeing after the supplied sessions, and there was a marked reduction in the feeling of distress. A recommendation of further research in this specific are was made.

To understand why support is needed, it is useful to understand the experience of loss that mothers go through. This study looks primarily at the experience of support from the point of view of mothers. Support following stillbirth is an important area for investigation, which is also notably under-researched. However, because the studies that look into support experiences specifically after stillbirth are limited, I have chosen to remain attentive solely to mothers in order to progress the knowledge base within this topic. Discussion of partners and effects on extended family were not avoided in the interviews and analysis. However, I am remaining focused on mothers because they require specific support due to the physical experience of giving birth and subsequent grief management. There is a point for further research to acknowledge the experience of support for those who don’t identify as birthing people. Experiences of the effects of stillbirth for this demographic are not researched in this study and merit their own investigation to fully explore and understand support practices.

There can be a typical and natural expectation by mothers who find out they are pregnant that they will have a healthy baby at the end of their pregnancy. However, when their baby dies before being born, they have their reality turned in a very different direction. Parents look to midwives and doctors for support either after being told the news or while still in labour. Stillbirth can occur at any point after 24 weeks (NHS, 2018), and this is why it is so important to have support during this time. The grief that mothers experience from the moment they are told their baby has died may come with unique nuances. This literature review theorises the various stages of grief (which come with their own experiences) that a mother can go through, including how support can be helpful, and concludes that a mother’s grief after stillbirth is different from that when a child is born alive but subsequently dies.

The following section explores existing research on stillbirths, stillbirth support, and support experiences. The research question comes from the perspective of counselling psychology. The experience of the researcher is also explored. Searches for appropriate research titles were carried out within the following databases: Medline; Web of Science; PsycInfo; and the City, University of London Library online database. The reference lists of particular articles are akin to the selection of titles. The following terms were used to search the existing literature titles in order to locate studies that were aligned to the topic to use within the literature review: when a baby dies; stillbirth and synonyms for stillbirth (i.e. perinatal loss, baby loss, child loss); bereavement and synonyms for bereavement (i.e. grief, death, ambiguous loss); female, female health and female experience; mother and maternal experience; and support and synonyms for support (i.e. support after stillbirth, parental support, experiences of support, continuing bonds and support for stillbirth). When initially putting ‘stillbirth’ into the databases, the results focused more on the birth, which I was not looking for specifically. I moved on to more bereavement terminology with a stillbirth theme, which produced focused results. When searching for stillbirth support, the results were smaller and I had to be creative by using more support-focused phrasing to gather as much literature as possible. The selected studies are written in English and use quantitative and/or qualitative data on stillbirth, support, bereavement, and support concerning parental bereavement and maternal bereavement. The studies most closely related to the research topic were selected. Their publication dates range from 1981 to 2021, with the majority dating between 2000 and 2021. In the following review, the studies are explored within themes that best reflect how the existing literature engages with the current research.

1.1 Mental Health following Stillbirth

In recent years there has been an upsurge in the amount of attention or coverage (through various media and research) given to the issue of stillbirth, highlighting the need for increased awareness of how stillbirth affects mental health. The following literature evidences how women’s mental health is affected by stillbirth and how it can result in more serious consequences, such as post-traumatic stress disorder (PTSD).

Pollock et al. (2020) produced a study using thematic analysis in Australia to explore the stigma experienced by bereaved parents who had endured stillbirth. The study used an online survey of closed and open questions with 817 participants from high-income countries, and results were based on self-perception; 38% of bereaved parents believed they had been stigmatised due to their stillbirth. Everyday experiences that were highlighted included feelings of shame, blame, devaluation of motherhood and discrimination. The parents also reported the silence of stillbirth during their antenatal care, with many healthcare providers not informing them about the possibility of stillbirth. The authors come from a mixture of backgrounds, including midwifery and psychology, and one is a charity member who specialises in stillbirth awareness. Drawing on this mix of medical, psychological and support-based input is a practical approach to this area of research, as it can be used to fully explore the medical and the emotional aspects of what parents' experience. They concluded that more research in this area was needed since the more data there is that backs up their findings of 'stigmatised feelings' or 'lack of being realistic' the more likely it is that actions can be taken to remove those negatives.

Cacciatore et al. (2009) examined whether maternal anxiety and depression levels were lower among mothers who received social support after stillbirth in the US. Congruent with the family stress and coping theory, mothers of a stillborn who perceived family support in the period after stillbirth experienced levels of anxiety and depression that were notably lower than those of their counterparts. Nurses, physicians and support groups were also important sources of support after a stillbirth; however, these sources of support alone were not statistically significant in reducing anxiety and depression in grieving mothers. It was concluded that community interventions could focus on the grieving mother and her family system, including her partner and surviving children. As this study was conducted in the US, it is helpful to note the different healthcare structures in the UK and the US. However, the themes found in this study are similar to others conducted in the UK.

In another US study, Wonch Hill, Cacciatore, Shreffler and Pritchard (2017) found that higher levels of distress following a perinatal loss could persist over the years, affecting the quality of intimacy within relationships so leading to relatively high rates of relationship breakdown among couples who had experienced stillbirth. Using a representative sample of women aged 25–45 who had ever given birth, they evaluated whether miscarriage, stillbirth and child death impacted self-esteem, and if the loss was moderated by maternal identity. They found that stillbirth and child death – but not miscarriage – negatively impacted self-esteem. The authors noted that the death of a baby, particularly during the perinatal period, could impact mothers' self-esteem due to the enmeshed nature of the loss. Because it is both physical and psychological, the degree of distinction between the baby and mother progresses and changes throughout the pregnancy. The authors also found that women who experienced stillbirth were the only group with significant levels of low self-esteem. The authors of this study come from backgrounds including sociology, social work, human development and family science, and the social sciences; it would have been useful to have seen how a psychological view would have impacted the study, seeing as it is looking at emotional wellbeing and how self-esteem is impeded. These three studies tell us that following stillbirth family support is important and so enabling this would provide a chance to mitigate the low self-esteem some mothers experience, which could then lead to fewer relationship issues.

Burden et al. (2016), who are academics, psychologists, and obstetricians, came together and conducted a systematic review of the literature describing the psychosocial impact of stillbirth. They reported that bereaved parents endured higher rates of depression, anxiety, and PTSD. They say that grief after stillbirth is often disenfranchised, because parents cannot discuss their experience or their baby with family or community members, which is at odds with the study by Wonch Hill et al. (2017), who state that sharing the memory of the stillborn baby helps manage grief. The consequences of stillbirth are enduring and can impact subsequent pregnancies, existing relationships, and attachments with living children. In extreme cases, the study notes, many bereaved parents were blamed for the death of their baby, which increased social isolation and even experiences of rejection from spouses, extended families, and communities. From their study, the authors were able to highlight the complexity of the findings by demonstrating the need for an improvement in bereavement care, to include emotional, psychological and financial support for both parents and the wider family, continuing into a subsequent pregnancy. They also noted that any improvements to bereavement care would need to be culturally and religiously sensitive and framed around individual cultural beliefs and resource issues in specific country settings. It is useful to note the mixture of authors again on this paper as it produced a balanced approach to the physical, mental and emotional effects of stillbirth, also highlighting the importance of the need for support to be tailored to individual needs/situations.

A psychologically focused study by Murphy, Shevlin and Elklit (2014) aimed to explore an extensive range of psychological responses to trauma in parents of pregnancy loss and infant death. This was to judge whether a trauma framework would be suitable for describing the full range of emotional reactions to a loss. The results showed that, for up to five years, post-loss bereaved parents expressed elevated levels of trauma-specific and psychological outcomes – particularly interpersonal sensitivity and aggression. It was also highlighted that parents who had experienced stillbirth attained significantly high scores in the depression, anxiety, detachment, sleep disturbances, interpersonal sensitivity, and aggression subscales. This study has some limitations, including the lack of information on any prior pregnancy or infant losses as part of the analysis, when stillbirth and infant death are different experiences. This could have contributed to the extent of trauma expressed by both samples as could other traumatic events not included in the analysis, which could have impacted the results. The article reminded me that I needed to be aware of this when conducting my own interviews to ensure I obtained a full picture of an individual's complex situation. However, stipulating the effects of stillbirth on mental health from a psychological perspective is unique and valuable to understanding the phenomenon.

In addition to further compounding the experience of grief, some women in the UK have an increased risk for stillbirth. Garcia, Ali, Papadopoulos and Randhawa (2015) conducted a scoping review of the literature to determine what specific maternity interventions had been made with regard to Black, Asian and minority ethnic (BAME) women between 2004 and 2014. The purpose of the study was to increase awareness of the need for and scope of particular maternity interventions. They found little evidence of any culturally specific interventions implemented over the period; however, they found that there was likely to be more local and community-driven support and interventions for BAME women.
The points above are further detailed a report titled ‘Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK’ (MBRRACE-UK) by Knight et al. (2018), which collated data of women in the UK whose babies’ deaths were during or up to one year after pregnancy, between 2015 and 2017. The study highlighted that Black women were five times and Asian women were two times more at risk of dying in pregnancy in the UK due to maladaptive care because of their culture and, on other occasions, their race. Coupled with the potential trauma experienced through stillbirth, the probability for psychological distress was high, and the study declared that a requirement for appropriate integrative care and support was still missing. The previous four papers highlight that the complexities of stillbirth for psychological health are significant and that multiple factors need to be considered when organising a framework of support.

Further investigation into the relationship between stillbirth and inequalities in the UK by Kingdon et al. (2016) revealed that health was a determining social factor in their meta-narrative study to investigate the association between inequalities and stillbirth in the UK. The study found that research investigating inequalities and stillbirth in the UK was underdeveloped. This was despite repeated evidence of an association between stillbirth risk and poverty and ethnicity. They highlighted where poverty, poor nutrition, less education, lack of healthcare access, and other issues exacerbates the unlikelihood of a healthy baby being born at term. The accumulation of stressors with the additional burden of stillbirth may create circumstances where the mothers’ grief is intense or unrelenting. This is especially pertinent to those whose care can be compromised due to ethnicity and race, which further compounds the heightened state of grief and the ability to access support (Khan, 2021). These findings are important as it highlights discrepancies in care across the wider arch of healthcare as a whole. Some areas may not be as bad as others but knowing more about this would enable a comparison review to take place. Also, knowing ‘stressors’ in life that would make the stillbirth more likely or reduce the likelihood of attaining support would be beneficial so earlier intervention can be made.

In their recent study, Fernandez Turienzo et al. (2021) found that procedures to control the spread of COVID-19 (e.g. lockdown, etc.) created further social and economic hardship for those already experiencing inequality in maternal, child and family health. The study highlights the example of pregnant women from some BAME groups and those from disadvantaged backgrounds who are more likely to suffer severe maternal indispositions, resulting in outcomes such as stillbirth and preterm birth. This can lead to significant problems with disabilities in the future and can have substantial implications for the mother's health and wellbeing, whose vulnerability levels result in their inability to access support networks. The study concluded with a call-to-action to support participatory community research. It highlights that there needs to be an alliance between researchers and community leaders/representatives to allow understanding around the complex and varied factors to inform public health strategies and reduce inequities among these marginalised groups within UK society. This was also demonstrated as a recommendation in Edge (2011, p. 261), where Black Caribbean women made suggestions for more 'collaborative, community-based models of care in line with policy, practice, and include the views of members of other ethnic groups.

The studies referenced (Garcia et al. 2015; Knight et al. 2018; Kingdon et al. 2019; and Fernandez Turienzo et al. 2021) focused on UK-based stillbirth, and by looking at only UK studies there is the potential for missing research from other countries that is relevant, even with their differing healthcare systems. However, as Kingdon et al. (2019) note in their conclusion (which echoes the other studies) there is a scarcity of UK research looking at inequality and stillbirth and how mental health and support is affected, and so it was important to build this up.

Rajan (1994), who writes from a US social care point of view, found that social isolation after stillbirth occurred in many households, leading to prolonged grief and the possibility that parents would lack a clear outlet for their psychological needs. Thus, parents became more dependent on their own psychological and emotional support. Rajan explains that parents were unlikely to share their concerns due to the emotional vulnerability they were experiencing and this was compounded by a lack of general knowledge in how to respond at a societal level. This, in turn, showed the lack of support parents received during this period. Rajan found that sympathetic social support makes a vital contribution to the mourning process, as support is varied across areas and countries, particularly in the UK, as researched by the National Bereavement Care Pathway (NCPB, 2020).

The mental health of mothers can be seriously affected by stillbirth. As previously discussed, the various elements and experiences of grief can be felt by some mothers more than others. Ünstündag-Budak (2015) explains that stillbirth is a particularly unexpected and sudden loss, as evidenced in studies undertaken from a medical and psychiatric point of view. Such studies include Janssen, Cuisinier, de Graauw and Hoogduin (1997); Badenhorst and Hughes (2007); and Horesh, Nukrian and Bialik (2018), a mix of psychologists and obstetricians who show that perinatal losses can be considered more anxiety-provoking than anticipated losses, resulting in heightened grief reactions. Kersting and Wagner (2012) explain from their psychiatry viewpoint that, following an unforeseen event like stillbirth, mothers may struggle with complicated or pathological grief and may have difficulty in their relationship with their subsequent baby. Difficulties in bonding, insecure attachment and controlling parenting were noted by Warland, O'Leary, McCutcheon and Williamson (2011), whose background is in midwifery. As the above studies have highlighted, there is an emotional effect following stillbirth. It would be useful to know about this topic from a solely psychological viewpoint, as currently there is little information around this in psychology journals. Having a blended approach to research in terms of medicine and psychology allows for a useful analysis of experience and for the development of support techniques and interventions.

So far, there has been a focus on the mental health experiences of mothers after stillbirth, and literature has come from various standpoints, including medical, social science, social work and (some) psychological. There is a focus on mental health within the studies, but the lack of psychological viewpoints is interesting, and the need for inclusion, like in Burden et al. (2016) and Horesh et al. (2018), will provide balance to inform research and progression of the subject. As stillbirth is a global phenomenon, the inclusion of studies outside of the UK is beneficial but taking note of the differences in healthcare is important, as it can impact how mental health is treated.

In the same year as the study by Huberty, Matthews, Leiferman, Hermer and Cacciatore (2017) the National Bereavement Care Pathway (NBCP) was launched and subsequently supported by the Department of Health and the All-Party Parliamentary Group (APPG) on Baby Loss. The NBCP has been developed to improve the quality of bereavement care experienced by parents at all stages of pregnancy, including baby loss up to the first 12 months. Their focus is to ensure all bereaved parents are presented with the same high level of empathic and safe care when their baby dies, and to ensure that professionals including counselling psychologists have access to guidance materials and training to support their work. The NBCP aims to increase the quality of bereavement care provided by healthcare professionals after the loss of a baby and this academic study aims at widening the knowledge behind support being provided. There are five pathways: miscarriage, termination of pregnancy for foetal abnormality, neonatal death, sudden unexpected death of an infant and, of pertinence to this study, stillbirth.

According to the NBCP, in England, between 2017 and 2019, 32 hospital trusts piloted the project, with a further 37 signing up. Of those remaining, 57 had formally expressed their interest in the project. By June 2021, 82 NHS England trusts (63%) had committed to the approach, with a further 47 (36%) expressing their formal interest, and only two trusts are yet to seek interest.
In Scotland, the government has pledged funding and support, with a plan to pilot, implement and embed the NBCP across Scotland – this commenced in March 2020 with an official launch. Currently, five NHS boards in Scotland are early adopters for the NBCP and are piloting the pathways across their units and services in hospitals and the community. These include NHS Ayrshire & Arran, NHS Dumfries & Galloway, NHS Fife, NHS Grampian and NHS Lothian. This information has been included because a number of the women who were interviewed were from Scotland. The general premise of the study is to look broadly across the UK at how support is implemented and to evaluate the extent of whether the objectives being laid out by government agencies are being met.

Comparatively, the National Assembly for Wales and the Northern Ireland Assembly have total access to all the information about the NBCP but are still considering how to use it to improve bereavement care in their nations. In Northern Ireland, the baby-loss charity Sands has a strong presence, which volunteers run. There are also other local charities available.

A scoping survey of bereavement services in Wales (2020) found an absence of support explicitly relating to pregnancy loss in the areas of Ceredigion, Carmarthenshire and Pembrokeshire, and only one provider of pregnancy loss support in Gwynedd, Anglesey and Powys. There are also low levels of support explicitly relating to stillbirth in Pembrokeshire, Carmarthenshire, Ceredigion, Gwynedd, Anglesey, Powys and Swansea. Consistently, the lowest levels of provision across all categories of aid are in Ceredigion, Gwynedd and Anglesey. The survey also found that, across Wales, there were more bereavement services available following adult death compared to any of the other main categories of death. Pregnancy loss was the most lacking support provision, followed by stillbirth.

One of the nine standards that the NBCP (2020, p. 4) follows is that ‘all bereaved parents are informed about and, if requested, referred for emotional support and specialist mental health support when needed’. This is where counselling psychology could be the point of contact because, as explained previously, there are a number of services across parts of the UK. There are counselling psychologists in the majority of these trusts, which means there is an opportunity for specialist mental health support to be accessed. There are still significant gaps and inconsistent support following a stillbirth, which is an area that all the mothers in the interviews considered a supportive aspect of care. There has been research by Burden et al. (2016), who found that stillbirth is associated with substantial direct, indirect and intangible costs to women, their partners and families, healthcare providers, the government and wider society. Appreciating the costs of stillbirth is essential to evaluate the cost-effectiveness of interventions to prevent stillbirth or ameliorate the negative effects of stillbirth. They also found that mothers can have adverse experiences, including stigma, social isolation and disenfranchised grief, which are widespread among parents whose baby is stillborn. This needs to be addressed through focused interventions and support activities including parents, communities, care providers and relevant stakeholders.

In summary, there is great potential in developing clinical practice to meet the needs of mothers who have experienced stillbirth. There has been a significant development in NHS-based support, which has not been fully evidenced in this study. Since it appears that change has begun to be implemented across the UK, replicating this study without the two-year minimum period since the stillbirth occurred would be a way of developing the research area.

1.2 The Mental Health Effects of Grief after Stillbirth

As explained above, mothers need help to navigate this period. Various stages of grief will be explored, looking specifically at how stillbirth and grief manifest together. These elements are not just explored empirically; more theorised approaches will be discussed due to the nature of stillbirth. Grief following stillbirth is visceral and unique in terms of death coming before life, which is not the natural order of things (Murphy & Cacciatore, 2017).

There is extensive literature on how distress can impact the mother’s mental health and her relationships. While it can be acknowledged that everyone will have a different reaction to experiencing stillbirth and may have a wide range of individual factors as described above, grief (in whatever form that takes) will affect a mother’s life from the minute they find out their baby has died, and support from then on is greatly needed (Kirkley-Best & Kellner, 1982). The literature explores the grief of mothers following stillbirth, particularly how various stages of the birth and the moments after can each be seen as separate grief entities, with additional theorising of how support can be included and how this impacts the mothers' mental health. The first theory is the 'loss of the assumptive world', exploring the moment when mothers are told their baby has died. This is followed by the 'dual-process model', which navigates the intervening moments of naturally seeking normality between births or after birth. The exploration of 'continuing bonds' highlights memory-making moments with the baby and being a family. Finally, there will be an examination of 'ambiguous loss' and 'disenfranchised grief', mainly focusing on how stillbirth has nuances that should be kept in mind when looking at the support needs and experiences of affected mothers.

Theory of 'Loss of the Assumptive World'

This term was first coined by Parkes in 1971 (Kauffman, 2013). The assumptive world refers to a person's belief that the world functions methodically, with probability. Kauffman (2002, p. 2) describes the assumptive world as the 'ordering principle for the psychological or psychosocial construction of the human world', meaning these beliefs are a way of shaping one's reality, both physically and mentally. Knowing this term 'assumptive world' is beneficial for this study because it can bring a theory-based approach to a lived experience such as stillbirth and help the reader view the natural human assumption of things and what happens when this changes.

Beder (2005, p. 258) positioned the assumptive world as 'reflecting all that a person assumes to be true about the world and the self on the basis of previous experiences'. When the assumptive world is lost through sudden loss, for example, Beder (2005) goes on to explain that the assumptive world being lost means 'the guidelines with which the self navigates the world are overturned. The world is no longer a safe place…' (p. 259). In relating this idea to the current research topic, when a mother finds out she is pregnant, and if she has not had any prior experience of stillbirth, there may be a self-assumption imposed that her pregnancy will end with a healthy live baby being born after the typical 40 weeks of pregnancy. The mother may have a strong sense of an 'assumptive world' and not want to intentionally factor in other 'potential' elements of reality. Ravaldi et al. (2018) found that when women and their partners enter into pregnancy there can be an expectation that the pregnancy will be uneventful. This assumption is known as being in the 'believed world' (Black, 2020, p. 318) and is described by Kauffman (2013, p. 2) as a 'normative constancy of experience and belief' meaning the baby being born is what is going to happen. This can be argued as being based on a trust in modern science and doctors who they perceive will treat them during their pregnancy. This perspective can be defined as there being no thought of loss, as this is not in the parents' mind – they have a firm 'believed world'; however, it needs to be acknowledged that not every individual will be prescribed to a 'believed world' and this research will show

how varied this can be. Malacrida (2016) states that having ‘meaning’ is an essential element of human experience; especially when a disaster occurs. There is a need to regulate meaning and make sense of a new, unanticipated and unwelcome reality.

A study by Ünstündag-Budak (2015) acknowledges that the stillbirth experience is one where the order of natural events is altered. The nature of stillbirth is typically death first, then the baby’s birth, which can result from trauma. They also acknowledge that the mother does not know the baby’s identity, which the authors highlight as a double dilemma, meaning the mother has not been able to form an external bond with her child, as would be typical in other deaths. The study notes the need for ‘particular psychological restructuration’ and the importance of acknowledging this type of loss. Ünstündag-Budak (2015) adds that it is crucial to examine the stillbirth experience for itself, as it is different from other perinatal losses. This level of consideration is needed when attempting to improve care being provided to those that have experienced stillbirth.

The loss of the assumptive world is the first phase where some mothers may need support, and the shock of the believed world being lost can be painful. Having to give birth while still in this moment is a lot to bear.

Theory of ‘The Dual-Process Model’

As described by Stroebe and Schut in 1999 and again in 2010, the dual-process model is a simple mechanism to explain how a grieving person, in this study’s case, a mother, can make sense of and cope with a significant loss. The model helps bring a theoretical perspective to understand the complex and sometimes unusual behaviours people in grief exhibit to those looking in on the new reality of loss. It is important to note that Stroebe and Schut don’t use empirical evidence to validate their theories. There have been some criticisms of the dual-process method, such as seeing grief as a linear experience, which is not fully inclusive of those experiencing grief. It also only offers a narrow perspective on one’s internal process and focuses too much on confronting one’s emotional experience (Schut, 1999).

Stroebe and Schut (1999) highlighted that bereaved people oscillate between orientations of loss and restoration. They describe ‘oscillation’ as a method by which a person takes a break from the taxing effort of coping with their loss. Lundorff, Thomsenm, Damkier and O’Connor (2019) note that moments of both loss and restoration orientations involve managing, which may become burdensome over time. They describe that, when oscillating to the restoration orientation, a person looks for distraction from the pain of loss and even actively avoids feelings of grief. Knowing more about this period of oscillation highlights that support can be of great use to help bring a sense of normality to a time when a person’s life will have likely changed irrevocably.

In a study by Shepherd, Patzelt and Wolfe (2011), they note that the person may seek new opportunities, including new work roles and/or relationships. With this current study focusing on stillbirth, the restoration orientation could be viewed as an action or thought of potentially becoming pregnant again in a period of loss. Black (2020) states that, in these moments, a mother is seeking some element of restoration. She wants to move from what may be overwhelming sadness in her loss. This does not mean she is trivialising or ignoring her loss; it may simply mean she needs a break from her sadness to address her own needs. The latter point is an area that mothers may find hard to manage, as they do not want to appear disloyal to their baby, as Pollock et al. (2020) explain. Black (2021) offers a clear example of this process, in which a woman who has experienced long labour and has given birth to her stillborn baby may want to bathe and put on some fresh clothes or even laugh and share moments of pride with the midwives and family about who the baby resembles. Having support during this period of loss and having others aid the moments of restoration are acts of support for mothers.

Theory of ‘Continuing Bonds’

Continuing bonds refers to an ongoing relationship or attachment experienced by a bereaved person to their deceased loved one (Klass & Walter, 2001). Even though in some instances continuing bonds are comforting to the bereaved, in others, they can create tension in relationships (Testoni, Bregoli, Pompele, & Maccarini, 2020). Field and Filanosky (2010) demonstrate that continuing bonds are complex. It appears that measuring the health and nature of continuing bonds is more complicated than a simple adaptive or maladaptive theory. The complex nature of continuing bonds may be impacted by the attachment style of the bereaved, the type of death witnessed/experienced by the bereaved, and many unexplored factors that may or may not be associated with post-traumatic growth (Field & Filanosky, 2010) and healthy attachment. This potential complexity tells us that this specific theory can be utilised within a support programme but must be handled with a considered approach and personalised based on the particulars of a person’s loss to enable the patient to move forward with their grief.

The meaning of pregnancy and the notion of an expected baby can vary widely (Black, 2020). A mother’s continuing bond can be held in a ‘solace filled object’ in their grieving process (Klass, 1993, p. 345). Testoni et al. (2020) note that, through accepting the memory of their baby, the object can become an extension of the mother’s self, which preserves a psychological rather than a physical closeness to their baby. Without the possibility of physical closeness to their stillborn baby, Cacciatore, DeFrain and Jones (2008) note that parents may seek ways to maintain psychological proximity as they adapt to their loss and adjust their expectations of life after their baby's death. This tells us that having a tangible and structured process of memory-making (which is a common approach used in maternity units) gives a mother the opportunity to build a personal psychological bond with an object (e.g., footprints), which she can use as an opportunity to hold the specific memories of her baby.

Murphy and Thomas (2013) acknowledge that, with only a short time to be able to hold and be physical with their baby, parents often seek ways to incorporate their stillborn child into their family's history. It is becoming a more common occurrence for parents to spend time in the hospital making memories and creating transitional objects to reflect the continuation of bonds with their baby. They explain that transitional objects are mementoes and other tributes that connect the deceased to their loved ones. For families whose baby is stillborn, few opportunities and little time exists to accumulate materials that will serve as transitional objects, but some can be collected with help from midwives (e.g., newborns' clothing, footprints, hand moulds and pictures) by mothers wanting to engage in special moments. These objects are not simply memorials – for some families, they connect their baby's life with theirs and serve to establish and continue bonds of attachment. The study also highlights how the use of transitional objects can aid grief by giving the opportunity for some mothers to return to their baby at various points in their lives should they feel it is right at the time.

Jones (2020) referenced a study by Valentine (2008), whose findings demonstrated that the bereaved try to manage the painful paradox of the deceased's absence/presence through the materialisation of the loss, which encompasses activities and memorialisation as well as ritual. Jones (2020, p. 20) also noted that Walter (1996) emphasised a need for 'Western society to acknowledge the dead's presence and permit the bereaved to retain the deceased in their ongoing life and honour the memory freely'. Opportunities for camaraderie and openness were found to help maintain a connection to a stillborn, as evidenced in the results by Jones (2020). Their data showed that hospitals and relevant charitable organisations offered parents opportunities to engage in activities that aided in developing bonds with their stillborn babies. However, the data also found that it appeared that, outside of these stillbirth community environments, few culturally embedded rituals or points of reference were available to parents. Instead, as will be analysed later in this study, parents found inventive and imaginative ways to express their relationship with their baby – spanning a broad range of activities and experiences – which greatly supported mothers.

Theory of ‘Ambiguous Loss’ and ‘Disenfranchised Grief’

Ambiguous loss is when a loss remains unclear (Boss, 2007). The developer of the theory of ambiguous loss, Pauline Boss, found that there are two types of ambiguous loss (Boss & Yeats, 2014). The first is physical: a loved one is physically absent but kept psychologically present because there is no validation of whereabouts, or status as dead or alive. The second is psychological, when a loved one is physically present but psychologically absent due to, for example, memory loss. In relation to the current study, stillbirth would come under the first type of ambiguous loss, where the loved one is not physically here, but their memory lives on. As acknowledged by Cacciatore, DeFrain and Jones (2008), for families of a stillborn baby, the nuanced experience of how the baby will be recognised and grieved for differs massively depending on the parents and their significant others (i.e. family and friends), their culture, religion or geographic location and how each interprets and experience stillbirth. There can be an occasion when the baby’s life is not wholly acknowledged (compared to a child born alive even for a short time), which means there is less validation of the baby’s existence for the mother to find support during her grief. Following on from the feelings of ambiguous loss that parents will be expected to experience, there is then the notion of disenfranchised grief, which can result in their baby not being acknowledged as a memory, which has a knock-on effect on the support the parents experience.

Lang et al. (2011) explored the ambiguity and disenfranchisement of grief and quoted Rubin and Malkinson (2001, p. 231) in summing up the experience with ‘many people find it hard intuitively to understand why the grief for a child who has not lived long enough to define him- or herself should be so prolonged or intense’. Lang et al. (2011) noted that bereaved parents often find it hard to reconcile their intense feelings with society’s lack of validation, and they concluded from their study that aspects of disenfranchised grief were clustered into the following experiential and relational categories: within the relationship, when communicating with health professionals, when interacting with extended family, community and society in general. These interactions can amplify couples’ negative experiences and fuel their perceptions of inadequate support. They noted that the effects of ambiguous loss and the sense of feeling disenfranchised not only encumber bereaved parents’ psychological wellbeing and efforts to cope and move forward but also significantly compromise marital, family and other relationships.

Perinatal loss, in this case stillbirth, is a traumatic loss, which increases susceptibility to complicated grief. Ünstündag-Budak (2015) noted in their study that it is important to emphasise that grief is a natural reaction to loss, yet a perinatal loss is not expected to trigger a grief response and depression-like symptoms compared to a loss of a baby or person that has lived. Nevertheless, there may be prolonged feelings of sadness following a perinatal loss, contributing to worsening mental health problems, such as complicated or pathological grief. This will be considered during the data gathering phase of this research to improve the researcher's empathetic stance.

1.3 Support from Others following Stillbirth

The need for connection can include connecting with close family, friends, work colleagues, newer acquaintances, support groups, personal therapists, GPs, midwives, doctors or someone who offers support when needed. The need for connection with others can sometimes be superficial, and it is just the need for the presence of someone rather than them being alone. Brierley-Jones et al. (2018) explored the various ways in which health professionals manage stillbirths and found that there is either a patient-led or health professional-led approach. They found that high-quality evidence is needed regarding the longer term psychological and emotional sequelae of different modes of delivery and varying time intervals and locations of women between diagnosis and delivery in stillbirth. There is currently not much evidence to explore these approaches.

Ryan and Pintrich (1998) acknowledged help-seeking as 'the ability to utilise others as a resource to cope with ambiguity and difficulty' (p. 117). There are two categories within help-seeking (i.e. a mother's decisions to engage in or avoid emotional support) – individual and environmental influence. Individual factors include self-efficacy beliefs, motivation, and self-regulating behaviours. Environmental factors include the environment and the opportunity for support to be obtained. These two variables (individual and environmental) are often interrelated and overlapping; by definition and in relation to this thesis, help-seeking is a social process in which the mother and the object of support are sourced and ideally engage with each other towards positive outcomes.

Mroz, Bie and Iwanowicz-Palus (2021) explained in their study that pregnancy loss is typically experienced as a traumatic event, which may lead to secondary psychological health disorders. The mother would typically experience loss and related medical issues associated with pain and changes in one's perceived quality of life. The purpose of their study was to evaluate levels of quality of life, social support and self-efficacy among women who had suffered a miscarriage, which is a different presentation to the current research of stillbirth. However, their findings were similar to the present study where women, after a miscarriage, reported that the poorest quality of life was in the psychological domain, while quality of life was better in their overall health. They also had a high level of self-efficacy. The types of social support perceived as being available were instrumental and emotional, and they received highly rated support. Social support and self-efficacy contributed to a perception of a better quality of life among the respondents. The study highlights that there is a need for different research to be conducted for both miscarriage and stillbirth due to their individual nuances of experience. There is a need to differentiate the two phenomena within research under the umbrella of baby loss so that each can be seen as its own experience and what psychological support is required.

An Iranian qualitative study by Allahdadian, Irajpour, Kazemi and Kheirabadi (2015) explored how social support can be adapted to aid mothers after the experience of stillbirth. They interviewed 15 women and, through content analysis, found that mothers of stillborn babies need support from their spouses and family and friends through sympathising, performing everyday activities and escaping isolation. The authors also came from a medical background, including midwifery and critical care. It was recommended that women in this position require support from a peer group to exchange experiences and trauma counselling centres to meet their needs. This study is similar to the current research in terms of content and, with it being set in another country, it provides an opportunity to explore whether needs are universal or country based. This was going to help me should any participants have been from an associated culture and it will aid future studies by broadening perspective of what support is available across the globe.

Murphy and Jones (2014) found that even close family members did not automatically understand the impact of stillbirth, and many parents were left unsupported. In the same study, White (2002) referenced that, following stillbirth, the relationships between maternal grandparents and adult daughters became particularly strong even when those relationships were previously strained. Also acknowledged by White (2002) was that grandparents would retain bonds with their stillborn grandchild. Though this study does not engage with the grandparents' experience, it does acknowledge the potential for healing and emotional recovery via the creation of continuing bonds using the method of memory-making. These memories would be created with the adult daughter or directly with the baby, which can be a supportive experience for the grandparents amid their grief.

A Swedish study by Erlandsson, Säflund, Wredling and Rådestad (2011), who are also working from a medical point of view, explores parents' support experiences over two years after their stillbirth. They found that the initial support parents experienced was from their midwives, doctors and priests at the hospital where the stillbirth occurred. The study then jumped to the point two years after the stillbirth, where support from friends and family was more prevalent and necessary. It was found that the need for professional support after stillbirth can differ, depending on the support provided by family, friends and social networks, but the mothers might not fully realise the value of the close relationships and how they have been held through their grief. The need for support is highlighted, but there is no specific mention of psychological support. However, there is evidence of a need for personalised support due to their profound loss and how this physical support can aid psychological outlook.

Similarly, Cacciatore Schnebly and Froen (2009) examined whether maternal anxiety and depression levels were lower among mothers who received social support after stillbirth. It was found that mothers of stillborn babies who had family support afterwards experienced lower levels of anxiety and depression than the comparative group who did not. It was also found that nurses, doctors and support groups were important sources of support after a stillbirth; however, these sources alone were not significant in reducing anxiety and depression in the grieving mothers. This highlights the need for family and community support to be present following the birth of a stillborn baby. The authors present a theoretical point of view that is not psychological but rather comes from working in obstetrics and human services departments. They discuss the need for mental health support, but there is little mention of mental health professionals being included. There was a focus on the medical professionals being the main but not sole source of support, and the need for a broad support network for mothers to recover.

Cacciatore, De Frain, Jones and Jones (2008), who are academics and therapists from the US, explored how parents perceive and cope with the death of their baby and how the loss affects them as individuals and couples. They found that mothers and fathers grieve separately yet collectively, and sometimes struggle to find meaning in their losses. Responses to a baby’s death can depend partially on the parent’s gender and the belief system around death as a couple and a family unit, the formed attachment to the baby, and whether they have social support. The loss of their baby may create conflict in the relationship, yet many couples can also experience a greater sense of closeness. The authors found that having a therapist help support them and help the relationship to grow after such a life-changing experience was important and highlights that psychology and supporting the mother and the couple overall is a support that some couples require when grieving.

In a UK study, psychologists Crawley, Lomax and Ayers (2013) explained that when mothers could share with others the memories of time they had spent with their baby, this sharing could be invaluable as it allowed the normality of motherhood to be experienced. Some mothers have family members who meet their baby, while others only have midwives connected within the moment and share the memory-making of their baby. Sharing memories and communicating with people is very validating for the mother. Crawley et al. found that the recounting of memories triggered a recovery process for the bereaved mother, which nurtured an experience of validation found in others' listening (this was an important point to hold in the interview of this current study). The authors went on to find that a mother's mental health became better over time, with perceived professional support and sharing of memories resulting in a natural feeling or need to talk more about the baby. In addition, they found that if the mother could speak and share her feelings and memories with others, there was a reduced likelihood of symptoms of PTSD. A study from a psychological point of view exploring the effects of stillbirth is unique and addressing how to manage PTSD is a positive development in the area of support.

Gijzen, L'Hoir, Boere-Boonekamp and Need (2016) conducted a study in the Netherlands that determined what support parents received after the death of their child and whether it was the correct type of care for their needs. They found that support initiated by professionals should always include listening to parents and asking them at key moments after their child's death whether they need 'extra' support, and what kind of support they would like to receive. Parents should also be explicitly asked about the emotional support they receive from their family and social network. Although this study is from the Netherlands, the exploration of it prompted thoughts for the current research to explore whether the interviewees had experienced initial support from professionals and to compare those experiences to see if it made a difference to their ability to process grief. Additionally, adequate communication skills and a respectful attitude are necessary for approaching the parents of a deceased child.

1.4 Exploring Support following Stillbirth

Once a mother has left the hospital, there is little research on how they find their support amid intense grief. One study by Bakhbakhi, Burden, Storey and Siassakos (2017) found that some mothers react well to losing structure, while others find it overwhelming once they leave hospital after giving birth to a stillborn.

One Swedish study was produced by Säflund, Sjogren and Wredling (2004), who come from midwifery, obstetric and nursing backgrounds. The study found that the information provided to parents moments before and after the stillbirth is of the utmost importance as the information will guide the parents on what will happen over the coming period. They describe information giving and sharing as 'support in chaos' (p. 133), which is how structured information can help relieve despair. For example, after telling parents that their baby would be stillborn and would be imminently delivered, the need to manage the mothers' shock and the need to give information were finely balanced but would ultimately support the parents during delivery, which was noted to be an impactful point over the whole experience. When they were told that their delivery would occur imminently, the parents in the study stated that they needed all the information, advice and support available every step of the way – this would have been a great support to them at the time. It was subsequently found that, although these parents wanted structured information, when it came to the midwives and doctors supplying ‘all the information’, it became harder for the parents to engage fully with what was being said. From this study, it is clear that each professional needs to consider the dissemination of information to parents. Using these considerations within the questions of the current study could in turn help define considerations that need to be made by health professionals when caring for people going through this situation. Healthcare professionals supporting the mother have an important role in remaining empathetic and informing the mother of what is happening when the birth of the stillborn is about to occur. This supportive delivery of information needs to be able to guide them through the difficult process.

A study by Bakhbakhi et al. (2017) recommended that, before discharge from the hospital, parents should be provided with details about what to expect on their return to the community, including being given a single point of contact in the follow-up period. The study noted that most parents wished to acknowledge the stillbirth and their new situation with healthcare staff. This led to further findings around the continuity of care following a stillbirth. In the same study, it was found that the interactions between healthcare professionals can have a lasting impact on parents, and carefully considered communication is essential throughout this time. There was a further review by Ellis et al. (2016) within the study around the necessity of clear, easily understandable, and structured information given sensitively at appropriate times, which helps parents through their experience. Continuity of care is important to parents, and it was recommended that they are under the supervision of a dedicated and consistent bereavement midwife and obstetrician (Ellis et al. 2016; Säflund et al. 2004). In addition, an inclusive approach should be taken to ensure that partners are involved in decision-making where appropriate. Given that this study highlights key aspects of the necessity of support, I was intrigued to see if the data collection produced experiences that correlated to the best practices highlighted here. Also, it was interesting to investigate whether the mothers/parents did find continuity of care after stillbirth beneficial.

A study conducted by Lee (2012) found that parents and healthcare professionals in Australia agreed that the period between hospital discharge and follow-up consultation was characterised by delay and a lack of information for parents, with levels of support varying. Parents explained that there was the assumption that follow-ups with the primary healthcare team would automatically be arranged, contrasting with what bereaved parents experienced.

The study found that streamlined, standardised and collaborative care was urgently needed between hospital and community settings, as recommended in the UK study by Bakhbakhi et al. (2017). There is a particular need for clear pathways at the coalface of primary and secondary care to support parents after stillbirth, which was also found in the study by Ellis et al. (2016) – a combination of Australian and UK-based medical professionals and academics. All three studies found a strong need for good communication with the primary healthcare team (including GPs, community midwives and health visitors) to ensure continuity of care. The studies by Bakhbakhi et al. (2017), Lee (2021) and Ellis et al. (2016) highlight the need for support, and the processes of support following stillbirth are similar in countries even as far apart as Australia and the UK. With the findings of the previous three studies in the literature suggesting that clear pathways were the method by which parents should be supported after stillbirth, I wanted to clarify if this was something that the participants experienced and, if they did, whether it was helpful in their situation.

The Australian study by Boyle, Horey, Middleton and Flenady (2020) found that the needed levels of, and access to, support were not available in all situations. The study explained that adequate support addresses both the short- and long-term needs of parents and other family members. Support should be based on recognising that parents have experienced the birth and death of their baby with consideration of psychological, physical-health and practical support needs. The results found that parents required immediate support to manage the initial stage of their grief and pathways in their communities once they had left the hospital. The study recommended that healthcare professionals and maternity care facilities bring together research, parents' lived experiences, and insights from maternity care providers, and it also strongly recommended having a clear and transparent approach to support. The study presented an overview of the updated Perinatal Society of Australia and New Zealand Stillbirth Centre of Research Excellence, one of a few institutions focusing on developing knowledge of stillbirth.

In correlation to the above study, Mayers, Hambidge, Bryant and Arden-Close (2020) found that, to help support their partners, fathers specifically wanted healthcare professionals to sign-post them to someone they could talk to for emotional support and to be taught coping strategies that would help them to support both their partner and baby. As there is limited research around the father's point of view following stillbirth, this study's findings suggest that health professionals and perinatal mental health services need a better understanding of what resources fathers need to support the mental health of themselves and their partners. In the current thesis, including the partners is not a focus but was to be an aspect explored within the participant interviews to understand the role partners played in providing support should the mother introduce the topic to their interview.

When there isn't a transparent network of support and mothers are left to navigate their grief and self-manage the loss of their baby, there can be detrimental results. Gold, Leon, Boggs and Sen (2016) conducted a longitudinal study of mothers who had a stillbirth or infant death in the US – not a typical study exploration. The study assessed the mothers' mental health over nine months post loss, through their self-reported depression and PTSD symptoms. They found that, nine months after their loss, the women showed high levels of distress with limited access to support. This study highlighted that needing insurance cover to pay for support and medical bills exacerbates the distress, which is a significant difference from other countries researching this topic. It was useful to show that having more social support was protective against both depression and PTSD, and public insurance was a significant predictor of a positive PTSD screen but not of current depression. A final point was discovering that bereaved African American mothers have low treatment-seeking rates even when symptomatic after their loss. This is a worrisome finding given health disparities in perinatal loss among African American mothers (Anna, 2020) on top of the evidenced overall high risk of depression and trauma during subsequent pregnancies (Lazarides et al. 2021). As previously stated, this is an element that can be evidenced in the UK and the US.

Iran-based Navidian, Saravani and Shakiba (2017) conducted a study to understand psychological grief counselling on symptom severity of PTSD in mothers after stillbirths. The study was conducted on 100 women who had recently had stillbirths. One group received four sessions of counselling over two weeks, and the other received routine postnatal care. The results showed a positive impact from psychological support on reducing the severity of PTSD. The recommendation of integration of intensive psychological interventions in the maternity care system seems essential for quicker transition through grief stages and the prevention of severe cases of PTSD. This evidence-based paper highlights the need for therapy and support for women after stillbirth, which is echoed in other countries (Cacciatore, De Frain, Jones, & Jones, 2008; Cacciatore, 2013). Despite country of origin, most literature reviewed highlights the benefits of psychological interventions. It will become apparent within this study whether, when received, treatment does aid mothers in working through the stages of grief.

1.5 Broad Options of Support following Stillbirth

As detailed in the previous theme, evidence shows that women who have a stillbirth need support. Shakespeare et al. (2020), who come from various countries including the UK, Ireland, Australia and the US, found that the experiences of grief vary, and there is a need to recognise the emotional state that mothers could be in following the stillbirth of their baby. The study states that a lack of recognition can exacerbate the grief and lead to potential trauma, as previously noted in Gold et al. (2016). However, if the mother has received positive support, this can improve the bereavement experience. The need for high-quality care as support can moderate both immediate and long-term adverse outcomes. These recommendations can be found in new national guidelines in England and Scotland (NBCP, 2020) to guide healthcare workers responsible for providing care to bereaved women after stillbirth. But if this support is not there, then mothers have to go out and source it themselves. The literature below shows examples where mothers have had to procure their own support. The literature evidences potential situations where recommendations for national guidelines have not been followed and was going to help me understand potentially complex scenarios being described during the interviews I conducted.

Barriers present when seeking support include ignorance of symptoms, inability to disclose distress, the attitudes of others and cultural expectations. These are evidenced in the study by Button, Thornton, Lee, Shakespeare and Ayers (2017), who explored why women may not seek help for perinatal psychological distress despite regular contact with healthcare professionals. Their meta-synthesis identified three main themes, which were: identifying a problem; the influence of healthcare professionals; and stigma. These themes build on the current understanding of help-seeking by recognising the need for women to be able to frame their experience, for healthcare professionals to educate women about their roles, the need for continuity of care and the way that being seen as a ‘bad mother’ causes some women to self-silence. This demonstrated that further research is required, mainly about effective means of identifying perinatal psychological distress.

Social Media

Over the past 7–10 years, social media has become a significant element in people’s lives. Studies have looked at how people with mental illness or other life-changing situations seek support during this time. A US study by Naslund, Aschbrenner, Marsch and Bartels (2016) found that people with mental illness turn to social media, including Facebook, Twitter or YouTube, to share their experiences or seek advice from others who have experienced similar conditions. This emerging form of communication among online communities consisting of patients and individuals with various health concerns is called ‘peer-to-peer support’. The study noted that people reported benefits from interacting with others online from more significant social connections, feelings of group belonging, sharing personal stories, and gaining strategies to cope with the daily challenges of living with a mental illness. Within online communities, it was found that there was an opportunity to challenge stigma through feelings of empowerment and providing hope. By learning from others online, individuals could gain awareness of important healthcare decisions, promoting mental healthcare-seeking behaviours. These individuals could also access psychological and physical wellbeing interventions delivered through social media that could incorporate mutual support between peers, help encourage treatment engagement and reach a broader demographic. There were very few studies similar to this, and it is a growing topic of study now that the COVID-19 pandemic has produced a new acceptance of offering support and information more readily online (WHO, 2020).

Many studies relating to social media support the continued awareness-raising of stillbirth, but Maiorescu (2015), based in the US, studied how the UK-based charity Sands could further develop a robust online community. There was a recommendation to form an intimate online community based around respect and encouragement, to break taboos and help cope with loss. This communication style would lead to increased user involvement, more disclosure, and the strengthening of relationships among users, while also increasing interactivity. However, in the study, Sands' communication encouraged its users to post, retweet and/or volunteer. While this type of encouragement can alleviate pain by increasing self-efficacy, it fails to provide a venue for increased interaction among online community members. A survey by UK charity Tommy's (2018), which had 1,116 participants, looked at the outlook on pregnancy and baby loss and the role social media plays. The results showed that, although Sands' posts had a high presence of respect and encouragement, the users' comments did not reveal a close online community since care, intimacy and closeness were present in less than half of the users' comments. The results showed that 84% felt they had an online community after baby loss, and 45% made new friends. The survey also revealed that, of the respondents who had experienced miscarriage (79%) and stillbirth (21%), 70% said that they felt guilty, 77% felt angry and 80% felt envious of pregnant friends (Tommy's, 2018). The survey shared that over 66% of women felt 'bombarded' by pregnancy news and stories following baby loss, and 57% were upset to be targeted by online pregnancy adverts (Tommy's, 2018). These studies highlight the nuances of social media and how it can support some but be too much for others to bear, which in turn can exacerbate the feeling of loneliness that mothers experience when their baby is stillborn.

The Workplace

There is a dearth of literature around how stillbirth impacts the experience of work and the support it could provide. However, a recent study by Australian authors Obst, Due, Oxlad and Middleton (2020) surveyed Australian men who were part of a more extensive study exploring men's grief following pregnancy loss and neonatal death. The study investigated the variations of offered leave and how the leave and support provided by employers was perceived. The results found that nearly all men shared their loss with the workplace, which resulted in 74% being offered some form of leave to support them after their loss. The most typical types of leave provided to the men were compassionate leave and sick/carers leave. Not all men wished to take extended paid leave following pregnancy loss or neonatal death, though they believed leave should be available if there was a need. There was little opportunity to understand the view of a mother and the workplace; this will be shown in the analysis chapter.

Support Groups

Many support groups are available to mothers at a national and local level, mainly run by charities like Sands and Simpsons Memory Box Appeal (SiMBA). Hunt (2020) found that mothers who contact bereavement groups or have a supportive religious community promote a sense of identity loss, allowing for a meaningful experience. Cacciatore, Schnebly and Froen (2009) noted that engaging with a community brings a social context to grief and is commonly sought by mothers who experience stillbirth. There is specific support that comes from groups of people who have had similar experiences, e.g. stillbirth, and it can be a place for information sharing or comfort – knowing that there are others there who have been there and can understand to an extent what the mother has been through in her loss. A few studies recommend involvement in support groups, but it is still a growing study area, particularly in the US (Cacciatore, 2007; Gold, Normandin, & Boggs, 2016).

Raising Money for Charity

Within the study by Hunt (2020) there was an exploration of Talbot’s (1999) study, which suggested that, following the death of a child (in this case not stillbirth but the loss of an older child), bereaved mothers interpret awareness-raising, volunteering and fundraising as a way of nurturing their lost child. The study suggests that these activities become a way of parenting the child and maintaining a connection in life beyond loss. Mothers who engage in such activities may experience new facets to their identity and revised narratives of being a mother and continuing to nurture. Talbot’s (1999) findings enhance a discussion regarding the potential for personal transformation in the aftermath of parental bereavement and how bereaved mothers may choose to connect with their children. Cacciatore (2014) also found that volunteering in settings that allow the bereaved to support those who have shared a similar experience might encourage feelings of acceptance and understanding. In raising awareness, the bereaved may experience agency, increased empathy and a sense of satisfaction to challenging society around engaging with the stillbirth experience. There is not much research in this area, and there is room for development to understand how this experience supports mothers after stillbirth.

1:1 therapy

When searching for evidence and literature on how mothers' mental health can be supported through the medium of counselling or therapy after stillbirth, little relates directly to the overall effects of different approaches.

Forrest, Standish and Baum (1982) studied the practical aspects of the management of perinatal death. The study explored how a counselling service was introduced for parents whose babies died in the perinatal period. Families were randomly assigned to either counselling or routine hospital care. It was found that socially isolated women and those whose relationships were deficient in intimacy resulted in a higher incidence of psychiatric symptoms at six months. It was also noted that those who were pregnant again within six months had a higher prevalence of psychiatric symptoms in the unsupported group. The duration of bereavement in terms of grief after perinatal death was noticeably shortened by support and counselling. This study was followed up by a letter to the *British Medical Journal* from another group of practitioners, Davies, Bourne and Lewis (1983), who agreed that of all paediatric hospital services, the average baby follow-up clinic 'is probably that which has the least thought devoted to it' (p. 145). However, in their experience of using a similar approach, it was essential to implement counselling further and have a carefully considered criterion for follow-up care, which should be offered as standard.

This view is backed by a later study by Cacciatore (2013), who shared that there is little evidence on intervention efficacy in the period of acute grief following perinatal death. The study describes the death of a baby to stillbirth as the ultimate paradox for healthcare professionals and parents due to the convergence of life and death and the ultimate contradiction it represents. They note that, in general, positive interpersonal relationships and strong social support are two types of intervention that are known to reduce the intensity of grief. This suggests that, while not the sole element affecting grieving parents, support can reduce the risk of long-term adverse effects of grief. This means that parents can manage this time with appropriate care and consideration, and they need not suffer alone and is something I will endeavour to explore further within this research.

Ünstündag-Budak (2015) explored a need to inform practitioners and provide evidence-based therapies and interventions for the psychological support of women, adding that therapeutic interventions should consider the condition of the mother's continuing relationship with the deceased infant. For example, Betz and Thorngren (2006) discussed narrative therapy techniques regarding the experiences of ambiguous loss. This model can be used flexibly: the primary premises include letting family members share their stories, empathising with their feelings, and encouraging them to take authorship of new and more meaningful stories about their losses. Bosticco and Thompson (2005) also suggested using narratives and storytelling to facilitate the bereavement process. Their review was on the role of storytelling or narratives in grieving and bereavement. The article is a conceptual framework provided by the literature review, and the examples of applications of the concept to grief work will prove helpful for future researchers in their attempts to study this process and guide others through their bereavement experiences.

1.6 The Support Needed for Pregnancy after Stillbirth

If women become pregnant again soon after stillbirth, there is heightened anxiety about the potential for the experience to be repeated (Meaney, Everard, Gallagher, & O'Donoghue, 2017). As previously explored, there is potentially undiagnosed or explored trauma from their stillbirth and when there is a subsequent pregnancy there may be feelings of fear throughout.

Studies have found women have a higher chance of postnatal depression (PND) or PTSD in the period after their baby dies or when they become pregnant again. Turton, Hughes, Evans and Fainman (2001), based in the UK and South Africa, found many women suffer from negative psychological symptoms after stillbirth and subsequent pregnancy. They noted that stillbirth had not been demonstrated to be a stressor for PTSD at the time of publication. They did find, however, that PTSD symptoms were prevalent in the pregnancy following stillbirth. PTSD was associated with depression, anxiety and conception occurring close to loss. Symptoms generally resolve naturally around one year postpartum. However, because some women continue to suffer chronic symptoms of PTSD, the possibility of this diagnosis should be recognised and assessed in an accessible way.

Based in Australia, Robson and Leader (2009) found that women often want increased monitoring and request early birth dates in these pregnancies but that, in many cases, the medical benefits of such practices remain uncertain, and the reassurance is short-lived. Robson, Leader, Dear and Bennett's (2009) study, published in the same year, found that women surveyed in their subsequent pregnancy after stillbirth wanted increased foetal surveillance and early delivery, but not necessarily elective caesarean section. Of the total respondents, 93% reported that more medical tests were made available than the routine care usually offered in pregnancy. A total of 81% wanted an early delivery and 26% wanted a caesarean delivery, irrespective of medical direction.

In a similarly themed UK study, Wojcieszek et al. (2018) conducted an international web-based survey of 2,716 parents, which showed comparable findings, with wide variation in care received across geographic regions. For example, 67% of parents received more antenatal visits and 70% received additional ultrasound scans; however, only 10% had access to a bereavement counsellor. A further UK and Canadian study by Ladhani, Fockler, Stephens, Barrett and Heazell (2018) found that parents often had extra antenatal visits and more scans in the subsequent pregnancy, but they rarely had additional emotional support. They also found that many parents felt their healthcare professionals did not always listen to them, spend enough time or involve them in decisions, and didn’t take their anxieties seriously. They also found that parents were more likely to receive a variety of extra care in the subsequent pregnancies if their baby had died later in pregnancy compared to earlier in gestation.

As well as having extra medical monitoring and specialised clinical care after stillbirth, it is critical to address parents’ unique psychological needs. Mills’ (2015) UK-based study found that most women who have a stillborn baby will think about and act on having another baby soon after birth, with around 50% becoming pregnant within a year of the loss. When the mother becomes pregnant again, maternal anxiety and heightened emotional vulnerability are more likely to be noted. These feelings often extend beyond the postnatal period, thus increasing the risk of adverse pregnancy outcomes and disrupted attachment – a potential cause of parenting and social difficulties in the longer term. The interim findings raised the need for comparable, appropriate and sensitive care for parents in subsequent pregnancies across the UK. Their data suggests that many parents receive inadequate emotional and psychological support, and therefore, there is a need to improve the evidence base underpinning care, which was also acknowledged in a similar study by Silver, Siassakos and Dudley (2018). The more studies there are conducted around this topic, the more evidence-based care can be improved.

Five years later, a similar study by Graham, Stephens and Heazell (2020), who are all UK-based, produced a survey of maternity units highlighting that a small number of parents had explicit written guidance on what support was open to them in a pregnancy following stillbirth. They found that there was little high-level evidence to direct the management of pregnancies following stillbirth. The study found an absence of evidence, which meant there was considerable variation in care for parents. In turn, it increased the risk of poor health outcomes during future pregnancies. Most parents in the survey shared that they did not receive adequate emotional and psychological support, as per the previous study by Mills (2015).

A study by Ayers, Fitzgerald and Thompson (2015) evaluated a brief online self-help intervention designed to promote a positive mood in mothers of babies and toddlers in their pilot study. It is important to note that stillbirth is very different from the situation in the noted study; however, it is useful to explore the intervention style in that it is accessible and self-help-based. The self-help intervention was satisfactory to most women and meaningfully increased positive mood compared to the contrasting condition. This effect persisted after controlling for self-esteem, anxiety and depression. These results suggest that a simple self-help intervention focused on changing beliefs about oneself as a mother can immediately impact women's moods. The notable change in or management of perspective could be used in a situation where mothers have experienced stillbirth, and a pilot would be useful to explore this, as a self-help package would be of use for some mothers.

A consideration made by Australia-based authors Lee, McKenzie and Horsch (2013) suggests a decision-making model regarding the subsequent child. They proposed considering different groups of women with differing needs – including women who immediately desire to conceive, those who struggle to conceive as an obsessional focus and those who conceived quickly. It was recommended that, for each of these women's groups, psychological support should be centred on helping women deal with guilt and resolution of grief. As well as acknowledging the adaptive qualities of continuing bonds, this should be integrated into the support model used in counselling, psychotherapy and psychological intervention. Currently, this model of support is not widely available or consistent within the UK. Ünstündag-Budak (2015), who comes from a Turkish psychological and academic background, interpreted that the loss experienced in stillbirth was considered an ambiguous loss due to the complicated nature of grieving for an 'unknown' child. As stillbirth is such an emotional and physical loss, the want of another child comes with its conflicts and uncertainties. Parents are also left with the emotional dilemma of 'replacing' their baby and becoming parents to another. As Hughes, Turton, Hopper, McGauley and Fonagy (2001) noted, disorganised attachment is more common among infants born after stillbirth, which may have extended adverse consequences for families. The study also found that parents expecting a baby after their stillbirth may benefit from specialised care to monitor the pregnancy and from emotional support that specialises in the nuances of their experience and grief.

1.7 Conclusion and Rationale for the Present Study

Stillbirth is a life-changing event that shifts the psychological state in nuanced ways. Also, from the moment the information is passed to the mother, how it should be systematically and psychologically supported is difficult to identify. This chapter has given depth to the experience of loss that stillbirth entails and how a mother begins to process this grief. The review highlighted the locations where the studies were conducted to show that calls for support and the experiences of mothers or parents combined can be seen globally and not just in the UK. The studies conducted in the UK explored through the review made recommendations for further research and supported greater accessibility. Australian and New Zealand journals, closely followed by US-based studies (chiefly led by Caccatorie, who specialises in this area), have been making strides in supporting parents and suggesting how health systems can aid mothers who experience stillbirth. The various theories supplied to detail this loss show the different stages in which a mother oscillates, from being told the news to leaving the hospital and beyond. Upon discharge from the hospital, mental health can vary depending on many factors. There is the potential for PTSD or PND to set in should support not be available readily. The literature highlights a need for connection with others so that support can be gained. There is little literature evidencing how psychological support can be part of the support network – the question posted about what support there is was also explored. There is clear evidence in the literature surrounding healthcare professional support, but the evidence lessens in terms of how mothers can benefit; the current research highlights how the lack is not beneficial to mothers' mental health. The literature explores the need for self-support, and the exploration of literature in this area is again limited; however, there is evidence to show that offering psychological support is of great benefit and having a structure for the mother to have as a guide would be helpful. Literature on pregnancy after a loss as a general theme is becoming more commonly available, and focusing on researchers from various backgrounds, including medical, academic and third sectors, increases the knowledge base. There is much greater evidence of how mothers experience anxiety after a loss, how this affects subsequent pregnancies and how bonding with their baby is potentially affected. However, there is little evidence of how support factors into this period. There is evidence of how scans are offered, but the desire for emotional support was found across the literature.

Rationale

Current qualitative literature on stillbirth is supplied from predominantly health-based perspectives rather than purely psychological ones. Perspectives include the nursing and midwifery fields, the baby's burial/cremation, and the initial grief reactions from various points of view, e.g. fathers, healthcare professionals, and other family members (Swart, 2020). Generalised baby-loss studies focus on how parents make meaning around the death of their child or baby (Paris, Montigny, & Pelloso, 2021). Hunt (2020) shared that it has also been known that qualitative studies of the experience of stillbirth in terms of the emotional aftereffect can engage more deeply with the lifeworld of the mother.

Stillbirth research and the specific focus on support are limited from a counselling psychologist's perspective. For my research question to be meaningful, the 'world' needs to have gaps in knowledge that this research and the research question have answered. Due to a direct engagement in a person's experience and reality, a qualitative study is well-placed to explore the nature of what support means to mothers after stillbirth. This research was designed to explore qualitatively, from a counselling psychology perspective, the subjective worldview of these mothers by bringing to congruence their experiences and highlighting common themes of support following stillbirth.

Positioning the Research Aim and Question

This study uses critical realism as the research paradigm, which defines a basic set of beliefs. The study aims to generate themes based on the subjective accounts of a small number of mothers' experiences of any support received or not received following their stillbirth. The study aims to provide an opportunity to gain deeper insight into mothers' experiences of support following stillbirth.

This research's primary outcome is to increase awareness of a mother's perceived support experience.

The research question to be explored is:

- Following stillbirth, what is a mother's experience of support?

Support in this study is understood as any action or relationship that positively benefits a person (Finfgeld-Connett, 2005). Cacciatore, Schnebly and Froen (2009) suggest that various factors influence the delivery of support, i.e., assessing the need and providing the support. However, one crucial aspect of support is that its existence is recognised by the person needing it. Bolger et al. (2000) suggest that people may be unable to stipulate what was supportive to them in times of need.

A mother's experience of stillbirth support (e.g., charity involvement, religion, family, friends, partners, private counselling) has had limited inclusion in existing research. Therefore, very little is known about this specific experience for mothers in terms of research. The literature shows many psychological effects that can last years (Chung & Reed, 2017). Omitted from the current research is another aspect of this experience: precisely what the mother does or does not access amid the initial grief. The period following stillbirth is where support is most vital (Ávila et al. 2020), and there is little knowledge due to this being unknown to those outside of the mother's lived experience.

Relevance to Counselling Psychology

The values of counselling psychology will lead the focus of this research, i.e. be reflective scientist-practitioners, work creatively, compassionately and collaboratively, and work ethically and effectively (Woolfe, Dryden, & Strawbridge, 2003). What will be generated from this research is a subjective understanding of what support is provided to mothers following stillbirth. This study comes at an opportune time, given the recent societal awareness of baby loss. Understanding the diverse experiences of mothers when seeking, finding or being unable to obtain support following their stillbirth will further psychological understanding, as very little literature focuses on this topic.

Chapter 2: Methodology

2.1 Overview of Chapter

This chapter shows a detailed account of each step this research study has taken. The chapter begins with a description of this project's epistemological and ontological position, followed by the methods used to conduct the research, including the ethical considerations, participants and tools. The researcher's position is contextualised, as is the approach of the prevailing literature and the positioning and outlining of analysis and findings. The use of thematic analysis as the methodology is also discussed in detail to outline the approach to the data and adherence to quality standards within qualitative research.

2.2 Epistemological and Ontological Considerations

Epistemology for counselling psychology research and practice could be considered as ever evolving. Each counselling psychologist will take on a different position in how they garner knowledge. Additionally, each counselling psychologist is also a research practitioner (Clarke & Braun, 2018; Murphy, 2017) who holds empirical information equal to practice-based knowledge. The duty of holding tensions between plurality in research and practice suggests that consideration and working with multiple underlying theories and modalities is central to becoming a counselling psychologist. Numerous conventions surrounding knowledge answer the question 'what and how can we know?' This relates to a researcher's epistemological and ontological position, shaping their approach to attaining knowledge (Willig, 2012). For this study, I found Willig's (2012) explanation of the epistemological description of knowledge most suitable for my understanding.

Willig (2017) acknowledged different ways of understanding epistemological approaches; the three focal epistemological perspectives are realism, social constructionism and phenomenology. She also discussed methodological pluralism, which allows the researcher to position themselves between different paradigms of application. In my effort to critically understand the subjective experience of my participants, I have undertaken a critical realist epistemological position for this study.

Willig (2012) elaborates on the variations between each paradigm to discuss the intersectionality of positions and the possibility of holding more than one, causing tension in how knowledge is acquired and understood (Willig, 2017). In exploring these various positions, Willig (2012) states that phenomenological knowledge within research helps reflect the participant's subjective experience and doesn't claim to be wholly accurate or hold a relationship to the world's supposed 'objective' constructs. She goes on to describe social constructionism as concerning itself with how each person constructs their subjective reality. I felt the most conflict in determining how to approach my study as I agreed with this approach to knowledge, due to it being different to an observation about a phenomenon and the way it relays the subjective experience. Again, this approach was also considered, as I wanted to understand each person's experience.

Conversely, the realist paradigm assumes that the research subject can be understood due to the researcher holding the potential to uncover and communicate patterns within the subject material. This paradigm merged the two previous approaches and allowed me to be free in how I interpreted the knowledge I was attaining, while retaining the reality of social and real-world boundaries. Within Willig's (2017) description of the various epistemological stances, critical realism is positioned to accept data as informative of the real world while acknowledging that it is understood through the subjective lens of the knower, meaning we can appreciate the observable phenomena of mental health through an interpretative lens by focusing on the client's personal experience within the broader context. In relation to this study, I am positioning myself to accept the mothers' accounts of their support experiences as informative of their real worlds. I hold the stance of acknowledging that the mothers' experiences shared with me will be understood through the subjective lens of them being the experts in their worlds and the experts on what their experiences were based on in their wider life experiences.

Critical realism amalgamates human activity's role by referring to the social world and understanding (Ryan, 2020). Agazzi and Pauri (2000) explain that reality consists of elements outside an experiential realm that are unobserved but are accessible by methodical enquiry. Meaning that, while it exists, a reality is only 'natural and immutable' (Guba & Lincoln, 1994, p. 110) insofar as the effects of history's social, political, cultural, economic, ethnic and gender factors give society its current reality. Willig (2017) notes that research with a critical realist approach has an assumption that data edifies reality. Instead, it needs to be interpreted to access the underlying constructions of the data.

Willig (2013) states that assumptions shaped by the research question and my role should be acknowledged before clarifying the data collection and analysis process method. The research questions and rationale for these are laid out earlier in this chapter, which led the study to take a position of critical realism based on its suitability for questions that seek to explain outcomes (Given, 2008). Pilgrim (2019) illustrates that critical realism aims to provide accurate insights into 'our being in the world'; these are linked to precise explanations (including causality) about the world and concrete experiences.

This study explores a mother's subjective support experience after stillbirth and acknowledges their expertise in the broader social dimension. There was an opportunity to identify these experiences' portrayals via the personal knowledge of culture, language and political interest rooted in gender, race or social class, as Staneva, Bogossian, Morawska and Wittkowski (2017) noted. This study recognises that the mothers are not representative of all mothers who have had the experience of stillbirth and subsequent support. Therefore, the current research places itself along this continuum, asserting that some reality does exist independently of discourse. Critical realism allows for the subjective construction of personal stories shaped by social processes and the internal structures that enable or constrain certain types of stories being used. This stance complements the objectives of the study. Each participant's subjective account and perceptions of support was very different due to the aforementioned lived reality. Therefore, the physiological changes (being pregnant and experiencing stillbirth; Walsh & Evans, 2014) and then being able to source the support they need to help them navigate the changes - both physically and emotionally. Walsh and Evans (2014) explained that unobservable structures cause observable events, and the social world can be understood if people understand the structures that generate events. I wanted to have the broad scope of the observable and unobservable included within the study should they arise within the data collection, such as a mother's past and present socio-economic (and other) situational circumstances and the individual historical and cultural context of each mother's life . Applying critical realism to this study requires a more in-depth investigation of contextual factors. These include a presence in explored experience, physical spaces and institutional structures – particularly those applicable in exploring support experiences following the physical experience of stillbirth. Including the various accounts, mothers understand their psychological reality (Walsh & Evans, 2014).

Furthermore, critical realism assumes lay knowledge is equal in value to expert knowledge. This corresponds with the counselling psychology principle of the client as the expert. Pilgrim (2019) states that analysis is built by how data is viewed. The central approach to understanding the participant's subjective experience is by locating it within the context in which it exists. For this study, we cannot expect a mother to know the underlying mechanisms for how various conditions contribute to their experiences of seeking or not seeking support.

2.3. Thematic Analysis

In terms of methodological approach, thematic analysis (Braun & Clarke, 2006) fits well with my critical realist position and my research question. It allows clarity for any main themes identified in the data while permitting the researcher to appreciate these themes under the canopy of generally recognised theories or realities, locating the data within an existing social context. Thematic analysis is thought to capture the data's meaning, make links between themes and map out concepts, ultimately adding value to descriptive information (Braun & Clarke, 2006; Willig, 2012). Braun and Clarke (2006) state that the researcher's verdict is essential in identifying themes within the data, thus practising ongoing reflexivity. Braun and Clarke (2021, p. 332) describe the reflexivity within the analysis process as the researcher being 'immersed in the data, by reading, questioning, imagining, wondering, writing, retreating, returning'. I was able to enact the reflexivity surprisingly naturally by allowing myself to not see the analysis as a linear process and mechanically looking for codes in the data. I found it to be a process that required me to sit with the stories that the women had shared and that I was able to form 'pictures' and 'links' from within the data by allowing myself time for inspiration to happen and insight to grow.

There are relatively few studies exploring how mothers who have experienced stillbirth experience support; thus, this research is exploratory. Thematic analysis is a practical methodological framework as theories can be applied flexibly (Braun & Clarke, 2006; Clarke & Braun, 2013; Willig, 2013) without needing a single theoretical assumption about what may be learned from the data (Willig, 2013). Within the thematic analysis, I can interpret a participant's account of an individual's perspectives, highlighting similarities and differences and producing interesting insights (Braun & Clarke, 2006; Kivinen & Piiroinen, 2004). Essentially, the thematic analysis data analysis process enables a summary of the critical features of a data set and supports the production of a clear and organised report (Kivinen & Piiroinen, 2004). The thematic analysis primarily focuses on patterns of meaning across data sets instead of the mother's individual experiences, enabling the analysis to generalise the cohort's reality (Martin, 2020).

Terry, Hayfield, Clarke and Braun (2017) state that thematic analysis is a good option to analyse and synthesise data supplied by mothers using semi-structured interviews. There are always limitations within a methodology, thematic analysis has developed since the early years of Braun and Clarke's 2006 paper introducing the approach. Braun and Clarke (2006) note that thematic analysis has been critiqued for not identifying with any epistemological position but suggest it can be applied flexibly to many types of subjects and study. However, they also stipulate that thematic analysis can be a realist method; it can detail subjective experiences, meanings and individual realities, which suits this study. Now in their more recent study (Braun & Clarke, 2021) they have found that there are challenges for researchers in the way thematic analysis is conducted. The challenges noted in the paper was mainly around the building of the codes and themes as this can be a point there the essence of thematic analysis can be missed. The building of the codes needs to be done thoroughly and it can be seen as an unnecessary point by some less experienced researchers using thematic analysis. I did not have this problem. I found the approach to be a clear and focused way to analyse my data that allowed for reflexivity (an important element to the thesis overall) to be included, which they call ‘reflexive TA’. I had some slight confusion differentiating codes and themes in the beginning, since reflexive TA makes a distinction between codes and themes, but there is no absolute distinction between codes and themes across thematic analysis methods. As the process of analysis can be manual, I was able to develop themes from the codes conceptualised from the data.

Despite this pool of richly informative research, few studies engage in face-to-face, qualitative interviews, which provide the researcher with the opportunity to explore maternal experience. Existing research in the field is often located specifically within culturally homogenous settings, engaging in unpacking the localised experience of a population group that may be far removed from Western culture (Sisay, Yirgu, Gobezayehu, & Sibley, 2014; Yamazaki, 2010).

This study does not look in depth at a participant’s feelings, thoughts and perceptions, which create their individual experience, which is found in the phenomenological approach (Tuffour, 2017). Although the research questions aim to produce knowledge about a specific human experience, it is not overly concerned with generating knowledge about the mother’s subjective experience. A phenomenological position isn’t suitable for this study because the research questions demand an understanding of what may develop from these experiences, i.e. context (social, political, cultural, systemic, relational, psychological).

Qualitative analysis needs to be compatible with the epistemological position (Willig, 2013); thus, thematic analysis has been selected. According to Braun and Clarke (2006), thematic analysis can be steered from different epistemological stances (e.g. realist, social constructionist, phenomenological). This study includes an explanation of the mother’s subjective views and opinions and individual experiences. Thematic analysis is preferred because it allows me to interpret the person’s experience and the context of these experiences (Martin, 2020). Finally, this study is not aimed at developing an understanding of the social and discursive construction of phenomena or focusing on the language used by the mothers (as in social constructionist discourse analysis) (Augoustinos, 2017); therefore, discourse analysis wouldn’t be an appropriate method.

- Inductive Analysis

The specific topic of support after stillbirth is not very well researched. Braun and Clarke (2006) explain that thematic analysis and an inductive approach form new patterns. An inductive approach allows patterns within the data to be highlighted and themes to be derived and strongly linked to the data (Braun & Clarke, 2006; Willig, 2017) in line with the epistemological position. However, to claim a purely inductive approach would be naïve, as themes don't directly embody the spoken word (Braun & Clarke, 2006) or 'emerge' from the data, but are actively constructed by me, informed by the literature and my own experiences, beliefs and assumptions (Kvale & Brinkmann, 2009).

- Semantic Analysis

The analysis focused on the semantic content of the interview transcripts. Braun and Clarke (2006, p. 88) explain that a semantic approach recognises themes by 'explicit or surface meanings of the data, and the analyst is not looking for anything *beyond* what a participant has said or what has been written'. A similar study by Thomadaki (2012) found that a semantic approach is aligned with critical realism, as it focuses on finding mutual semantic themes within and between the interview transcriptions. Aligning with Willig (2017), this study has an active approach that is not looking to identify underlying ideas of the participant's interviews.

This study concentrated efforts on analysing semantically to enable clear interpretation. This ensured a faithful representation of the participant's views. Further, the semantic approach allowed participants' statements to be analysed from a perspective consistent with the understanding and opinions of support following stillbirth.

2.3.1 Analytic Strategy

While epistemologically and methodologically positioned within the qualitative approach, I believe thematic analysis (applied in a critical realist framework) is an appropriate way of contributing new information that can be understood and placed alongside current empirical knowledge. I have endeavoured to achieve this within the study by ensuring the richness of the data and demonstrating the seven stages of thematic analysis proposed by Clarke and Braun (2013), which can be seen below.

Stage 1: Transcription

As the researcher, I used orthographic transcription, as Clarke and Braun (2013) set out. I familiarised myself with the data by doing the transcription myself. Orthographic transcription is a verbatim account of all verbal (and sometimes nonverbal [e.g. crying, sniffs]) sounds. It was important for this study that the transcripts retain the information needed from the interviews. This type of transcription allows for its original nature to remain, because adding punctuation can modify the meaning of the mother's accounts of support. The verbatim transcription is practically suited to the purpose of analysis.

Stage 2: Reading and familiarisation

After completing the transcription, I familiarised myself with the data by repeatedly reading and listening to the recordings. At this stage, I recorded initial thoughts and ideas relating to the data as preliminary notes and used notes detailed during and after the interviews. This process led to the beginnings and production of initial codes.

Stage 3: Coding

Braun and Clarke (2021, p. 340) state that a code is ‘conceptualised as an analytic unit or tool, used by the researcher to develop (initial) themes’. They further explain that codes can be thought of as ‘entities’ that capture (at least) one observation and display (usually just) one facet. In this study, after giving full and equal attention to each line in the data set, I highlighted features of the transcribed interviews that appeared relevant to the research question as codes (e.g., where support was evidenced and further reviewed where support was mentioned in terms of a ‘hope’ or ‘reflection’), in line with Braun and Clarke’s (2006) recommendations (see Appendix L for a representative example). I then coded the data by typing notes in the margins of the transcript (see Appendix L).

I followed this with a traditional and low-tech manual cutting and pasting method (Green & Thorogood, 2010) to develop a table of codes linked to one another. Data extracts with the same codes were collated and compared; I then summarised these multiple codes with an overarching code (see Appendix M). Having coded and highlighted each interview, I was able to go back and search for examples of quotes from the mothers that represented the code (see Appendix N).

To reduce researcher bias and confirm the coding manual’s coherence, I presented the work to my research supervisor at this stage, and any discrepancies were adjusted for consistency. This final version of the coding manual then guided the remainder of my analysis, involving identifying themes.

Stage 4: Searching for themes

At this point, I used a mind-map approach, which made the whole process much more accessible to me than purely cutting and pasting into a table. I attempted to use the table method, but I found it hard to focus the coding analysis and identify broader themes in that layout.

I grouped the codes under sections that appeared to carry a common thematic narrative (see Appendix O). In this process, I took samples from quotes within the broader interviews to make sense of the themes overall and coherence within the individual themes. The codes under each theme included contradictory positions of the mothers under the same topic. I also had to remind myself that I was looking for experiential language rather than just a list of people who provided support.

Stages 5 and 6: Reviewing, defining and naming themes

After identifying the themes and subthemes, I used the coding mind-map to bring together the codes and quotes from the mothers. This was to ensure an adequate overview of the layers within and across each interview (see Appendix P) with the purpose of thematic analysis offering an overall view of the meaning of the data set (Braun & Clarke, 2013). It appeared essential to define and name the themes according to the overall experiences in the data, as interpreted through the research question, guiding the study and keeping the focus on the themes being produced.

A relevant title was assigned to each theme and subtheme, based on the summary of the overall descriptions, and I ended up breaking down each theme into its own mind-map so that I could see what I was working with (see appendices Q–T). Naming the themes was a considered process that continued throughout the writing stage of the analysis to ensure a good fit and fidelity to the quotes from the mothers.

Stage 7: Writing – Finalising analysis

According to Clarke and Braun (2013), the writing up of the themes is a final essential component of the analysis process to help shape the overall argument of the research project. Part of achieving a coherent story in relation to the research question is through the iterative and immersive process of making sense of the researcher’s data. Accordingly, my findings from this research project are reported in the results chapter, with the subsequent interpretation of the results in the discussion chapter. During this process, I became emotionally invested in the representation of the mothers, and I had to remember that it was about the best representation of the theme and who had detailed it most efficiently.

2.4 Methods and Research Design

2.4.1 Ethics, Permissions and Data Storage

2.4.1.1 Ethical Considerations

There are numerous ethical considerations when researching this topic because of the possible vulnerability the mothers may experience. In order to address these ethical considerations to protect the mothers and myself, a process of informed consent was required by individuals, to show their understanding of the research protocol and decide whether they wanted to voluntarily agree to participate in a study (BPS, 2018). Signed consent was obtained from each mother involved in the study (see Appendix G). Following the interviews, each mother was debriefed and given the contact details of charities and other bodies who could offer support should they need it (see Appendix H). To warrant that the research adheres to the British Psychological Society (BPS) Code of Human Research Ethics (2017) and the Code of Conduct, Ethical Principles and Guidelines (2018), ethical approval for this study has been obtained from the City, University of London ethics committee (see appendices A and B). Basic ethical principles guide this research, such as respect for a person, beneficence and justice, which was upheld through assessing the risks and benefits of individual participation in the study. There were further amendments to the ethics form to cover the changes made to the study, which included the changes made due to the COVID-19 pandemic and the number of people being interviewed due to the great interest in the study (see appendices C–F).

Before recruitment, I attended a training session based on support for experiences of baby loss provided by SiMBA at Dundee Hospital. After discussions with the training providers, the CEO of SiMBA was contacted to aid in constructing the interview schedule (see Appendix K) and questions so that they were semantically appropriate.

Research suggests many women welcome the chance to give their views about their experience in confidence so that their stories can be used to help improve stillbirth awareness (Crawley, Lomax, & Ayers, 2013). However, it was understood that taking part in this study may upset them or raise other issues or concerns about their care. All mothers were acquainted with their right to withdraw from the study at any point before the analysis began. Emails were sent out to each mother informing them that analysis was starting, and that they had a final opportunity to withdraw.

I asked the mothers the name of their baby and explained that I would inevitably talk about their stillbirth. One unique attribute of this study was around the area of pseudonyms given to each mother to uphold confidentiality. Initially, it was planned at the very start of the process for mothers to be informed through the information sheet that the thesis would be available to them should they consent to their details being held until the final version was completed. This is still the case; however, during the lead up to interviews, it became apparent that using the baby's name would be a way to bring the baby who had sadly died into the interviews by their mum, who was telling their story as well as documenting the support they experienced after their death. I felt it was important and ethically appropriate to use the baby's name within the study in the form of, for example, 'Charlotte's mum'. This would act as a pseudonym for the mother and bring her baby into the research and, having consulted my supervisor, it was agreed, as it wouldn't compromise the mother's anonymity, and the mothers wanted their babies acknowledged in this way in the thesis. As confidentiality was of primary importance, no other names or identifying characteristics have been used in this study or any future publications. All the mothers remain anonymous, with names and identifying features being changed or removed from the study.

As an alternative point of consideration, I chose not to use groups as a data collection method because of my inexperience in providing groups and, even more so, because I wanted to hear each person's experiences individually. This, I felt, was going to produce more data in terms of what each person needed and how they experienced support in various terms. I also felt that there might be more confident speakers in a group setting in terms of personality, making others less likely to share their feelings due to feeling less comfortable talking in a group.

The interviews were 'participant-led', and I remained on constant alert to signs of distress. There were tears, but this is when I could give them space and share an opportunity for a pause. There was then a natural progression of the interview to talk about the birth, which is not the focus of the study. It was up to me to manage this and tactfully move the conversation towards the topic of support post stillbirth. This process had been discussed with the CEO of SiMBA, and we agreed that following the natural progression of their timeline, leading up to support, was a positive way for the mother to begin the interview. During this time, we were acknowledging her baby and the fact that her stillbirth happened. It was essential to distinguish that each interaction was not a one-to-one therapy session, but rather a research interview. Each interview was approached reverently, and empathic listening skills were utilised throughout due to the emotional nature of the topic.

If at any point the mother became upset, the interview would be paused. There was a discussion as to whether the interview was too challenging to continue. The decision was ultimately mine; using my professional opinion that ceasing the interview would be the most appropriate course of action. The complex nature of the topic was at the forefront of my mind at all times. At no point was a mother coerced to explore areas that they found too difficult. I was attentive about giving time and space when the expression of emotion was experienced.

Recordings and interview transcripts were stored securely and separately. The mothers were informed that all data was to be retained for five years following completion of the research project, before being destroyed. All interview recordings, transcripts, consent forms (see Appendix G) and notes were kept in a secure location in the form of a hard copy and a secure encrypted online drive (OneDrive) that the university provides access to, permitted only to me. Any printed copies of the transcripts were stored in a locked filing cabinet.

Any pre-conceived expectations were set aside in the interview process, and the mothers were not led towards specific notions. Ways of relating were monitored to ensure that neither the interviewer nor participant were put in a position that could affect the interview, whereby a rupture could occur. This is where my counselling skills were helpful, as I could keep myself separate from the participant's emotional experience during the interview.

I was entrenched in the research for a long time; the need for supportive supervision was vital. There was communication with my supervisor over the entirety of the research process and I ensured I had regular engagement in personal therapy to support my wellbeing during the production of this thesis.

Participant wellbeing

All the mothers were provided with a participant information sheet (see Appendix J) before signed consent was sought. Following the interview, the mothers were given a debrief sheet (see Appendix H), which included additional information regarding the study and contact details of support organisations that could be accessed if the interview triggered feelings of distress. Suitable safeguarding protocols were followed, and the mothers were offered opportunities to halt or pause the interview. It was agreed in advance with my supervisor that if a participant became overly distressed, they would be encouraged to contact their GP or, if in severe distress, support would be sought from emergency services and that my supervisor would also be contacted.

2.4.1.2 Sampling and Participants

Sampling

Thematic analysis studies need to be sure of their commitment to thoroughly explaining their interview content (Braun & Clarke, 2006), typically requiring a smaller participant size. However, Willig and Rogers (2017) note that small samples are likely to be homogenous, with the mothers fitting within a distinct group, which will, in turn, allow the research question to feel like it has a personal connection to them. Sampling aims to obtain the broadest possible range of knowledge and perspective on matters within this study. Brockwell (2013) explained that a detailed reflection of personal experiences is the primary driver of thematic analysis, and small homogenous samples are better suited. However, if the study aimed to find out what support is provided to women experiencing stillbirth, ten qualitative interviews would not be appropriate. A large-scale national survey would be more appropriate and would use more quantitative methods.

The current study has recruited 14 women. Following a thematic analysis methodology, Lyons and Coyle (2016) note that a minimum sample of ten is considered suitable, given the restraints of this study (in terms of time to produce), while also being appropriate to capture adequately detailed information about mothers' experiences of support. Terry et al. (2017)

concur that this ensures no risk of superficial analysis, which can be found with larger samples. Saturation is evaluated by noting when similar themes appear, and no new themes are found (Braun & Clarke, 2019).

The following inclusion and exclusion criteria were implemented for the mothers to be protected and for the study to be ethical and focused on the topic. They were used during the recruitment and during screening calls to ensure the sample's homogeneity.

Inclusion criteria

1) Only women that experienced stillbirth (as defined by the NHS [2018] – a stillbirth is when a baby is born dead after 24 weeks of pregnancy) were included in the current research project. Therefore, for the nature of this specific study, the experience of miscarriage (a miscarriage is the loss of a baby before 24 weeks) (NHS, 2018) was omitted.
2) No age restrictions were applied to the upper age limit. However, a minimum age of 20 years was used because the mothers were potentially younger than 18 years old at the time of their stillbirth. Being aged under 18 years will mean a different support experience compared to individuals over 18 years. For example, the mothers would have had to be in school/college and would be entitled to time away from education for a maximum of 16 weeks. An over-18 mother would have had different experiences. All experiences are meaningful but, in this case, having a minimum age of 20 allowed for only adults to be included.
3) The above criteria were taken to include women from any socio-economic, ethnic, religious or educational background.
4) Pre-birth factors and other maternal characteristics (such as the method of conception, relationship with the father of the baby, or medical history) are not considered inclusion criteria.
5) Mothers participating in the study experienced stillbirth at least two years before the interview and not more than ten years before. A minimum of two years was deemed ethically appropriate to discuss stillbirth and the support experienced since, as time passed, the intensity of grief may have lessened.

Exclusion criteria

6) The exclusion criterion was if the mother had, or at least reported having treatment for, a severe mental health condition such as psychosis or extreme levels of PND. During the initial phone call with a participant, the question, 'Are you currently in therapy or seeking treatment for a mental health condition?' was asked, and I took their answer as truth. In order to protect the mothers as much as possible, I did screen

for potential vulnerability when talking on the phone by inquiring how they felt about talking about their children and actively listened to their responses. I also listened out for any signs that made me feel concerned for them, such as their language and tone of voice. When I was talking to them, I stressed that this was not an easy conversation to have and that I wanted to make sure that I answered any questions. Some mothers were very open with their experiences and were certain of their ability to manage the interviews.

2.4.2 Research Procedures and Materials

Telephone screening participants

A short telephone conversation – around 15 minutes in length – was held between each mother and me to check whether they each met the inclusion criteria. The call went thoroughly through the inclusion and exclusion criteria of the study and confirmed that they understood that participation was entirely voluntary. This call was handled sensitively and thoughtfully, as the topic of stillbirth is highly complex. The potential for complicated reactions to the interview was discussed. The nature of how responses would be managed was also laid out and agreed upon with the mothers.

If there was a disclosure that the mother was being treated for a mental health condition such as psychosis, they could not proceed with the interview. Also, if they were undergoing therapy, there may be a risk of this interview hindering their treatment. If there was no disclosure of a severe mental health condition and both researcher and participant were happy to proceed, the participant was formally recruited and follow-up conversations were organised to discuss the logistics for the interviews.

It was made clear that breaks could be taken during the interviews if they felt they were needed. During the screening call, I established that the interviews would be held in their homes, and I was very open with them that I appreciated that they were at home and had other needs to attend to but encouraged a quiet space.

Final suitability was established after the inclusion criteria had been met. At the end of the screening call, the participant was offered a date and time for the interview – which would take place via the video call platform, Zoom. All documentation was sent via email, and an electronic signature was used to confirm the informed consent to participate.

Recruitment

Towards the end of 2019 and the beginning of 2020, initial contact was made to charities that work specifically with stillbirth, for example, Sands, Tommy's, SiMBA Charity, Abigail's

Footsteps, Beyond Bea, Our Missing Peace, Petals and Aching Arms. All were content to take part in the study following ethical approval from City, University of London.

A research proposal was submitted to each of the charities to provide complete clarity of the study. One of the charities, SiMBA (based in Scotland), was enthusiastic about participating and subsequently offered its social media platform to promote the study. The charity explained the need for research like this and was pleased to be involved. A specially designed social media post (see Appendix I) was published on SiMBA's Instagram platforms to encourage SiMBA's subscribers to participate in the study. My contact details were included, and they were encouraged to contact me by email.

Recruitment of seven of the ten mothers was made within the first 48 hours of the post being live on SiMBA's Instagram feed. There was a need to decline participation at this early stage. This was because some of those who initially came forward did not meet some of the inclusion criteria. For example, not meeting the minimum two-year period since having their baby was the main reason, I declined inclusion. This was done via email, and I took my time to address the presented information on why they wanted to take part. Upon reviewing the inclusion criteria, I would be clear and succinct about why they could not participate. There was one occasion when there was questioning, and my response again validated their enquiry and politely explained the reasoning. I did not have any negative pushback from interested parties, and they wished me well in my research. However, it was interesting to see that some women want to share their stories at any point after their baby has died. This may be a consideration for future research, which might allow all periods to be included. Managing the inclusion criterion was necessary so that the integrity of the study was upheld and the mothers who did not meet the criterion were not put into a situation where I was unable to support them. When sharing the full criteria with the mothers, they were set out in lay terms, and the structure was evident. However, in hindsight, the initial recruitment posts could have been laid out differently to make the inclusion criteria more transparent. This is an important point for future social media recruitment. Separate to the social media recruitment, I also had one mother recruited by word of mouth, who was given the same information as the other mothers.

Initial contact with all the mothers was via email to exchange introductions, with a copy of the information sheet (see Appendix J) being included to introduce the study. The information sheet was detailed, covering the purpose of the study, what would happen in taking part and the benefits and disadvantages of taking part. The sheet then moved on to the process of getting involved, which led to the inclusion and exclusion criteria. The potential for withdrawal was included, as was how their personal data would be stored and what would happen if there were problems or concerns.

From using only one charity, recruitment was nearly complete. This was followed by succinct communication with the other charities to inform them that I did not require their platforms for recruitment. I acknowledged my appreciation for their support and informed them that the initial recruitment phase had been reached. The communication was very cordial. The following week, a colleague who had previously agreed to promote the study attracted three further mothers via their social media using the same post as SiMBA (see Appendix I). The final mothers reached out less than 24 hours after this advert was posted.

Recruitment took place in February 2020. In the following weeks COVID-19 put the UK into lockdown and the nature of the interviews had to change (see appendices C and D). Communication between myself and the mothers became periodic, to keep everyone updated over lockdown. Due to other factors pausing the research, there had been a consistent desire for the interviews to occur, and they were happy to wait until I was ready to begin interviews.

As the interviews formally began in November 2020, a couple of people had to withdraw – one because she was pregnant again, and the other wanted to be put on hold. At this point, I had to bolster the number of mothers, so a recruitment notice was put out again, this time via a colleague of mine (from a psychological background) who has a social media following mainly linked with baby loss. She put out the same social media post (see Appendix I) as used before, and I was contacted by ten women who wanted to participate. I had to decline one mother due to her not meeting the inclusion criterion, and after sending out invitation I did not hear back from three of the potential mothers by the deadline. During this period, I had to edit my ethics form to formally include the new maximum participant number of 20 (see appendices E and F).

Table 1 demonstrates the timing of the mother’s birth and how their baby was delivered, for context in how the mothers experienced their various losses at different points of pregnancy. All mothers gave birth two years before (2018) or earlier at the time of the interview and all identified as cisgender women.[1]

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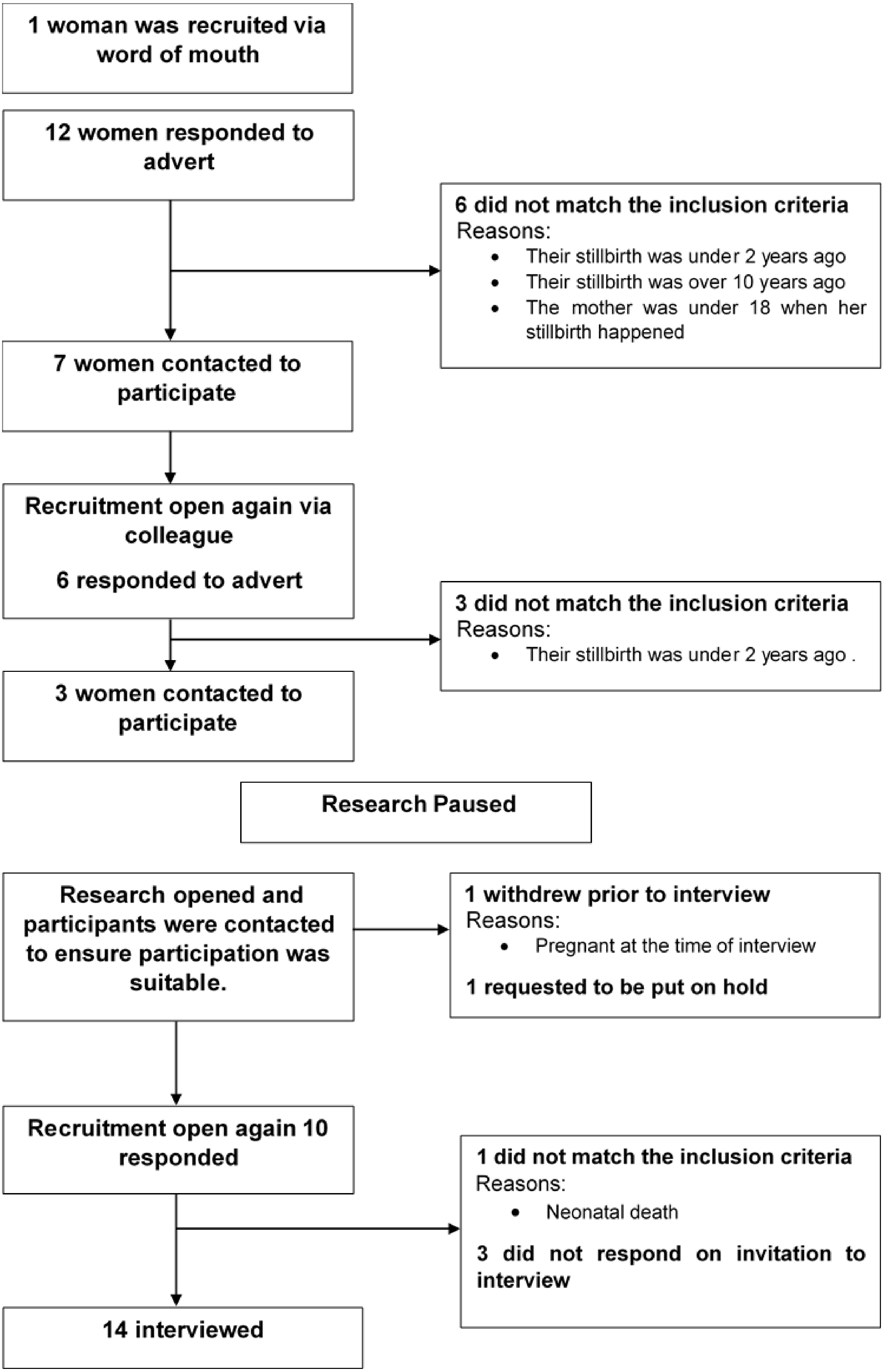
[1] Cisgender woman: someone who identifies as a woman and was identified as female at birth.

Table 1: Timing and method of births

Name	Mum's Ethnicity	Location of Baby's Birth	Weeks at which baby was born	Delivery
Maeve's Mum	White British	Scotland	40 weeks	Vaginal Birth
Isobel's Mum	White British	Northern Ireland	39 weeks	Vaginal Birth
Felix's Mum	White British	Scotland	27 weeks + 5	Caesarean
Stanley's Mum	White British	England	26 weeks	Vaginal Birth
Michael's Mum	African American	England	35 weeks	Vaginal Birth
Orla's Mum	White British	Scotland	27 weeks	Vaginal Birth
Aria's Mum	White British	Scotland	40 weeks	Vaginal Birth
Ruarai's Mum	White British	Scotland	41 weeks	Vaginal Birth
Jesse's Mum	White British	England	26 weeks	Vaginal Birth
Edie's Mum	White British	England	38 weeks	Vaginal Birth
Herbie's Mum	White British	England	41 weeks	Vaginal Birth
Freddie's Mum	White British	Scotland	41 weeks + 3	Caesarean
Arthur's Mum	White British	England	36 weeks	Caesarean
Miles' Mum	White British	England	39 weeks	Vaginal Birth

In total, I interviewed 14 women (13 of whom had come through social media, one who was recruited through word of mouth), and the interviews took place between November 2020 and February 2021. Acknowledgement of the lack in diversity within the recruited participants can be found in the reflexivity section at the end of the chapter and within the limitations section of the discussion. Diagram 1 (below) demonstrates how the recruitment process took place.

Diagram 1


1 woman was recruited via word of mouth
12 women responded to advert
6 did not match the inclusion criteria
Reasons:
• Their stillbirth was under 2 years ago
• Their stillbirth was over 10 years ago
• The mother was under 18 when her stillbirth happened
7 women contacted to participate
Recruitment open again via colleague
6 responded to advert
3 did not match the inclusion criteria
Reasons:
• Their stillbirth was under 2 years ago .
3 women contacted to participate
Research Paused
Research opened and participants were contacted to ensure participation was suitable.
1 withdrew prior to interview
Reasons:
• Pregnant at the time of interview
1 requested to be put on hold
Recruitment open again 10 responded
1 did not match the inclusion criteria
Reasons:
• Neonatal death
3 did not respond on invitation to interview
14 interviewed

2.4.3 Data Collection

Interview schedule

The interview schedule (see Appendix K) included open-ended questions as prompts and a guide for the interviews. In producing the interview schedule, I sought a clinical psychologist colleague with personal stillbirth experience to ensure the interview schedule was appropriate. She reviewed the questionnaire's language and suggested elements that would give the participant as much breadth to share as possible. The final copy of the interview schedule was then sent to SiMBA's CEO to review the vocabulary and questions. Subsequently, we had a positive conversation around what is generally known in her experience of discussing stillbirth with mothers. She mentioned that using the baby's name could be meaningful for mothers to have their babies held in the conversation like they would be if they were alive. This was very helpful and led me to take this forward in the research interviews comfortably.

The questions focused on the research question and having read existing literature; the initial questions were formed to have a preamble around what brought them to the study. I then asked about their experience with their baby as it was essential to acknowledge the baby as part of the conversation and to discuss how they made memories. Then we moved to look at what support meant to them, which was then followed by questions around what support they did or didn't get. The semi-structured interview style allowed the interview to flow, and the interview was tied up with a question to check whether I had missed anything. This question was useful, as it did prompt a few of the mothers to give further details. Each interview lasted between 45 and 90 minutes. After the interview, each mother was debriefed as part of the interview process.

Interview setting

Due to the pandemic and lockdown commencing in March 2020 I had to move from seeing the mothers in person. The thought behind this was that meeting in person would have given me an opportunity to meet the mothers and be able to support them if needed. I had thought to meet them in their homes or in a communal place but this had to change. I consulted the university on what online platform was deemed suitable for confidentiality and security to which they advised Zoom. Other platforms were not permitted meaning Zoom was the option I took on.

At the confirmed time and date, the interviews took place over the video-conferencing application, Zoom. Zoom allowed me and the participant to meet face-to-face via video link. I only recorded the audio from the interview to analyse, which is identical to how it would have been set up had the interviews been face-to-face in person. Zoom provides a secure platform, which keeps confidentiality intact.

As the research was conducted via Zoom, considerations were made before the interviews began. Gray, Wong-Wylie, Rempel and Cook (2020) found that even when interviews are online, there is little difference to the experience overall. There was the consideration for the researcher to ensure that the participant had a quiet and comfortable space to take part in the interview, like face-to-face interviews (Gold, Normandin, & Boggs, 2016). There needed to be clarity on how good their internet connection was, so that potential disruptions were limited. This meant there was a need for an immediate backup plan so that the data collection could continue in a supportive way. Should there be a malfunction with the connection, there would be attempts to reconnect the call, and telephone could be utilised or the conversation rescheduled. I called the participant immediately to make sure they were well and we managed the issue together. This provided support for the participant throughout the whole interview timeframe, and ethically it was good practice to support the participant in any way possible. Due to the sensitivity of the interviews, making sure that the participant was comfortable with using the online platform was essential, and any set-up concerns were noted before the day of the interview. Also, my counselling skills were required to build rapport quickly and ensure the interview could be completed efficiently. There is a need for transparency concerning confidentiality and using online interviews. The video-conferencing platform is the preferred choice of City, University of London and has been advised as the platform through which candidates should conduct online interviews.

The advantages of Zoom allowed me to meet with the mothers in neutral settings where each party felt comfortable. I was able to save on travel costs, which would have been high; I was willing to pay these costs but in hindsight doing the interviews online saved me potentially hundreds of pounds. I was able to be flexible with my timings so that the mother was as available as possible. Most of the interviews took place in the evening after the participants' children had gone to bed, which allowed them space to talk. I even conducted one interview while a mother was at work and spoke to another while they were abroad. Zoom allowed much more flexibility for everyone and there were very few internet malfunctions. Having the interviews online did have its disadvantages, for example, I found that I lost the essence of having the 'connection' with another human being; this was a theme that many found during the initial two years of the pandemic. I was able to mitigate this by using my honed skills of talking to people online, which I had picked up during my placements. I was able to build rapport quickly and be candid with the mother as to what the process would be like. I found overall that other than the physical connection, which can give further depth to an interview, I was able to mitigate any issues that were more logistical and technical, i.e. internet dropping or links not working, by being professional and using my innate skills to put a person at ease. I have found confidence in using online platforms and was able to get the interviews produced effectively.

Interview process

Two weeks were allocated for the online interviews to occur, so the mothers knew when their interview was. During the pre-interview phone call, the date for the interview was confirmed. Interview email invitations were sent to the participant's email to have the correct login details.

The mothers were sent a copy of the consent form (see Appendix G) to sign via the chat within Zoom on the interview day. The form was already signed by me so that the participant only needed to add their signature and send it back via email or Zoom chat. This allowed us to keep document sharing as simple as possible on a digital platform.

During the interview, all the mothers were made aware that they could stop the interview for a break and resume when they chose or could cease the interview altogether. As a trainee counselling psychologist, I would use my counselling skills to aid anyone who became upset or distressed.

A debrief sheet (see Appendix H) of support networks with contacts for the participant was provided at the end.

2.5 Ensuring Quality in Qualitative Research

The flexibility of thematic analysis also brings weighty responsibility on my part to ensure the quality of the data presented. This involves a clear stance from the outset on the theoretical position and epistemological assumptions that guide the researcher (Fletcher, 2017). Unless the research has been conducted and presented to a realist perspective, by definition, the subjectivity of the research position will allow for flexibility in interpretation (Kalu & Bwalya, 2017). The evaluation of qualitative critical realist research through the realist quantitative research criteria could principally be compared to evaluating the experience of a party through the number of people there. Therefore, as Fletcher (2017) and Yardley (2008) explain, a robust criterion for evaluating the qualitative research process needs to be applied and demonstrated to ensure that the value of the conclusions are projected truthfully and without reservation to the standards.

To ensure high-quality qualitative research, numerous criteria are available to determine the study's rigour and credibility. Yardley's (2000, 2008) quality control recommendations were used to ensure this study achieved a high standard of academic value. Yardley's (2000, 2008) Quality Control Points are noted below in the title bullet points. The following text demonstrates how this study implemented the standards of high-quality research.

- **Sensitivity to Context** *(e.g., theoretically relevant literature, empirical data, focus on the socio-cultural setting, sensitivity to participants' perspectives and inclusion of ethical issues).*

Chapter 1 reviews relevant literature on this topic to contextualise the current investigation. This enabled me to reflect upon the sensitivity of the approach I would need to make when collecting the data. All ethical issues, particularly those on support, are important for this population and documented within Chapter 2. I then conducted interviews with mothers who experienced stillbirth and needed support, which produced empirical data. The analysis of the interview content was deciphered using thematic analysis, which ensured codes and themes of the mothers' perspectives were created whilst remaining conscious of the perspectives that they had provided in the interviews. Chapter 3 incorporates direct quotations from the mothers' transcripts.

- **Commitment & Rigour** *(e.g., in-depth engagement with the topic, methodological competence/skill, complete data collection evidenced, depth/breadth of analysis).*

Engagement with this topic was very important and knowledge gained from this engagement has been beneficial to ensuring the findings of the research are thorough. Reflexivity was included in this study (see Chapters 2 and 4), which facilitated engagement with the topic and deepened analytic interpretations in yielding robust findings. Guidance was sought from my supervisor, other researchers, and peers with great qualitative methodology skills to enhance my competence and ensure a rigorous study. Interviews lasting 60–90 minutes allowed participants to voice their experiences and generate data. After analysing 14 participant transcripts, the data was coded with the aim of attaining saturation where it naturally occurred. Chapter 4 outlines the study's limitations in general, and Chapter 2 details the limitation of the diversity of race among the participants.

- **Coherence & Transparency** *(e.g., clarity and strength of description/argument, clearly presented methods, data and thoughtful reflexivity).*

Chapter 1 presents the rationale for this study and why it should be conducted. Chapter 2 demonstrates in detail and with clarity the methods used, specifying the analytical process and how the findings were developed. Individual, methodological, and epistemological reflexivity was considered and is recorded throughout the study across Chapters 2–4. Specifically, in Chapter 3, a section on reflexivity offers openness on how the findings were sought and how I observed my researcher's influence. This shows that as a psychologist I have been considerate about the topic, its participants and I have remained aware of any unconscious biases or limitations. It was also important that I applied reflexivity to my own personal reactions to the topic so I could move forward with the research in a clear and professional manner.

- **Impact & Importance** *(e.g., theoretical (enriching understanding), socio-cultural, practical (i.e., community, policymakers, health workers)).*

The study focused on the support experiences of mothers following stillbirth which has brought to my attention the need for support to be implemented and has given direction to my future work as a psychologist. Chapter 3 presents the study findings which were analysed using thematic analysis and explored the connection with others, the system of support, finding support and pregnancy after loss. Thereby enriching understandings of this understudied area. Chapter 4 discusses the unique contributions of this research, how the topic fits within the counselling psychology field, wider implications, and applications of the findings; particularly the need for support after stillbirth and how it can be implemented.

2.6 Consideration of Researcher Reflexivity

While completing the Counselling Psychology doctorate applications, I listened to a podcast. The topic of discussion was baby loss, and one of the women had experienced stillbirth. I listened to the podcast and was amazed by the woman's courage to describe what she had gone through. I found research about stillbirth, but there was limited information about therapeutic support. A year later, when the research process began, I wanted to focus on the topic that had inspired me. After many revisions, I chose this research question because it encapsulated what I wanted to discover.

I hoped to find out what mothers' experience of support is. Hearing about their experiences allowed me to understand what they had gone through and gain insight into finding support and being beneficial or finding a need for more. When writing my research question, I had to think about the phrase and my relation to it. I had not experienced pregnancy or stillbirth, which meant that I was in the position of an 'outsider' researcher. I could not say that I understood their experience, but I hoped to learn about their support experience.

The study’s recruitment was conducted through social media groups where most participants active on the social media platforms are White women. As shown in Table 1, the recruited participants highlight the lack of diversity among the participants. I had recruited one non-White participant, who did not demonstrate the breadth of experience that mothers across all parts of society experience. Having such a narrow point of view coming from the participants was not intentional as the study’s recruitment was accessed through national charities where those following the page could apply. However, there was a flaw to this approach as I was looking for a small number of women, and I met the required number of participants quickly. If I had been more thoughtful of who I was recruiting based on the various demographics and been more selective, I would have had wider and more diverse experiences to analyse. I have included literature in the previous chapter where there is evidence of how support is so important to minority groups and there is a need to understand the experiences of minority groups better. I acknowledge that the lack of recruitment from minority groups in my study should have been thought about more at the forefront of my recruitment than the approach I took of getting participants recruited and focusing on their ability to meet the inclusion criteria. I have taken this reflection and will continue to be more aware of my choices and how I approach diversity within my work and not look to getting ‘the job done’ to the detriment of whose voice I should be including. It is my hope that further support studies will look to include the wider voice of mothers and what they need in terms of support when they have had a stillbirth.

I maintain that the mothers are the experts, and they are the focus of this study. I can bear in mind my experiences, but I have found that I have been turning my view towards wanting to advocate for these women, and I think this is where I need to be mindful of what I find in my research, as I need to remain balanced and not wholly focus on the negatives in order to prove a point.

I found the actual interviews very enjoyable to conduct. I admit I was nervous during the first couple, but the mothers gave me no need to worry as they were very open with their stories and answered all the questions easily. As the interviews went on, I became used to the process and was able to experience the various ways the women presented their stories and shared their experiences. Some were able to communicate how they struggled, others shared how they could do things independently, and others were very positive about their support. The varied experiences were very helpful in developing the research.

I endeavoured to keep track of my engagement and be aware of occasions where the content of someone’s story and their vulnerability may strike a chord, while remaining in a professional stance and frame of mind. In order to uncover my biases and assumptions during the making of this research I made sure to maintain a research journal to log my reflections on the process. Supervision and therapy aided me in developing this research. These processes allowed me to realise that support is something I always want to give rather than receive and this was something that I needed to hold in mind at the start of this project and at times during it, assuming that all mothers want support in the form of psychology.

Support is something that I have needed from time to time, but never felt able to ask for. This became particularly potent during the first year of my doctoral course when I sought help to understand my learning style. I came away from this support experience learning that I have a learning difficulty and that the years of struggle experienced uniquely navigating academia was because of a specific reason. Support is tough to access due to my experience of being called ‘silly’ or ‘stupid’ for not understanding something. I doubted this was similar in any way to how the mothers were feeling, but I was curious as to how they had navigated a profound loss and come out the other side with or without support. I needed to be mindful of how my experiences of support might impact my findings.

Chapter 3: Analysis

The analysis created themes, which were organised into four domains. The first relates to the need for connection with others. The second relates to the broader systems of support outside the respondent’s inner circle and the hospital. The third relates to where mothers end up in the search for the support they need. The fourth relates to how pregnancy after stillbirth is a myriad of experiences and how support is experienced. Before presenting the themes, some contextual information regarding the mothers’ support experiences is provided.

While not the focus of the results, the experience of being pregnant and the birth of the baby provide an essential backdrop to the mothers’ experiences with support; all the mothers naturally told their stories in a timeline from how they started finding out about their baby dying or having died, then on to the birth. From that point, all their experiences differed in various ways. Enquiring about this and the time spent on the labour ward / giving birth during the interview allowed the mothers to share the impact of positive or negative support. The information they gave was valuable and highlighted how access to support was attained differently by them.

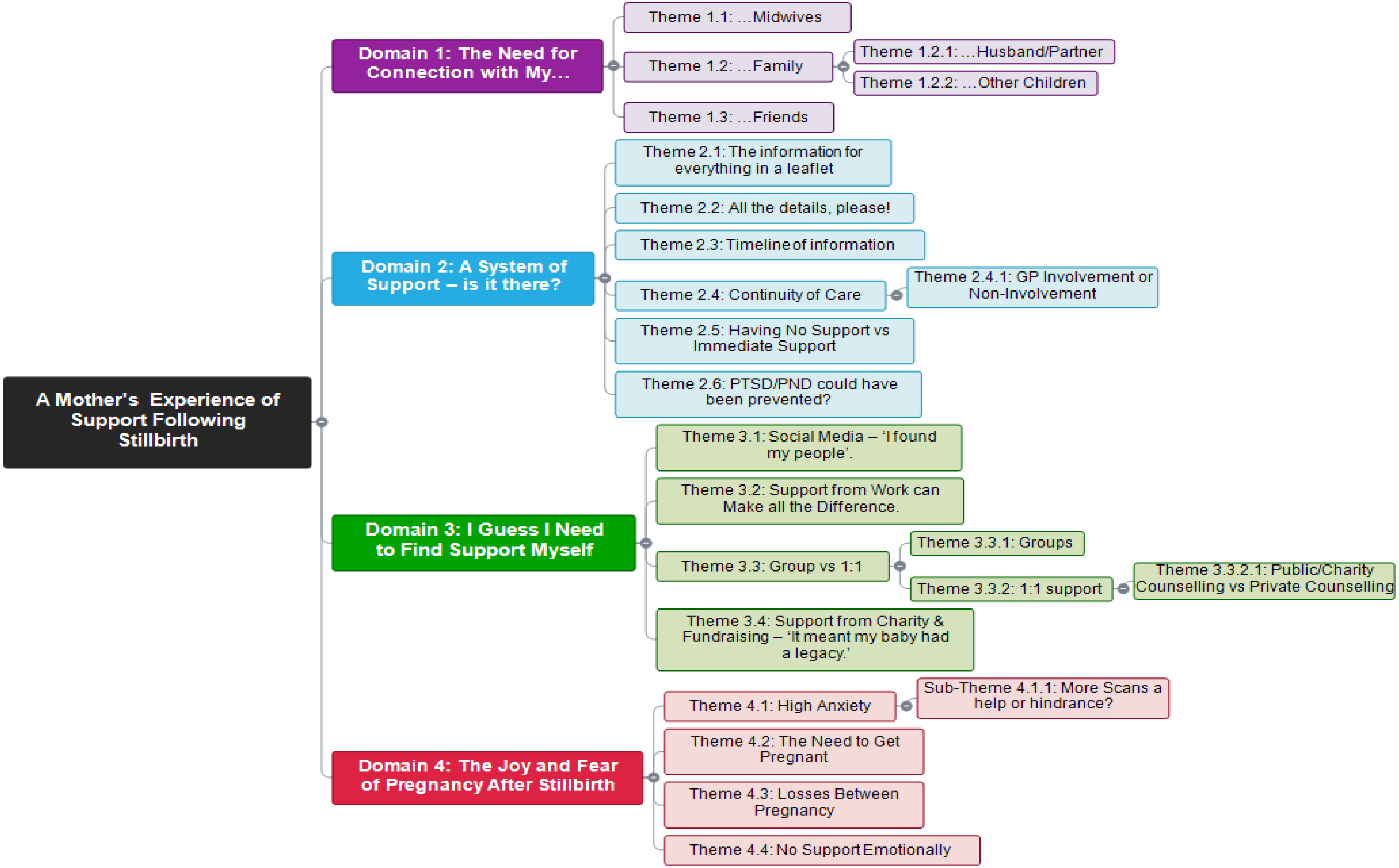
The mothers who took part were all at various stages in their pregnancies (however, all after 24 weeks). Some had time to ‘prepare’ for birth, while others experienced the birth quicker than ever imagined. Some had noticed their babies had stopped moving and went to their midwife, followed by scans and then the news that their baby had died. Others were at or past their due date and were in labour or were days from their due date when they were informed their baby had died. Experiencing stillbirth was not only a shocking and devastating loss but, in some cases, physical health was also a factor in the loss such as healing from a caesarean, which some of the mothers described as being deeply impactful.

During the interviews, a question around the meaning of support was posed to the mothers. They each came back with their thoughts on providing comfort, having information and options, needing flexibility and needing individual support for them as a mother. The main interlinked areas were support, being ‘listened to’ and for someone to ‘be there’. As in one of the main domains explored, the need for connection was significant. The mothers described the support as someone being there, giving them space, checking in and allowing the mother to lean on them. There was a strong desire to be listened to, and for the space to be held just for them. These elements were found across all the mothers’ interviews and are a major part of each domain.

The mothers’ interactions with healthcare professionals during and after their stillbirth was felt to be extremely important. Unfortunately, these were often inadequately supportive; lacking continuity of care and involving insensitive comments. On the occasional time when professionals were felt to be supportive, their acknowledgement of the significance of their loss was especially central.

In Table 2, there is a clear breakdown of how the themes and subthemes will be explained.

Table 2: Themes and subthemes



Domain 1: The Need for Connection with My…

When I initially asked mothers to share the story of their stillbirth and the experience of support, they all described their pregnancies and the birth of their child with very vivid details. They all stated who was there, and their feelings spanned from total shock, overwhelming love and visceral sadness. The way they had experienced the support before, during and after their baby was born was very potent, and the mothers were able to recall these moments in immense detail. In addition, they could reflect on the emotion in the room and surrounding parts of the ward, which added to the initial experience. Most mothers described the support experienced within the wards as mixed, in that some had midwives and doctors who were very present and there for their ‘every whim’. Some experiences that the mothers noted could have been better, and some mothers have taken it upon themselves to address these issues as a legacy to their baby, and to give purpose to their loss.

Theme 1.1: Midwives

All the mothers interviewed talked about how their experiences in the various hospitals across the UK were either made better or worse by the midwives and doctors they encountered. There were accounts of all aspects of midwifery from the midwives at the birth, the bereavement midwives and the community midwives. The mothers spoke of the importance of having a midwife they could connect with, which some mothers didn’t experience, and the mothers shared that the connections needed to be correct.

> *…the next day as I said the midwife we were walking along the corridor and she said – I don’t know what she said but she put her arm round me and I was just like right ok it’s – it’s like I am going to get through this cause whatever – sort of like presence she had um she was an older midwife and she um um and at that time there was no bereavement midwife in the hospital but this particular midwife was somebody who often kind of took on this role. Umm so she was very good at that umm and so whatever she said to me she just made me think right ok*
>
> Isobel’s mum

Many mothers spoke about the support post-birth, which was especially helpful as some needed the connection with the hospital to remain, which helped with the grief they experienced. This was helpful because the mothers could talk to and connect with the midwives who were there at the birth and could make the experience tangible. Others didn’t go back until their subsequent pregnancy.

> *So that night […] was with us and um (pause) just created the kind of most peaceful, gentle sort of environment possible and was very good at answering all our questions and all that kind of thing so she stayed beyond I think the end of her shift to make sure that I was ok […] and the support in the kind of immediate post-birth time umm came part from her and then another midwife who was with us during the day […].*
>
> Maeve's mum

Those who had a positive experience with their midwives were able to detail that the experience was incredibly supportive and helped them navigate a time full of unknowns. However, some did not have such a positive connection during this time, and their confidence in seeking help after leaving the hospital was limited. Michael's mum experienced both a positive and negative experience with midwives, and ultimately gave birth in the presence of a midwife with whom she felt at ease, which was great support for her.

> *…like the first midwife we had I just like didn't connect with her at all you know like just not at all we were – I was just like every time she left after I was like I really just hope she doesn't come back like I will just do this by myself…*
> *So uh yeah and um and then there was a shift change which was amazing because then we got the best midwife (laughter) for me uhh yeah [Midwife] ----- to actually do the delivery which was which was great and she was just like so calm and she was so amazing and ------ you know helped us through ---------- that process…*
>
> Michael's mum

In some cases, mothers expressed that they felt lucky to have a bereavement midwife during the birth and the ability to contact one after their baby had been born. The presence of a bereavement midwife was not mentioned in all the interviews that were conducted. Where mothers were able to experience the clinical services of a bereavement midwife, they had specialised support during this very intimate time; the specialist knowledge that the bereavement midwife can share can provide comfort. One of the mothers (Felix's mum) experienced a stillbirth of one of her twin babies. She shared how she had to manage the birth of her sons; one still being alive and the other who had died. She regarded the support from her midwife as brilliant because the midwife was able to hold the space for Felix's mum to feel her emotions and support them in those first moments of meeting her baby.

> *umm soo in the beginning I wa- obviously ----- you don't know how you are going to be in a situation like that and its slightly different for-for us because it was actually twins that we had. […]. Umm but actually thinking back I am so glad that – so the midwife we did have our bereavement midwife […] she umm – she actually was only on trial for a year at our hospital so even though it's like a horrible situation for us to have been in I am glad that it happened then because we got that support otherwise it might never have had somebody specialised in that area.*
>
> Felix's mum

The mothers who had not had a specialist midwife spoke of how they felt it would have been necessary, as this was not common in all hospitals. Some mothers did not have a bereavement midwife and noted that they would have benefited from having this type of support, recommending that they be available in all hospitals. When asked during the interview if she had had a bereavement midwife at the hospital, Orla's mum answered with a simple 'no'. She was unaware that they even existed but went on to note what she felt should happen.

> *umm I think there do need to be a – a specific team that says we deal with the bereavement side – we'll help them, we'll make up packs, these are the people to get in contact with things like that – even a referral to somebody or…*
>
> Orla's mum

Aria's mum noted the same thoughts on not having a bereavement midwife and wondered if they even existed in the UK.

> *yeah! Which they don't – or as far as I am aware they don't have in Scotland – um – you know ---- maybe implementing that if it shows that it works – because --- there's someone who is trained to know what you're going […] yeah I just don't think there's a service there and I think maybe that's something that should be implemented?*
>
> Aria's mum

After the mothers leave the hospital, there is, in some areas, a visit from the community midwife. Most mothers explained this as a check-up after the birth and, in some cases, they were asked how they were. However, a few mums acknowledged that the after-hospital support was lacking, and there was little contact back in the community. The mothers described a sense of feeling abandoned by the hospital support once home, and they were usually given little direction in how and where to seek support.

> *umm -- think yeah I saw her twice umm and the first time I saw her was you know it was quite a few days after Jesse I hadn't heard anything --- and then suddenly she did a home visit so I was quite disappointed that I didn't feel like there was a lot of support having come out of hospital.*
>
> Jesse's mum

> *[…] the midwife had to come to me until day ten to take off my bandage and then after that you were just ---- almost abandoned like just – that was it. […].*
>
> Freddie's mum

Theme 1.2: Family

I acknowledge this theme could be a thesis of its own, as there are so many facets to the support that families do and do not offer. How a family interacts with the loss of a much-wanted grandchild (in most cases) or niece/nephew makes the interactions with family potentially very difficult to handle, which some mothers did find. Some found it hard to manage their grief because they wanted to ensure their extended family was doing well. In most interviews, the families didn't know what to say or how to act. Sometimes this was particularly hard to manage, as the mothers were dealing with their own grief, and having to manage others' as well as their own – in as much intensity – could be too much at times. Some mothers also noted that relationships between family members and themselves were strained, when all the mothers wanted was help and encouragement.

> *…umm but my mum I think mum my mum would be the best with like us being upset um she would be very much like a problem solver a fixer like how can we make this better. […] if I didn't I knew she would be really upset that I was so upset […] and then my dad is very um like --- maybe traditionally stereotypically masculine like um let's not talk about emotions or ever mention it ever again and so his sense was that you just forgot that it happened and um --- that was really difficult um…*
>
> Isobel's mum

In other cases, a family can be a great support and, even if there is no clear direction or evidence of how they are supporting you, the feeling of support enables a mother to begin to navigate how they will live after their baby has died.

> *…family were – they sort of – I don't know they sort of helped --- guide us in a particular direction without us even really ------ realising because we were so kind of lost in a way at times and just by them doing that – that gave us the motivation and then I went to them ok well maybe we could continue this fundraising thing and sort of do something positive.*
>
> Miles' mum

Theme 1.2.1: Partner

I recognise that the main focus of the study is about the support that mothers experience. However, there was a great acknowledgement from all the mothers that they had immense support from their partners. They were very expressive of how the experience shaped their relationships and explained how some dads dealt with their loss. For example, Felix's mum raised that there is some support available, but sometimes the dads do get forgotten, and there is a broad thought that they do not need help – an assumption her GP made.

> *…so there was no support at all then umm nothing was- that was like when I had to go to the GP and even the GP – I'd said I mean we've not been offered anything like even [husband] and even my GP said 'well it is worse for you than it is for dad isn't it' and I just think 'oh my god!' like how can you say that? I do understand that people probably have that view but it's not worse for me it's not worse for him it's just different…*
>
> Felix's mum

Theme 1.2.2: Other Children

For most of the mothers, the baby was their first, which carries its weight of loss. However, there were cases where their stillborn baby already had a sibling. Arthur's mum shared the experience of having time to spend with her other child as being very supportive. She shares below that she was able to focus on her daughter, all the while knowing their other child had died. She commented that having that connection with her elder child before she gave birth to her stillborn baby was vital to her. This connection was more of an emotional nature and was comforting yet 'strange' to experience. Arthur's mum shared this moment because she experienced her children's life and death, highlighting the experience's complexity.

> *Like I said my daughter at the time was nearly three my eldest daughter. […] I just wanted to see her, I just wanted to be with her – […] So, it's a really strange place to be in and I always thought with that one. So, we spent time with her and then we went back into the hospital…*
>
> Arthur's mum

Theme 1.3: Friends

Friends played a large part in all the interviews, particularly mentioning how friends had been there in a practical sense. For example, where the car seats were taken from cars before the mothers left the hospital or there was food left on doorsteps. This was a great support, and the mothers who had this experience explained that it was a comfort to know that their friends were there, but that they didn't need to fully engage with them when the grief was too much.

> *Umm not many of them had ever known anyone to ever experience anything like this before but I think we were just so lucky with our friends like they just knew what to do. They um they sort of supported us on some of our walks and really helped fund raising…*
>
> Miles' mum

There were, of course, situations where friends could not hold the space for the mother, and there was a distance created between them, which can be seen in the quote below by Maeve's mum. The support that is lost in those moments and friendship is hard to bear during such a sad time Maeve's mum expressed. Sometimes the friendships were permanently broken, and friends lost touch with the mothers. Some mothers noted that the loss of a friend on top of the loss of their baby was experienced more painfully in later years, when the grief had lessened.

> *there were you know there were friendships that I lost um people that couldn't stay and couldn't be and they-they are still painful […] umm and I'd other friends who have completely lost touch with who I um wh- a few who just slowly disappear quietly you others who felt the need to write me letters and emails to tell me how self-absorbed I had been and how I had not been a good friend and things like that and uh...*
>
> Maeve's mum

In summary, this domain and the content from the interviews have all evidenced that some of the mothers felt immensely held and supported by those in their personal lives and in the most sacred moments of giving birth. There was also a great deal of support in its various forms from the mothers' midwives and doctors as well as other healthcare professionals. Not all experiences in this area were wholly positive, as some mothers explained in the interviews, with a lack of support from those they expected to aid them. The majority of mothers experienced positive support, but others experienced a lack of connection or care from their family or healthcare professionals. During this experience of lacking support, the mother endured high stress and anxiety and felt entirely and understandably unable to process their immediate grief. The support experienced from family and friends and other children was the emotional support that most mothers needed, because the connections were there already and they were able to access or utilise this support efficiently. There was, however, a lack of support from mental health professionals specifically, which was raised by the mothers, and their various needs were not met fully. Most mothers desire a space to explore their emotions with someone who can hold the space and be aware of their specific needs.

Domain 2: A System of Support – Is It There?

There was a constant theme from all the interviews: mothers were not supported after leaving the hospital. Nearly all mothers noted this, in there not being someone to see or a place to go once they left the hospital. The mothers were all given leaflets while in hospital, and there was a great feeling of being rushed, as well as filling in forms or being ushered out or wanting to be out of there themselves. When asked whether there was any presence of a psychologist or mental health specialists, there was very little response. Mothers found support in various forms, but there is a stark difference in availability depending on geographical location.

Theme 2.1: The Information for Everything in a Leaflet

Some mothers found the information extremely helpful, took all the leaflets and acted on the information provided to help them navigate this time. Others were given the leaflets but left them in a drawer and never looked at them again. However, not all were averse to the leaflets; some mothers liked having the option to read at their leisure when they needed support and guidance.

> *But so yeah we then got given – they give you a lot of leaflets while you are in the bereavement ward at […] and I think I am the kind of person who likes all the information. I’m like give me it and I’ll read it at my leisure. You know I will read the bits I want to read – just give me it…*
>
> Arthur’s mum

There was a need for a balance of emotional support and guidance from a human, as well as written information in the form of a leaflet. What some of the mothers received was someone to help guide them through the process about what would happen after leaving the hospital and provide an engaging way to access support.

> *yeah it was umm you get given a lot of leaflets umm when you go in umm, we got given a lot of information to read in our own time obviously no pressure to do anything or make any decisions there or then umm there were a couple of things we needed to decide while we were there […] it's mostly information rather than emotional support I would say…*
>
> Jesse's mum

Theme 2.2: All the Details, Please!

While some mothers were not able or willing to engage with leaflets, others craved and needed as much information as possible to self-help. Until this was possible, there was a feeling of great uncertainty expressed by some of the mothers, and they were unable to fully process what was going on and what had happened to them. They were taking on all that was given to them and were unable to settle into their grief and despair until they had a firm footing of information.

> *yeah and-and I guess like probably like as you said its different for everybody but for me like for me information comes to mind you know like I want to know you know like what's happening? what's going to happen next? What's going to happen after that? What are my choices? And what are the implications of those choices and you know what do other people do? How often does this happen? and you know what – what do people appreciate in this situation? what do other people regret later on? […]*
>
> Isobel's mum

Having books to read and guidance on what they should be doing – almost being told what to do – was helpful for these mothers. They felt able to relax when they were advised on how to do so and what they should be feeling during this unknown experience.

> *I like information and that I know that about myself I am very much a ---- there's a problem let me read around it – type of person let me find a solution umm and in this case I wouldn't have been able to find a solution but I tell you what I would've appreciated was um almost like a reading list (chuckle) of kind of books that – that I could've disappeared into to find that information out…*

Stanley's mum

Not all mothers wanted this style of approach, but it was clear that having enough information to guide the mothers through the initial period was what they found supportive.

Theme 2.3: Timeline of Information

A timeline was alluded to throughout the interviews, and there was a great sense that guidance was required. The timeline as detailed included being given check-ins, or being told what happens at funerals and during post-mortems, and being told about other, general things to expect. During the interviews, the mothers shared the need for direction and management of their expectations. Through the various experiences that were shared during the interviews, it was found that the mothers who had been given a broad scope of what would occur after they left hospital were able to anticipate the next stages more readily than those who had been told nothing. The mothers were unanimous in wanting clarity on how to manage this experience, and guidance on what was going to happen to them and their baby would have been useful.

> *Umm the bereavement midwife she was lovely she spent quite a lot- I'd say an hour with us she came in and chatted away and um sort of – offered – uhh not offered but told us of the different types of support we could have access to should we need to and what happens next umm you know obviously you have the baby and then the baby needs to have an autopsy and just took us through all the steps really and what to expect umm and what was going to happen so it's like it wasn't all a shock --- so we knew what was going on and we could prepare for it really.*
>
> Jesse's mum

Having such a massive loss and abrupt experience leaves mothers and wider families at a loss about what to do and what to expect. Having guidance about processes that take place after leaving hospital would allow them to have a rough idea of what is going happen to their baby (i.e. post-mortem, funeral etc.), alleviating anxiety around the unknown. When mothers were given guidance about what was happening to their baby after they had died, those able to engage with it found it very helpful. However, those that were unable to engage were not provided with any alternative avenues of guidance.

Theme 2.4: Continuity of Care

Another theme that was loudly voiced was continuity of care after a stillbirth. There was the need for awareness of what mothers were engaging with in the same way you would expect for a physical illness. The mothers expressed the need for people like GPs and other support services to be given the information about their loss to avoid awkward conversations. These awkward conversations led to some mothers becoming distressed and less likely to engage with support providers positively and led to others being missed by healthcare providers and becoming unwell in a physical or emotional sense.

> *…it would be helpful if people had a more joined up kind of way of having some support you know so that somebody did know 'oh hey you are going to Sands' and 'hey you're GP is helping you' and 'hey you are going to this you know the counselling at the hospital' and stuff like that and that it was all joined up in some way so that you – you know you have like – […] but somebody needs to have that kind of oversight about --- how's it all how's it all fitting together […] or where are the gaps – where are the gaps is it just you or is it your partner is not getting anything or you're not connecting or your immediate family's not connected in kind of support or helping whatever…*
>
> Michael's mum

Mothers documented this theme as almost a preventative measure; that it would help most mothers get back on their feet quicker than if they were left alone. The grief that mothers endure is indeed very raw in the beginning, and this is where the support from healthcare professionals is needed to move them forward in a way where they feel held.

> *Ummm yeah I think regular check-ins and somebody – somebody talking about the mental health side of things because no one does really and I just don't think it should be a case of here's a leaflet it's up to you whether you want to contact them I think it needs to be more […] that they that they are automatically referred to --- psychology or why don't why don't parents even if their children aren't born alive why don't they get access to perinatal ---- the support system that seems absurd that's like saying to you because your baby wasn't born breathing – you're not a mum now? I don't know it's a very undermining system…*
>
> Edie's mum

The continuity of care meant that the mothers could manage their support and know where to reach out. There were cases where mothers did experience good continuity of care, which can be seen in the next theme, and it was shown to be a great support in giving them the knowledge that someone was there for them, and that they had a point of contact when things were not going well, to have their experience validated.

Theme 2.4.1: GP Involvement or Non-Involvement

There were some stark experiences of GPs being involved to greater and lesser extents when supporting mothers following stillbirth. Ruarai's mum had a positive experience where she was able to see the benefits of having check-ins from her GP, and was able to utilise that support in navigating her grief following her stillbirth.

> *Umm and I also got a home visit --- from my GP and then a couple of follow-up phone calls as well just to make sure that umm. We live in quite a small community umm so I think --- we received a really personal level of care that I don't think necessarily everybody experiences because if you work- if it's a city hospital and a GP practice with 20,000 patients – you're not going to get that. Whereas you know I think our GP practice maybe has 5,000 patients and – in fact maybe not even that you know its…*
>
> Ruarai's mum

Compare this to the comments from Freddie's mum, who documented the typical process followed by GPs and noted the need for further support later on in the journey of grief.

> *well you obviously – as soon as you've had baby you get your 6-week check-up from your GP but after that 6 week check-up that you. Effectively discharged but you're still the emotions are still so raw 6 weeks in you almost need like to be taken back to the doctors at like 6 months at a year just to sit you down and ask how are you? Do you need anything is there anything we can do? Because you're just ---- it's a – you do you feel abandoned by ---- […] When really you need that support – like once it's kind of sunk in a little bit like at 6 months a year…*
>
> Freddie's mum

For some of the mothers, they had never experienced any situation that had left them with this feeling of needing help. Some mothers could reach out to their GP and get help right away, while others that were in greater need were not met with effective support. Some mothers were offered medication, some breathing exercises and some weren't given anything and told that it was 'just grief'. This final point was valid, but there was a need from the mothers for a space to be listened to, and they believed that the GP could/should/would be able to offer that but, as explained, this wasn't always the case.

Theme 2.5: Having No Support vs Immediate Support

When the mothers were able to get to their GPs or reach others for specific support, there was a consensus that there was a lack of support offered, and there were occasions where there was a need for some time to pass before help was offered. Being told that you are ‘too bereaved’ for support is a common occurrence in multiple settings and situations, but it seems that, in these mothers’ cases, there is a need for something structured or at least guidance as to what to expect or do during these early days of loss.

> *no I did contact the umm – the company I work with do the occupational health umm where you can have the counselling – and um the lady I spoke to it was in the immediate aftermath said to me – I was too bereaved for help (laughs) at that stage. It was too early on and in fairness I did – I mean it was just having that somebody to talk to that didn’t know me almost, that doesn’t – that you don’t filter what you say to – because they don’t – you’re not censoring anything because they’re not going to walk away and judge you.*
>
> Arthur’s mum

Immediate support was found to be a great provision to mothers who needed someone to talk to after their stillbirth, and Michael’s mum was lucky to be able to attend a support workshop mere days after her baby was born. This immediate support would not be suitable for all, as loss is incredibly personal, but it was an immense support for Michael’s mum. She processed the raw and painful grief from what other mothers note as ‘the pit, like the feeling of despair’. This experience is unique, and highlights that the opportunity to have support soon after the stillbirth was, in this case, received as a positive one. She highlights that early intervention aided the processing of the rawness of grief.

> *this umm – workshop which was um led by this doula who was um supporting women who’d had difficult births and did I want to come – along – you know just you know which and this was like my son was born on the Thursday and this was like Saturday so 2 days later (chuckle) I got to go to this workshop on dealing with difficult birth experiences (chuckle) which was which was amazing you know umm – you know I didn’t know what to expect and the other women what to expect and stuff so I like got to spend this whole day like processing like all of this stuff – which was – amazing umm you know like processing like dealing with this raw, raw grief --- with somebody who was there like literally holding and supporting me and just*

> *giving me that attention and that time and space and also kind of helping me ------- think through what all of that meant for me…*
>
> Michael's mum

Theme 2.6: PTSD/PND Could Have Been Prevented?

From the interviews, it was evident that some mothers fell through gaps in the support being offered. Some mothers who were interviewed experienced more extreme effects, like PTSD or PND, or varying levels of anxiety and depression from the stillbirth of their baby. The lack of support they initially experienced meant they had to source help themselves, or they would encounter setbacks during that time and be left to experience extreme anxiety, which led to spending time in hospital to aid recovery from such a trauma. These experiences were noted by a few of the mothers interviewed, and it was clear that reaching the point of having to spend time in hospital or be treated at a specific unit was not what they wanted, and their theory was that it could have been prevented had help been readily available.

> *I was just living everyday was just one long panic attack I was just one long panic attack. […]. Umm ---- he took me to A&E and they referred me to – uhh ---uhhh a ---- mother and baby unit at [Hospital] and I was admitted […] ------ and but it it that was what it took to get --- help and that's when the perinatal team got involved and I was- I had access to to psychology and rather than it being --- me having to go and speak to the GP and then being on a waiting list that that was them saying ok we have made an appointment for you here you come to us. […] they were checking in on me that's what I needed…*
>
> Edie's mum

The mothers note that if the support had been there and available earlier, the effects of waiting or searching for help might not have been such a catalyst. Having a space to share their feelings was greatly wanted by most mothers, and the feelings of shame when some got to the point of exploring their PTSD or PND was where the 1:1 support was most helpful. Having specialist support was a great relief for both Edie's mum and Stanley's mum.

> *I think almost ------ just under a year later I went back to IAPT and explained the situation again ----- um and then they put me in contact with a counsellor to do CBT […] I think it was just over a year I think it was just over a year and they put me in contact to do CBT and I said – they said you could either do it online or would you like to do it in person and I said for me do it in*

> *person […] umm I think I needed the time and the space to actually be able to do it um and then that's when it happened and then ------ we ended up having another baby umm a year and a half ago – and just after she was born ------ I was I was trying to explain I didn't know if it was PND or kind of triggering – um cause I ended up getting diagnosed with PTSD…*
>
> Stanley's mum

In summary, this domain, and the included themes, have highlighted that there is support available to mothers, but they need to be in the right frame of mind or position in their grief journey to find support in their local areas, which can often be offered in a variety of forms that are not specific to what is required. The families are given information on where to go, but the mothers have reported no great direction. The missing guidance wished for by nearly all mothers shows a need for mental health to be factored in specifically during the period spent in the hospital. Most mothers noted this as the point where they needed all the information, or a follow-up to be made. Most mothers pointed out that the need for support, guidance and advice from a health professional they can trust would be invaluable. A number of the interviewed mothers also documented that there was no helpful support offered, and they had to source what they needed themselves. Otherwise, they were left to muddle through and avoid acknowledging their feelings, potentially leading to experiences of further mental health distress. With this in mind, the need for continuity of care was of great importance for all the mothers. The GP came up as a central point of contact, and the lack of understanding or unawareness was felt to be a slight to the mother's experience on some occasions. When the mothers were back in the community, the systems and communication between different departments were very well connected in some circumstances found in this study, while others had to explain their situation multiple times before receiving any support. Thus, mental health strains like PND/PTSD were more likely to occur, which some mothers did experience.

Domain 3: I Guess I Need to Find Support Myself

This theme documents the situation and surrounding emotions when mothers have to go out and find the support they need. This suggests that there is support for mothers to find, but it has been noted to be difficult to attain and requires a large amount of drive to make it happen. There is a variety of support out there, and depending on what the mother needs, she has to source this independently. Some mothers described trying to access services, only to be told they were not able to be treated there. There was also the situation of the mother's locality and the limitations of support in the area. Then, the mothers can put themselves out into the world again and try to find support when they are emotionally drained due to their grief – these are some examples of what the mothers described when trying to find support.

Theme 3.1: Social Media – ‘I Found My People’

Social media can be a lifesaver for some, but it is not something all people can engage with. When asked whether social media was a support system for the mothers, there were mixed replies. Some felt it was a great source of information and support and were very involved in communicating with other mums, feeling that it provided an outlet in which to engage with each other’s stories. Other mothers found that having so much grief, anger or frustration within the pages or comments meant, in some cases, it only exacerbated the fragility of their emotional wellbeing, and they had to withdraw to protect themselves.

> *…not massively I mean I’m I’m not a huge social media user myself umm. I I am on or I am aware of like you know I’ve followed SiMBA’s page or Sands page umm you know things like that umm but it’s not something that I kind of actively engaged in. I tried for a while when I fell pregnant with my second […] – I tried they had a private group for – um women that were expecting following a loss but I actually found it too intense because everyone’s experience was so different and a lot of women – were putting up genuine concerns like what’s going on in your mind but I felt like when I was reading it every day it was making it too intense for me – I felt like I couldn’t escape from that worry...*
>
> Ruarai’s mum

There was also a sense of jealousy towards some babies and mothers when they were seen to be getting more ‘airtime’ than others. Amid grief, involvement with social media can create situations where the mother experiences feelings that can be detrimental to their wellbeing.

> *Umm but I think there’s elements of envy and there’s a bit of jealousy that there’s these other people’s babies are getting you know the kind of recognition and you know I sometimes see --- watch a documentary or something and be like well I have a story too you know which probably part inspired me to respond to you as well umm so its yeah it is a support but at the same time I think it can be very difficult as well to manage….*
>
> Maeve’s mum

There was a lot of support from charity social media outlets, where helpful information and opportunities to share their stories were available. This is where social media was a positive support system for mothers, because they felt they could engage in a safe and inclusive way.

There was an occasion where some mothers explained they formed their own groups to help support and make connections with others who had been in similar situations.

> *Umm anyway all of that being – in a way since social media has been a support to me um at points but it has also been umm difficult as well. I don't really know quite what the word is I kind of felt like an outsider at times which is has been hard. […] Um you know sometimes it's helpful and its supportive and to not feel alone in it cause I think the loneliness in grief is the hardest bit and to know there are other people out there that may be a little bit further along in their journey and can give you that hope that things will…*
>
> Maeve's mum

Theme 3.2: Support from Work can Make all the Difference

One area indicated to be a great source of support, when given appropriately, was the workplace. There were situations where mothers were given excellent provision by their workplaces and were supported through maternity leave in the typical sense and given continuity in their salaries. Having a period of leave and a salary kept available to them is extremely useful for mothers after stillbirth so they have time, without further worry, to grieve and begin to come to terms with their loss. However, there was a split between mothers wanting and needing time from their workplace to grieve and others wanting to return to work after a short hiatus, as this helped them manage their grief.

> *work were brilliant uh both for me and my other half ------ and they ----- it was really awkward because we gave birth at 26 weeks so technically I shouldn't have started maternity pay but […] just sent me a message saying ------ don't come back till you are ready there is no rush take as long as you need ---------- […] so I was paid full salary for three months so there wasn't the pressure either of having to earn […] so knowing there was financial security was really really helpful…*
>
> Stanley's mum

Those who wanted to return to work quickly described this desire as an opportunity to have their minds distracted from their loss. By getting their heads back into a workplace setting, they were able to channel their energies into other tasks, bringing 'normality' to their lives again.

> *…but also just being at work or with your friends or just you know kind of being in that 'normal' kind of kind of way of being ----- just softens things a*

> *little bit but at the same time you were probably hyper-aware of I am still in this space I can't shift it I want to it sounds like a grounding ----- place to just be --- like either aft-like post loss or after the loss…*
>
> Isobel's mum

The support from colleagues and how they can help mothers deal with their losses was also mentioned. However, there were situations where there were unhelpful and insensitive comments, or their colleagues ignored the mother because they felt an awkwardness, meaning they could not converse with them.

> *I was really lucky with my um my work that I was able to afford to be paid so I can take a year off and take the maternity. […] if you couldn't afford it or you need more time […] I know a lot of people do struggle and I do struggle going back to work to being my normal self […]*
> *umm I dunno I just feel that work is an area that needs looking at because --- […] I just feel like going back to work is a really tricky situation and I still don't think – you are never the same person […] You need to have maybe more of a staggered way back in to work or some counselling maybe to go into work and have some kind of emotional support because there are challenges that come up with work ------ but I think as an area it is a problem.*
>
> Herbie's mum

Theme 3.3: Group vs 1:1

After mothers have left the hospital with their leaflets and information, they can begin to look for support. Generally, mothers look towards the prominent charities within the new world they have been plunged into. Sands offers groups for people to attend and seek support from at any point in their journey. The interviews highlighted mixed emotions towards groups vs 1:1 support. It became clear that, if someone looks to interact with groups, it is their choice; some mothers thrived in the group dynamic and found it helpful. In comparison, others found it very intense and searched for a much more personal connection that mainly came in the form of 1:1 counselling or therapy to help navigate loss and grief.

Theme 3.3.1: Groups

Groups are a great option for mothers who need to connect with others after their baby is stillborn. They have the chance to meet with other parents who have been through a similar experience in the same local area and allow potential friendships to blossom. It allows for the sharing of stories and experience that helps people understand what is out there and it can give comfort to hear ideas and names of helpful practitioners who have been on the side of mothers who have been through stillbirth. The opportunity to gather information can be sought, and a community is formed that aids the process of managing the intensity of grief.

> *yeah so um I also joined my local Sands group that was also really really helpful for me um just because --- I couldn't again like I just couldn't ------------------- (sigh) --------- like be out in the world you know with this thing that had happened to me and that nobody could see and that nobody could understand basically […] and so I I really really felt compelled to be with other people who understood what my situation was basically so I wouldn't have to explain it all to that they would just know […] and um you know it just it just wasn't something that worked for my partner and I – you know it just wasn't something that appealed to us so um – so yeah so I went to the to the group and you know people talked about their stories and you know you kind of like start to build up a picture about how things work and you know different places and you know how people cope and-and you know that you know we just made some really amazing friendships as well…*
>
> Michael's mum

The groups, as mentioned before, are not for everyone. Some of the mothers could not connect wholly with the concept, but found they went to a group setting when they were initially looking for support. In addition, some mothers were unable to manage the collective grief in some groups, where others were either amid intense grief or needed comfort. This intensity, which some of the mothers found too overwhelming in combination with their own feelings, led to some stating a more specific and individualistic support package was required that would be more attuned to their circumstances.

> *…or group therapy and that's not for everyone. I didn't want to sit and talk about- I I didn't see the benefit of talking about what I'd been through and listening to what other people had been through. That wasn't for me I needed 1:1. Someone to help me navigate my feelings and go forward...*
>
> Jesse's mum

There was also the element that some mothers brought up where they were attending the groups and finding it helpful or were about to go to the groups when they fell pregnant again, and subsequently they felt it was not the right place to be. Some of the mothers noted that they felt unable to attend the groups because they felt they would upset the other attendees – an experience that Arthur's mum had when attending a group.

> *Umm like I say I don't know if I hadn't been pregnant again quite so soon; if I had continued going to them if I had got more support out of them. Um ---- the lady was lovely and she still messages now we still go to the Sands Christmas party which seems like a really odd thing to go to I appreciate but you know we still have that and all your children are welcome and stuff…*
>
> Arthur's mum

The difference in the experience of being part of groups highlights the need for various options when it comes to supporting mothers following stillbirth. Each of the mothers had a different experience and was looking for support, but with an individual essence.

Theme 3.3.2: 1:1 Support

For some mothers, the group dynamic is not for them. Some tried it, as mentioned before, but some preferred or needed to have 1:1 support for them to feel supported. There were accounts where mothers were told they were too newly grieved and were unable to access support. Some mothers acknowledged this point, and some did recall being told in the early stages of their grief that asking for help would not be suitable for them. However, others were desperate for support and someone to help them either share their inner and private feelings about the loss or support them in organising their thoughts.

> *it's almost that support for me that I would've found beneficial but I do think the 1:1 counselling support is something that needs to be offered and not even in a kind of well you are too newly bereaved to have counselling I think is probably one of the worst things someone's could ever say. It's like well actually I am not expecting you cure this but to just have someone to say ---- its ok I get it, I understand why you are feeling how you are feeling. Like you say it's just that validation around your feelings really and why things might be tough and ----…*
>
> Arthur's mum

Some mothers crave an individual and singular space to share their deep and sometimes dark feelings with someone who can hold the space for them. However, in some mothers' cases, the experience of 1:1 support was shown to be extremely helpful in managing their present and also future feelings towards loss and pregnancy.

> *umm I think I needed the time and the space to actually be able to do it um and then that's when it happened and then ------ we ended up having another baby umm a year and a half ago – and just after […] was born ------ I was I was trying to explain I didn't know if it was PND or kind of triggering – um cause I ended up getting diagnosed with PTSD umm so after I'd had […] our youngest I didn't know if it was postnatal depression or kind of triggering other bits. I went back to IAPT umm --- and again they were super good and really speedy like within two weeks I was seeing someone…*
>
> Stanley's mum

One mother tried desperately to get counselling for herself, but it wasn't until she was diagnosed with cancer that she could get readily available access to talking therapy. She acknowledges that she was under a lot of pressure and that having someone to talk to was a great support, and she managed everything.

> *yeah basically I was diagnosed with cancer during my pregnancy […] Umm and through the whole hospital they offer uhh and service of free counselling and at that point I felt like I'd been through so much with losing Jesse, and then getting pregnant again and-and then finding out about this diagnosis I was like I need to talk to someone […] and I just knew I needed to get it out and I needed to talk to someone […] And it's so easy whereas – when I lost Jesse and immediately afterwards I felt it was out of reach, I felt like I- it wasn't accessible. […] I remember saying to her you know it's sad that ----- I got the help I needed through having the cancer diagnosis that I should've got when I lost my son.*
>
> Jesse's mum

The accessibility that Jesse's mum experienced from her cancer counsellor was what she needed, and she could share her worries and concerns about her son's death within a safe space. Other mothers desired spaces like this one as it would/could allow them to have the opportunity to begin to let go or explore the raw emotion that some held.

Theme 3.3.2.1: Public/Charity Counselling vs Private Counselling

As noted by one mother, the offering of counselling within a specialised service is very much dependent on cost and availability in a given area. As above, the mothers expressed a need to have explicit options to source support should they feel the need for 1:1 counselling. However, some mothers raised that they could not afford to have private counselling and would look to the NHS. Specialist services that are sensitive towards stillbirth and even look after women who have had the experience seemed sparse to the interviewees. Some mothers were able to detail the benefits of having access to private counselling during stillbirth, which Ruari's mum details below.

> *So I got --- about 10 weeks' worth of counselling from her umm in the first instance […] then I stopped cause I felt I was doing really well – and but I went back for a second round of counselling albeit a little bit more intermittent when I was pregnant with […] uh it was just really managing the pregnancy – umm and she gave me a mixture of sort of cognitive behaviour stuff but also a bit of treatment for PTSD […]. But had I not sought that out privately I wouldn't of got it ----- I think that's- I think that's probably the only area where I felt really kind of let down by the public side of things because what if people are not in a position that I was in to be able to go and access that myself umm you know so that – that was yeah where we were supported support wise.*
>
> Ruarai's mum

There are also other examples where the mothers went through charities or the NHS for support, which again depends on the mother actively looking for help among the fog of grief or being directed to counselling by an NHS practitioner after they have experienced significant distress.

> *I think for me I would've – now that I'm with the perinatal team they have said that I could do with some counselling to help me through. They feel like I've not dealt with it the way that -------- would've benefited me so I think at that time I would have really of appreciated some somebody to speak to for some counselling...*
>
> Orla's mum

Some mothers – like Orla's mum – were only offered support after they'd had their next child. It was clear from some of the experiences that support was only provided to those who had a child while those whose baby had died at any point before were left to seek out help themselves.

Theme 3.4: Support from Charity & Fundraising – 'It Meant My Baby Had a Legacy'

Assistance from various charities was a massive part of the support experienced by mothers. In some cases, charity support was the most accessible and valuable. There are multiple charities nationwide that have played a central part in helping mothers and families get through their loss. Throughout the interviews, there was an incredible amount of support from charities, demonstrated in various forms. The mothers would reach out to the charities as it was often deemed the only accessible outlet. However, there were mixed feelings towards the support that the charities provided, with some mothers finding it incredibly helpful and others unsure or tentative about managing their grief among others.

> *so I contacted Sands --- umm and I went for a couple of befriending meetings --- it wasn't counselling as such. Umm and do you know it was really nice to speak to somebody who had been --- through something similar ------- but it just made me feel like a bit like a broken record because really you were there to speak about one thing and one thing only and there's only so many times you can go over old ground – so it was it was nice to know you know there are other people out there and people do understand what you've been through ----- and how you feel ----- but there comes a point where it's just like I don't want to keep going over and over and over this it just felt like sort of ---- those couple of meetings served a purpose --- and that was – I was good with that…*
>
> Aria's mum

Herbie's mother was offered counselling via a very uncommon charity, and it provided a great source of help in exploring her feelings around her loss. Most charities provide befriending, somewhat-effective support. However, most mothers noted that they needed more of a counselling style of support to help them understand their loss, as well as topics such as wanting to be or being pregnant again and the mixed emotions that came with this.

> *umm I can't remember what the word is but she like forwarded them our details and we went on like a waiting list and basically after 6 weeks I think or something or a couple of months of afterwards umm they contact you with umm – counselling…they offer you 6 hours of free counselling I think it is through the charity in [Location] so we then went to do. And it's meant – I mean you could do it individually or you could do it as a couple and [Husband] and I decided to do it as a couple because we were, we were kind of communicating still together and it didn't feel like one of us needed it more than the other or I don't know but we felt like it would be more worthwhile together so we did that for 6 weeks and then after 6 weeks that kind of ended umm…*
>
> Herbie's mum

Fundraising for charity was also a common topic among the interviewed mothers. Some mothers said that they found a purpose, and fundraising for a charity that either supported them or supported the maternity unit where their baby was born meant that they could provide their child with a legacy. The charitable efforts did have some moments where it would become more business-focused than about aiding the cause, as noted by a couple of mothers, but generally it allowed for a focus outside of their grief and connected them with others to help achieve a common goal.

> *Umm and we sort of threw ourselves into some fundraising for ------ certain baby-loss charities that hadn't actually you know particularly helped us but we just wanted to to do something positive and be able to help out other people – and so we sort of focused our year on that and ----. Umm ------ yeah, it sort of gave us a chance to have days focused on him…*
>
> Miles' mum

In summary, the mothers have been able to share through their interviews what it means to find support for themselves. The numerous ways they did or could find support helped each of them, to varying degrees, to find comfort and assistance in dealing with their stillbirth. Social media was an interesting point, as it has only taken flight in the past seven to ten years and is now a place for mothers to get instant support as a community, which can help. Not everyone liked social media as it was a place that could be quite intense and overwhelming. Some mothers noted it was helpful to be able to switch off and have space.

Charities play an initial and vital role in supporting mothers during the initial period after their baby has died through the medium of group support or offering befriending support. Support from charities and counselling via the NHS is available, but as explained by some mothers, the availability isn't always accessible or often comes with a prolonged waiting list.

Charity fundraising was also shown to be a key support outlet and a method through which mothers, and their more comprehensive support network, could channel their loss. The mention of legacy came up in a few of the interviews, and because of the nature of stillbirth, some of the mothers felt it was the best way to make sure their baby was remembered. There was an acknowledgement from a good number of the mothers that having 1:1 support from a professional who understood the experience of stillbirth was or would be the greatest support for them, because it did or would give them a space to grieve and acknowledge their child and the loss.

Domain 4: The Joy and Fear of Pregnancy after Stillbirth

One area that was very prominent in all the interviews was the topic of pregnancy after stillbirth. For some of the mothers interviewed, becoming pregnant again was the main priority in the months after their baby died. In other cases, however, situations were slightly different as there were other children to look after, or for various reasons there was little desire to get pregnant. What was also prominent from the interviews with the mothers was the potent fear and anxiety around their subsequent pregnancy, which led to some mothers not engaging with their pregnancy and just waiting for a baby to arrive. It was interesting to hear from the mothers that maternity staff proclaimed a low probability of a stillbirth happening again, giving some relief to some mothers or an unrealistic promise to others. There was an offering of more scans to alleviate anxiety, but again this was only a short moment of relief before the worry came back. Most mothers noted the missing support during this time, and their experience is documented below.

Theme 4.1: High Anxiety

High levels of anxiety were found in all the interviews regarding pregnancy after the stillbirth, and this endured into subsequent pregnancies. All mothers who were interviewed mentioned in some form the anxiety that they felt when it came to the subsequent pregnancy after her stillbirth. The desire for a child vs the fear of history repeating itself meant that there was a heightened sense of worry for nine months, plus the time between their stillbirth and becoming pregnant, which meant that their mental health did suffer at times. There is acknowledgement from the mothers that having anxiety was expected, but sometimes the attitude that the mothers encountered from most parties in their life made it hard for them to share their true feelings. The mothers needed support here; as they explain in the examples below, there was a lack of offering or understanding of what the mothers were truly experiencing in such a confusing and anxious time. Some mothers expressed how they had great anxiety around the potential for their subsequent pregnancy to bear the same outcome in terms of gender or twins, with a fear of history repeating itself. There were wishes from some of the mothers that a repeat of gender, for example, would be the baby that died coming back, while others hoped that it would not be the same as before. In comparison, others didn't engage until their baby was born, which caused anxiety before and after pregnancy because they hadn't been able to connect emotionally with this subsequent pregnancy.

> *…so obviously I lost Orla when I was 27 weeks – […] I just thought --- I need to make it to that point and I'll know if everything's going to be ok I just ----- as horrible as it sounds I just could not get attached to this baby that obviously I'm excited I got excited at the gender scan and everything but I*

> *could not let myself ----- buy anything I could not let myself choose a name, I could not let myself ------- love him until I knew ok I've reached this point right and everything is still ok I'm going to be fine we're going to be fine and as soon as I hit that point --- I was like yeah this is it I'm fine I'm allowed to enjoy it I'm allowed to be happy…*
>
> Orla's mum

Subtheme 4.1.1: More Scans a Help or Hindrance?

Having more scans was generally offered to the mothers, and was initially welcomed as it was a way for them to be in control and know that things were all right. Some mothers described the positives of having additional scans as a short-term alleviation to the anxiety. Having the opportunity for moments of certainty that their baby was healthy, as well as extra support from hospital staff, was described as providing a sense of control. However, as mentioned in the previous theme, the mothers said that having additional scans also brought feelings of anxiety in varying levels and that sometimes it was helpful, but for some, it was not. There were also encounters with hospital staff who were potentially unaware that mothers of a stillborn baby are entitled to have more scans. The effect of the hospital staff pushback or questions around the extra scans caused distress to some of the mothers, increasing their anxiety levels.

> *I was offered the same community midwife and I have had the same person so in some sense she knows me because she is very experienced and she has seen me for a long time there's no like um consistent follow-up or care. For example things like um on my medical history I'm allowed to say that having an early scan but you ring the hospital or you are on your own – you're told to ring the hospital and ask for it which is not meant to be protocol and when you ring the hospital you usually get someone quite abrupt on the phone who's quite like dismissive of you and then you have to like kind of openly share your history with them and they're like oh and then they try and back track a little...*
>
> Herbie's mum

The feeling of having a scan and seeing the baby was great, but then it was noted by a couple of the mothers that the sense of safety was short-lived. Having experienced such a quick change between life and death in a couple of hours like Arthur's mum, for example, there is significant uncertainty around whether to opt for more scans or whether specialised support around the uncertainty of their child's life would be of better help.

> *Umm but because of that we had a lot of scans with my pregnancy with my youngest daughter. Umm ---- but equally I I didn't find them that – that much support from the scans because you'd walk out of one and you'd know baby was ok at that time. But that doesn't mean an hour later they're still going to be and whereas I know other ladies who've felt that actually having that continuous monitoring really useful – but for me because I saw Arthur's midwife the day he died and he was perfectly fine at 11:30 in the morning and then something that day – and at the time obviously we didn't know until afterwards what had happened. So I kind of knew how fast things could change so actually ---- it would just be somewhere…*
>
> Arthur's mum

Theme 4.2: The Need to Get Pregnant

The need to get pregnant again following a stillbirth was a theme that was seen across all the interviews. Some mothers felt they needed to get pregnant right away, while for others this need couldn't be acted on immediately due to medical reasons, or they needed to take their time and allow their grief to pass. Either way, there was a great sense of need elicited from the interviews. For example, Aria's mother described the sense and desire to become pregnant again as 'tunnel vision'. In this time of intense grief, it meant that there was added pressure for the mothers for further pregnancy.

> *after it umm ----- but we were just so --- tunnel vision with regards to we need a baby […] (inaudible) baby we had this like ---- innate need just to like get pregnant again so we probably put a lot of strain on ourselves as well cause like it didn't happen instantly overnight…*
>
> Aria's mum

At times, there was medical advice given to some mothers stating phrases such as, 'maybe wait for a while' or 'it is too soon?', but there was no emotional exploration as to why the mothers were feeling this way. The deeper turmoil and feelings experienced in the time following their stillbirth was complicated for most.

> *I think my focus very early on was getting pregnant again because we'd had such struggles, such a journey to get pregnant we'd finally done it and cracked it. You know we have this one frozen embryo left um and I just wanted to go back as soon as I could and try again and that was really all that kept me going in those early weeks was for my hormones to settle and for my period to come back so we could go back and uh we were sort of*

> *warned against it all almost by our consultant at the IVF clinic who was saying you know you really need to think really carefully about this and what if it doesn't work and I remember my husband just saying well nothing is going to be as bad as what we have just been through.*
>
> Maeve's mum

Having the opportunity to talk during this inter-pregnancy time would appear from all the mothers to have been beneficial.

Theme 4.3: Losses Between Pregnancy

Having a loss of a baby following a stillbirth was experienced by some of the mothers, and they shared within the interviews the numbness that they had when they experienced miscarriage soon after their stillbirth. Unfortunately for some, there was further loss between their stillbirth and getting pregnant again. Some losses were very early in the pregnancy, but the desire to have a family or have further children continued, and the hope that things would be different is what kept the mothers going.

> *Um we got umm pregnant again quite quickly and I had two very early miscarriages at like about 5 weeks you know they were just kind of chemical pregnancies. Umm and then the 5th month afterwards we conceived our little girl […]*
>
> Miles' mum

The intensity of the multiple losses was felt differently by each mother, and they noted that having an awareness of the whole picture was key for health professionals and should have been a prerequisite in being supportive of their situation. Like Michael's mum said in theme 2.4 (continuity of care), there needs to be a central place for mothers to be able to say 'look at my record' which Stanley's mum also noted; a phrase that currently is spoken by few to get the right approach to their care. For Ruari's mum, there was a close time between her stillbirth and getting pregnant again. The encounters with health professionals were generally positive but it can be very hard for mothers with respect to the language used; an empathetic approach to care needs to be constant during these experiences.

> *I fell pregnant with […] ----- 10 months after I had Ruarai and I had a miscarriage in between. […] and they seem to treat them very differently but without taking account of the fact that it was a miscarriage less than 6 months after a stillbirth ---- umm […] I was almost numb to the grief of my miscarriage I almost couldn't grieve it um because I was still so caught up*

> *in the grief I had for Ruarai umm […] so it was um really intense period of time…*
>
> Ruarai's mum

Some other mothers felt that the subsequent losses were another emotional blow that set them back, but the need to get pregnant was a stronger need, and the compounded experience of loss did not get dealt with, which in some cases led to further support being needed.

Theme 4.4: No Support Emotionally

In most cases, there was a mention of the lack of support experienced by the mothers. It was down to them to find a source of support that would be personalised to each individual and give them the experience they needed to help them move forward emotionally. Each mother had a different experience, and it shows how there is a need for a central element of support; the charities can provide this and they are a great asset to have in the UK. However, sometimes the mothers need more, and they described that their mental health suffered when there was little support or guidance in navigating the emotions they encountered.

> *Um and particularly with the lack of support I had um and ------ you know the subsequent I would say breakdown that I had umm you know it makes me very angry the lack of support there is for mums. [...] Umm the fact that people don't talk about it umm – it's sort of a taboo subject.*
>
> Edie's mum

There was a continuous mention of the good-to-reasonable care they received when in hospital. Predominantly, midwives supported them and guided them through birth and in the time afterwards with their baby. When the mothers left the hospital, as has already been noted, they felt it became difficult to engage with appropriate emotional support. There was mention by some mothers that there is a general lack of awareness because stillbirth is still taboo. The mothers described the desire to be offered further support via NHS channels and how this should be the standard process, because it would help the mothers and the wider family. They described this support as giving the whole family an understanding of what had happened, and information about how to manage the emotions that each were having.

> *[…] something that I felt – really needed – I feel like not just mums but parents in general need extra support because we really didn't get anything to be honest […] I believe in quite strongly that it's a very taboo subject and*

> *it's something that you should be entitled to a lot more support through the NHS more than anything – […]*
>
> Freddie's mum

There is also awareness from the mothers that there isn't certainty around what they want, and they can often see and reflect on what is out there with hindsight. There was also an acknowledgement of how it is best to navigate the situation and that even the mothers are not sure how to manage it themselves. The mothers noted at various points that it can feel like an 'ongoing trauma' and that it is hard to keep going forward sometimes because of the constant knockbacks and comments, which subsequently trigger feelings of loss, even when they were in receipt of supportive interventions.

> *…they'd called me back the next day and said […] 'so what's your name and how old is baby?' ------- […] and then I had to explain – and then the next day she said 'oh no its fine someone will come round the next day' – no one turned up and when I called [...] Umm they said again […] the same questions 'how old is your baby?' No I don't have a baby – and I had to explain it all and each time […] but it's just triggers that you don't need […]*
>
> Stanley's mum

In summary, this domain was helpful because it was a theme that featured within each mother's interview. Nearly all of them shared details of how having their baby die meant that they were left uncertain of managing the loss and managing the desire to have a child. Most mothers fell pregnant again with their subsequent child/children within a year. Some detailed that the anxiety they felt throughout the subsequent pregnancy was awful and that it was during this time that the need for accessible, effective and structured emotional support was highest. The anxiety of having doctors 'promise' them that stillbirth won't happen again was also noted by a few mothers as not being helpful. However, it was met well by some, who felt this promise was supportive. Overall, the mothers collectively shared that emotional support from a healthcare professional or therapist was or would have been invaluable to them after the experience of stillbirth. The mothers added they had needed a space to bear their grief and to be held by someone who understood the mental and emotional toll they had all been through, especially as most went on to have further pregnancies soon after the stillbirth.

Conclusion of Analysis

In conclusion, the analysis has given great insight into what support looks like for mothers, and how it has impacted them – positively and negatively. Some mothers have been able to share really positive experiences of how their communities, charities, families and so on came forward to help them, which in turn allowed them to help themselves move forward. However, there were other occasions where the support was not engaged with or was not found. In these situations, the mothers felt alone or fearful of what to engage with. This was due to their feelings of grief and loss being so intense. Adding in the need to become pregnant as soon as possible, which carried its own pressures, meant that there was little space for the mothers to fully engage with processing the complexity of their loss.

Not all of the mothers felt the need to engage in any external therapy as they were given strong support from friends and family. Some praised work as a distraction and a practical support method, where they enjoyed being back and distracted by other tasks. However, some described their colleagues as either being too helpful, or creating an awkward working environment. This again highlights the taboo feelings towards stillbirth that still occur, and is not conducive to a mothers' supportive environment. There are various areas in which support could be improved or accessed more readily; however, there is evidence, as described by the mothers, where interventions are accessed that subsequently brings about the opportunity for positive support to be experienced.

Some mothers commented that, once you have experienced stillbirth, you want to warn everyone. But the conversation is not readily engaged with, and the mothers even noted that people who were aware of their stillbirth would cross the street to avoid them, and other pregnant friends actively kept a physical and emotional distance.

The desire for another baby after the stillbirth is quick and was found across all the mothers interviewed and will be discussed as part of the analysis. As acknowledged above, this was not the initial focus of the study, yet all mothers were highly expressive in how the lack of support after their stillbirth led to their subsequent pregnancy, leaving them with high levels of anxiety and even withholding emotion towards the foetus. In addition to this, the mothers often noted actions that allowed them to talk about their baby when appropriate for them and have someone who just listened to them. Having space to express their grief was lacking for all interviewed mothers, and not having a guide on how to do this was difficult to deal with, highlighting the need for support to be more easily accessible.

Chapter 4: Discussion and Conclusion

4.1 Overview of Chapter

This research project aimed to understand support received by mothers following stillbirth from the perspective of their subjective experience. The findings were divided into themes highlighting the various avenues they had to explore in order to find support, as identified by the mothers themselves, and detailing their experience of engaging in these features. Subsequently, this chapter considers the key findings concerning the project's aims and the central research question, with links to existing literature. Coming from a critical realist epistemological position, the connections made to the literature are tentative and attempt to make sense of the mothers' experiences and develop the sharing of knowledge of the field. Following this discussion of the key findings, the chapter then considers the implications, recommendations and limitations of this study and its findings.

This study explored women's support experiences following stillbirth, including what hindered or facilitated support and what made them feel supported or unsupported. Overall, the findings are consistent with previous research, which suggests that there is a split between the experience of silence surrounding stillbirth and the fact that support from friends and family as well as other opportunities is often lacking both in its availability (Mills, Ricklesford, Heazell, Cooke, & Lavender, 2016) and appropriateness (Peters et al. 2014). There were a number of themes demonstrating the various places mothers had to explore. Additionally, themes reflected the complex nature of interactions that took place. Adequate and appropriate support was rare, but it had a profound emotional impact when it was available.

One of the important components of this study's findings is the subjective experience that each mother brought, and how it has been able to bring to life what the timeline a mother generally goes through means to them. Specifically in relation to the four themes discussed in the previous chapter, many of the disclosures by the mothers are reflected in the literature, which can be understood as confirmation of how these mothers experience support. On the other hand, the particularly valuable findings of this study relate to the unforeseen inclusion of how pregnancy after stillbirth requires a differing type of support to that which a mother may need immediately after a stillbirth. This had not previously been explored in research relating to stillbirth, as they are generally kept as separate entities; therefore, its inclusion stands as the unique contribution of this project. To understand the significance of the mothers' experiences, we must also understand how the support search is conducted and what options exist for mothers. The psychological effects of stillbirth mean that searching and knowing where to find support outside of the hospital is a minefield that can be dependent on postcodes and locations across the country. When evaluating and exploring the key findings of this study, I refer back to the research question and existing literature to locate mothers' experiences within the shared knowledge in the field. The research question is: following stillbirth, what is a mother's experience of support?

4.2 Discussion of Findings

This study explored women's experiences of support following stillbirth, including what hindered or facilitated the finding or accessibility of support as well as what made them feel supported or unsupported. Overall, the findings are consistent with previous research, which suggests a great need for support following stillbirth due to the emotional overwhelm and stress that some women experience (Burden et al. 2016). It was also found that navigating different options on their own was a stressor in itself (Peters et al. 2014). There were several themes regarding availability and guidance around where to find support. Adequate and appropriate support was rare in most cases, but it had a profound emotional impact when it was available. Additionally, themes around support when women are pregnant with a baby following their stillbirth were a prominent theme, and there is some research, but it is still uncommon in terms of addressing how support and mental health can be actioned.

Domain 1: The Need for Connection with My…

The first domain accounts for the mothers' requiring connection. They described the feeling of connection that could be found through various people who were immediately close to them, including family, friends and midwives. The mothers all shared their own experience of this type of support, and it was found that there was a mixture of experiences.

Firstly, the mothers' support accounts coincide with the various theories of grief and loss explored in the literature review. The 'loss of the assumptive world' can be seen metaphorically as the first phase, when support is required by mothers. Beder (2005) details that the loss of the assumptive world means that the natural order of things – in this case, that the baby will be born healthy and well – is what the mothers who were interviewed all referenced as the expected result. The mothers interviewed were able to share that they were not aware in most cases that stillbirth could happen and that it came as such a shock; even when they had noticed changes to their babies' movements, they still held hope all would be well. The mothers all shared their experiences of how the news was broken or when they knew that something was wrong. When they realised their baby had died, their world was changed and the assumptive world was lost.

People experiencing dual process experience moments of wanting normality. In this study's case, the mothers experienced moments of wanting to do 'normal' things they did before their baby died, such as going back to work or laughing with friends. The mothers explained the processing of the loss, which can be seen via the theory of 'dual process'. It has been noted by Stroebe and Schut (1999) that this can be seen as odd, and some of the mothers commented that others around them thought it was strange; they were back at work so early, for example. Some mothers explained that they found that there were points after their stillbirth where they needed to move away from it and be 'normal'.

An area of research that has been looked into more commonly is memory-making by the parents with their baby. This is also seen in the 'continuing bonds' theory, where parents are encouraged to spend time with their baby as a general practice. But for some mums this was too much to bear, and they could not make the memories with their baby. More research would be helpful as a great deal of research focuses on the benefits but there is little research available in which the mother doesn't hold her baby. Having a psychological view on this would aid understanding of the continuing bond theory within stillbirth. The lack of connection that some mothers can make with their babies, or just the experience of having a stillborn child, has been known to compound and result in PTSD or PND, as seen in Chung and Reed (2017). This was evidenced in the interviews within this study and can also be seen in research by Murphy et al. (2014), which can in some cases be felt five years after the stillbirth. The mothers all wanted guidance or support during the early stages, and they felt they were left to find support themselves, which, in some cases, did not happen. Daniels, Arden-Close and Mayers (2020) found that fathers reported witnessing their partner's traumatic birth. They felt this affected their mental health in the time following the stillbirth. However, there is no nationally recognised support for fathers to use to help them to come to terms with their experiences.

A number of the mothers shared that they felt the pang of grief but were unable to honestly share their loss with others due to stigma, as noted in Betz and Thorngren (2006). They shared their need to find a 'community' through groups and social media, which allowed some to forge relationships while others hovered on the periphery, as being with others was too much to hold. Some interviewed mothers described their desire to share the loss with others while others found it more difficult to do so. Research also attests that because not all family or friends were able to meet the baby, there is a disconnect in social norms in which the ability to share loss and grief with everyone is taken away, as seen in disenfranchised grief theory. Some mothers described a conscious choice not to talk about their baby with certain people because of the lack of empathy and understanding of the loss. Peters, Riitano, Lisy, Jordan and Aromataris (2016) also cite that the stigma around stillbirth is still present in society and say that the need for both the public and clinicians to have awareness in psychological terms needs development.

Some experienced incredible support and were given the time and space to manage their grief and feelings of loss. Some of the interviewed mothers gave accounts of their friends and family stepping in with practical support, like being given food or having people check in on them without being overbearing. In contrast, some mothers experienced a lack of knowledge from various places about how to support them after stillbirth. The consensus regarding practitioners was that there was a split between experiences, from great support to very little support. In some instances, most support could be sourced from charities; however, charities don’t always offer professional mental health support, which is one thing that most mothers consistently noted as a source of support. The mothers explained that there is information from charities such as Tommy’s and Sands, but there is not a great deal of direction in forming a connection with the right person who can ultimately help them make sense of their loss. The need for connection with the people closest to them was a great support, and when it is made available, the evidence highlights a reduction in anxiety and depression, which is consistent with the work of Cacciatore, Schnebly and Froen (2009), Horesh et al. (2018) and Kersting and Wagner (2012). Those studies similarly found a great need for community and closely monitored support following stillbirth or ‘perinatal loss’ due to the predictors of complicated grief potentially being present. Some mothers explained that connecting with the midwives who helped birth their babies was also very important. Some found the need to keep in touch with the midwives after leaving the hospital but realised that they could not be there all the time. Some mothers spoke of having a clear direction on what to do from the midwife; it helped them immensely with seeking support. The support and connection between some mothers was very positive, and the relationships grew more substantial from the loss and brought them together. This was through the shared experience of loss and the love they had for their babies.

Sometimes, however, a relationship needs a lot of work to help manage the amount of grief that is experienced. Connecting was not always easy for all the mothers, and external support was required. Finding this support to sustain the relationship was difficult at times, and having a more precise direction for managing the grief and relationship was needed. Having family around was not always ideal, as the grandparents of the stillborn baby will also be experiencing grief, and it was explained by one of the mothers that she was unable to have quiet for her grief because she minded her parents’ emotions before her own, which is also expressed in Swart (2020). There were also those whose experience was not ideal, and they were left to navigate their loss without much connection to other people, instead relying on themselves or their relationship with their partner. As documented in Ünstündag-Budak (2015), parents had not counted on the family because they were unsure how to acknowledge the baby being born. Some mothers expressed that this lack of acknowledgement or connection to their baby by their family or friends was very unsupportive and hurt them deeply. A couple of the mothers expressed their friends' poor treatment, and there is not much research around this specific topic pertaining to stillbirth, but in broader grief literature, this is not uncommon. However, when found among grief of a stillborn baby, the feelings of loss of a friendship can affect mothers more (Tommy's, 2018). Some mothers shared that the connection between themselves and the initial midwife was not great, and she felt uncomfortable on top of the feelings she had while in labour. There is broad research around having a proper connection with your midwife when it comes to labour in general, but nothing when it comes to stillbirth and birth. Ellis et al. (2016) conducted a systematic review to understand and improve care after stillbirth, including some accounts from midwives who help mothers give birth to stillborn babies, but further investigation needs to be done into how the two parties can communicate.

Domain 2: A System of Support – Is It There?

This domain covered various aspects of what finding help or seeking support after experiencing stillbirth could look like. The previous domain considered the various processes in finding connection and how mothers went about searching for this but this domain is different as there is a process of 'help-seeking', which in this study is in the form of information and whether it was accessible or not. Bembenutty and Karabenick (1998) studied students and how they managed help-seeking in academia, but the same premise also works here. Their findings associated help-seeking as a form of self-regulation and proactive strategy that prepares people for managing change or diversion in life. Nelson-Le Gall and Resnick (1998) viewed help-seeking as an essential tactic in which people cope by staying actively involved with a task. The process of seeking help may sound simple, and in certain times it is. However, when there is grief during that time, it can, in reality, be challenging, as it is an active process for (in this study's case) the mother and is influenced by several individuals and environmental factors, including peer and family connections, access to facilities and their ability to manage the loss in a way that will allow them to engage with the support, when encountered. Wenzel (2016) found that people who have suffered pregnancy loss may not always seek help due to feeling inhibited by shame, narcissistic injury to the sense of self and identity, fear that needing help is a sign of inadequacy or that they are not grieving 'correctly'. They also experience their losses at different points, making it difficult for researchers to recognise patterns in their needs and to design and test practical interventions.

After the mothers had been discharged from the hospital and had said goodbye to their baby, they were all given leaflets on managing the time after leaving the hospital. Leaflets played a considerable part in the experience of all the mothers, but there is very little research on how best to manage these moments. The mothers shared that some relished this and took in every bit of information given to them, while others could not look at the leaflets and could not recall anything featured in them, which is also highlighted in Warland et al. (2011). The information shared at this point was mixed, with some wanting all the information and support to feel prepared and ready to manage this phase of grief. Some mothers needed a kind of timeline that would give them broad points to look out for or aim for when it came to managing their grief – leading to a key finding that mothers' needs around receiving written information vary, and that there may be variations of preferences in how information or support is disseminated.

One area within the 'system of support' was continuity of care. Several mothers shared the difficulty of recounting their stories to various charities, departments, therapists and other outlets. The mothers shared that their midwife had told them how to manage these situations and pick and choose when to share the baby's memory to manage anxiety. The anxiety that mothers have during these moments has received little attention in research. However, evidence highlights mothers' emotional reactions after the first six months to a year and even beyond, evidenced in Forrest et al. (1982). Boss and Yeats (2014) document that the need for stability is helpful to mothers and wider families so that there is a place where understanding of the experience of grief for their child can be held. Continuity of care was particularly desired within GP practices and among midwives and doctors when the women gave birth again. Even with the community of midwives, the mothers reported different people treating them, which heightened their anxiety. Sometimes medical professionals congratulated the mother on the baby being born without knowing or reading the notes that her baby had, in fact, died. Continuity of care in this area is developing and will be covered in a later section where the most current practices will be demonstrated.

Many interviewed mothers, unfortunately, shared their stories of having no emotional or sometimes even no practical support. There was a need to be guided into being supported and offered a service, but it was a very varied process in these women's cases. One mother had a stillbirth, and when she was pregnant again, she was diagnosed with cancer. She was offered counselling to discuss her cancer quickly, but she talked about her stillborn baby when she was supported by the cancer charity. Another mother was supported by a local charity that specialised in baby loss and provided counselling for free, which helped her with her grief. Some studies, including Ünstündag-Budak (2015), Betz and Thorngren (2006) and Bosticco and Thompson (2005), were featured in the literature review, highlighting the need for immediate support following stillbirth in mental health, but there is little provision outside of specific charity offerings or private therapists. Some perinatal services admit mothers whose baby has died, but this is not always common. However, it was found in this study that some mothers don't want immediate support; they find it very hard to process and prefer to be left alone, and that is for them to choose.

Very few mothers were guided into psychological support, even though there is growing evidence of a great need. Nevertheless, having a clear support channel was, in one mother's opinion, an 'excellent option for mothers' who found themselves in a situation where direction would be in most cases 'gratefully received'. The need for someone to talk to about their loss was consistent across all mothers interviewed. However, a couple of them were scared to open the proverbial Pandora's box, and it was not until they had their subsequent child that they considered talking to someone, which was also found in Lazarides et al. (2021).

Some mothers did struggle after their baby had died. Even in the immediate aftermath, interviewed mothers found that they needed a great deal of support due to their grief turning into deep anxiety and depression. It got to a point for some of the mothers that they were diagnosed with PTSD or PND. This is not uncommon, and has been documented in research (Anna, 2020; Burden et al. 2016; Crawley, Lomax, & Ayers, 2013; Navidian, Saravani, & Shakiba, 2017). Some mothers were diagnosed with PND and severe anxiety when their second child was born and were struggling to find help in managing the feelings they were having. There was also regret in these feelings as they did not hold their baby due to the overwhelming fear of giving birth. These feelings are found in the meta-analysis by Burden et al. (2016), who identifies maternal experiences of deep regret surrounding decisions not to hold or spend time with their stillborn baby and suggests that the decision not to hold may be linked to feeling unguided by medical staff and unsure what actions would be deemed 'appropriate' following the birth. Following this experience and their anxiety with their second child, the mothers ended up spending time in a mother and baby unit where they could get the support they needed, including medication. The mothers also detailed that if they had the continuous support of the GP and community midwives in the first instance, there was hope that they would not have ended up as 'poorly' as they did. There was another mother who sought support for mental health soon after her stillbirth and was diagnosed with PTSD but was able to get the help she needed relatively quickly. The staff saw her and realised that she needed specialist help and she was able to be treated with her subsequent baby, which had triggered her PTSD. Both mothers had to get to the point of needing a great deal of help and support because there were no clear avenues of support they needed. Some studies highlight the need for support following stillbirth because of the high risk of PTSD or PND, which can be demonstrated and evidenced in studies by Cacciatore, De Frain, Jones and Jones (2008), Cacciatore (2013) and Turton et al., (2001).

Domain 3: I Guess I Need to Find Support Myself

The interviews highlighted the difficulty of finding support that is readily available in some cases, and that there was ultimately a need for the mothers to go out themselves to find it. A study by Cacciatore (2014) documented the psychology behind wanting to give to others when in a state of grief, like having a stillbirth. They stated that volunteering in settings where others have a similar bereavement allowed for feelings of acceptance and understanding. In raising awareness, the bereaved may experience agency, increased empathy and a sense of satisfaction that they can challenge people who are not in their ‘club’ to engage with the stillbirth and their loss. The mothers in this study provide further evidence to this point and have found that having a clear direction in supporting others via raising money was a support that parents could hold on to. Some mothers found that giving time and raising money for the charities that had helped them during their moments of grief allowed them to have a sense of purpose, gave their baby a legacy and allowed them to share their baby’s name and make a tangible difference to others who may have felt the same at some point. Baugher (2015) explained that grieving informs the assumption that an individual must ‘resolve’ their own grief before they can effectively and appropriately care for others who are suffering or facing loss too. According to Worden (2015), resolving grief requires accepting the new reality of the loss, facing the pain of grief, altering their life to be without the loved one, and rearranging the emotion towards the loved one and moving on with one’s life. Worden explains a critical point to note, in that a person who has experienced the loss can go on to care for others. Accepting the reality of the loss and having an openness to experiencing the pain of their grief is a demonstration of the dual-process model by Stroebe and Schut (1999), which, in this study’s case, evidenced how when a mother processed the emotions of their loss, their future pregnancy was more manageable. Comparably, those who felt unable to access, and at times repressed, their emotions found that there was a disruption to their ability to read social cues and compromised the ability to respond to the needs of others effectively as well as their own needs at times.

During the interviews, there was the contention of who should provide the support, but, be it the NHS or the mothers being given guidance, they ultimately have to find it themselves. In most of the interviews, the missing thing for most mothers was that of simple 1:1 support. Some mothers were lucky to have this offered to them privately, while others had access to local charities and groups who could provide opportunities for them to vent. Others went private for their support, and as it was with someone who was learned in baby loss and perinatal psychology, they could hold the space for the mother. This particular mother explained that having the freedom to go and talk was so helpful in managing her grief that she learned about her grief and how she could control her emotions when she was pregnant again.

Having the opportunity to talk to other mothers who have been in a similar situation can be either helpful or overwhelming. The theme of group vs 1:1 support was consistent throughout the interviews. Some mothers found significant support within the groups offered by charities like Sands and Tommy's, which can provide space for families to come and share ideas, experiences and the memory of their baby. Some mothers became very involved in their group and felt great pride in helping and managing the groups. They shared that it felt like a community and supported them during their initial period of grief and beyond. One element of the group dynamic that a couple of the mothers mentioned was that, when they became pregnant again, they felt unable to attend the groups, which left them outside of appropriate support and unable to find what they needed at that time. It was interesting to hear that some of the mothers thought that certain groups could cater to women who had been pregnant before. They shared that they had the added fear of their subsequent baby dying, which can be seen in a study by Boyle, Horey, Middleton and Flenady (2020), who noted that practical support needs to include a 'flexible menu of support offerings' (p. 109) that recognises a continuum of support needs, and that this should be made available to all parents; they also noted the importance of collaboration between the hospital community and families. Little evidence exists to indicate who is most likely to benefit from different types of psychological support, and not all parents will require formal interventions. Some parents may find the support they need in their existing networks, while others may benefit from specific supportive interventions or a combination of supports that will meet their needs at different times.

Parent support groups and the support of those who have had similar experiences may be helpful for many parents, which was well documented in Hunt (2020). One mother detailed her experience of using a local community charity that worked with women who had experienced various forms of loss, including stillbirth. The mother was told about the charity, and a few days after leaving the hospital, she went to the charity and found support in those early days – some of the best help she could have ever imagined. This is also documented in Mills (2015), who highlights that this type of loss may not follow the traditional types of grief and that there may be an immediate need to have a space, but then there may be a break, and then they might come back for further support.

Some mothers felt that there should be a service or provision for mental health support for all mothers, which is currently not available or widely accessible Huberty et al. (2017), aimed to identify and evaluate intervention studies that focus on outcomes from women who have experienced stillbirth and aimed to provide specific recommendations for future research and intervention work. They ultimately found that intervention research is deficient in women after stillbirth. The authors note that it is crucial to advance and implement interventions to improve mental health, especially in the ‘interconception period’ (i.e., stillbirth aftercare). They go on to recommend that further intervention research is needed to understand what appropriate support and effective delivery of support interventions are required – mainly focusing on the feasibility and effectiveness of various approaches, the timing and duration of interventions, and making sure that they are culturally sensitive and appropriate for racial/ethnic minority women experiencing stillbirth. There is also a small amount of research where the impact of societal racism and social inequalities can play a large part in why stillbirth occurs and how support is needed to be tailored to different communities to get the best support possible. Each mother had their own experience of support but having a small community-based group that can support mothers in the early stages of their grief was great support for one mother who felt supported by women who lived in her area and were of a similar cultural background to her. Research into COVID-19 is still new at the time of writing, but a study by Fernandez Turienzo et al. (2021) found that lockdowns and having communities supporting each other was a way in which marginalised communities can get the help they need. Kingdon et al. (2019) also conclude and echo other studies that there is a scarcity of UK research looking at inequality and stillbirth and how support is supplied.

Social media was described as a great help to mothers who felt alone and were looking to share their story or who wanted to be in a more voyeur position and view others on various pages sharing their story, which helped them not feel alone. It was not always a great help as some mothers pointed out that holding space for their grief was hard enough but hearing and seeing other people’s feelings of loss and the anger in the forums was sometimes too much to bear, and they had to withdraw. There is little study on how the various social media pages aid or hinder mothers who have experienced stillbirth, but from the interviews, it came down to the person and how they felt towards social media and how much they engaged with it. Some found it a place of information sharing and telling others about their baby to make sure people knew about them, while others were not keen to do that. The leading charities have pages, and a study by Maiorescu (2015) looked at how charities’ social media pages could make themselves more supportive, and ultimately found that there is a need for intimacy among the online community, which would lead to more disclosure and strengthening of the relationship among users.

Another area that came from the interviews was that of support from work. This area has not been significantly researched and could help develop understanding from a workplace point of view. One study by Obst et al. (2020) was based in Australia and came from the dads' point of view about how work helped them get through the initial grief period. There was little on this topic from a mother's point of view, which would be helpful. The mothers who were interviewed did talk about work and how, in its way, work was valuable. Some had positive experiences with employers who gave them maternity leave, and they were able to spend that time physically and emotionally recovering. They also explicitly mentioned that this was a great help, because not having to worry about money during that time helped them recover. It was a great support, as noted in Hazell et al. (2016), where the parents' experiences of the direct, indirect and intangible costs of stillbirth in high-income countries were explored; one participant was quoted to say, 'It's difficult as I had already purchased all the baby items and then had additional tests to pay for. I wouldn't have minded [the tests] if my child lived but having to pay for them after he died was difficult, and a constant reminder as the bills kept coming' (p. 607). Others found work supportive in that they returned to work very quickly and could use their jobs as a distraction, and they threw themselves back into work and managed their grief. In a study by Ogwulu, Jackson, Heazell and Roberts (2015), their synthesis showed that men returned to work earlier than women, with all fathers returning to work and most mothers on either full- or part-time leave by the third month after a stillbirth. Some mothers from this study acknowledged that they were potentially using work as a coping mechanism but really should have taken more time to manage their emotions and sit with their grief, but ultimately became burnt-out in subsequent pregnancy.

Some mothers tried to access counselling through their work as it was an avenue that was open to them but, unfortunately, they were turned down from being offered the support due to being 'too grieved', as it had not been long since their baby had died. In the study by Hazell et al. (2016), it was also acknowledged by a participant that there was a high cost to accessing support, which they could not get through their work, and felt that the financial cost was due to the long-term needs of their grief and subsequent pregnancies. This showed a continued need for accessible support for mothers and fathers following stillbirth.

Domain 4: The Joy and Fear of Pregnancy after Stillbirth

The final domain and themes came from a topic that I was not anticipating. The mothers all spoke of their subsequent birth (nearly within a year of their stillborn child) – also found in Mills (2015) – and reported that there was a great deal of support needed. The mothers' mental health needs in most cases were exacerbated, and they were put under a great deal of stress. This was an interesting point, and due to the commonality across every interviewed mother, it stood to reason that it should have a theme of its own. This is also a point of consideration because it would be interesting to understand what support is needed for those who don't fall pregnant soon after their stillborn. Studies that specifically focused on stillbirth suggested that such women were vulnerable to increased rates of depression, anxiety and PTSD (Wenzel, 2016), primarily if the subsequent pregnancy occurred within one year of the stillbirth. Some studies have recommended that women not conceive again until at least one year after the stillbirth to allow time for grieving the loss and processing the trauma.

In Meaney et al. (2017) and this study, the mothers had a lot to share in the interview about their anxiety in the pregnancy after their stillbirth. The anxiety covered most of the pregnancy as there were fears that history would repeat itself. The mothers all articulated various worries, including the inability to fully connect with their pregnancy due to the not fully dealt with grief and loss. Côté-Arsenault (2007) used the Lazarus cognitive model of stress (Lazarus & Folkman, 1984) to examine other cognitive processes during subsequent pregnancy and found that perceived threat and threat appraisal were associated with the intensity of pregnancy-related anxiety i.e., the perception that the new pregnancy in the context of the previous loss represented a threat to the judgement of one's ability to cope with it.

An interesting phenomenon from this study was that all the mothers noted the need to get pregnant again right away. This was a point that I had not expected to be as prevalent in the research due to my assumption that getting pregnant again for these mothers would not be the priority. Some mothers had conceived their baby who was stillborn via IVF and became pregnant again; they had one more embryo to use to try pregnancy again for potentially the last time. During the interviews, they shared that there was a great deal of hope and no emotion due to the desire for a child being so great. Other mothers shared in their interviews that they spent the weeks and months after their stillbirth counting the days until their period came back so that they could begin trying to become pregnant again. These varied experiences were also discussed by Mills (2015), who explored the provision of care in pregnancy after a woman has had a stillbirth. The mothers in this current study shared various stories of an 'intense desire to become pregnant', which becomes enmeshed with the grief and loss of their previous pregnancy. The mothers described this period as confusing, anguishing, stressful and constant, which has been known to manifest into PND, anxiety and even PTSD. There hasn't been much literature around this specific period and how they managed the emotional pressures between the stillbirth and the next baby born alive. Some pressure that the mothers noted was that of people asking whether they were pregnant yet. There was also a strain on relationships between the couples and broader circles, i.e. friendships and family, which also took its toll on the mothers.

It is important to note that in the period between their stillbirth and the next child being born alive there were other losses in the form of miscarriage. A couple of the mothers experienced this, and they explained that at this point they felt very alone and unsupported during the whole experience. They thought they had to keep going, and the compounded grief was at times hard to bear. One mother did reach out to their GP and midwife, and due to the small community she lived in, she could be given access to professionals. However, mothers who lived in larger cities and towns where the capacity needs to go further found that they were given the news that they had miscarried and then left to go home. Most mothers who found themselves in this position explained that there was little to no acknowledgement that they'd had a stillbirth previously, which was not supportive. Unfortunately, this approach is common with miscarriages and has been well documented in research and anecdotal studies (Malacrida, 2016) and was experienced by some mothers from this study. They shared the 'numbness' they felt when they encountered a miscarriage soon after their stillbirth, and the care following this was 'non-existent'.

All the interviewed mothers expressed that when they became pregnant again and had a history of stillbirth, they nearly all returned to the hospital where they had given birth to their stillborn. Many of the interviewed mothers expressed that there was 'high anxiety during the subsequent pregnancy and most looked to their consultants and midwives for support and that they would 'ideally' be the same as their previous pregnancy, which most mothers preferred, but in reality it was different people. It was interesting to hear many mothers talk about how their doctors would try and reassure them that they would be fine and that everything would end well. A level of scepticism was felt by the mothers that there was a chance that it could happen again. As there had been no opportunity to manage this anxiety, the opportunity for practical management of their pregnancy was welcomed by most. A study by Graham, Stephens and Heazell (2021) found that women who have had a stillbirth are at a higher risk of giving birth to a small for gestational age (SGA) infant. The Royal College of Obstetricians and Gynaecologists guideline for detecting a SGA foetus recommends that women with a history of stillbirth should have regular ultrasound measurements of the baby. The mothers interviewed in this study shared that they were offered more scans but added that they wanted doctors to be aware that while the ultrasound scans provides an element of comfort for the mother, this feeling of reassurance is short-lived. They also shared that they might be anxious before scans because the in utero foetal death in their previous pregnancy would likely have been confirmed by an ultrasound scan; this was also explained in the study by Graham, et al. (2021). However, even though there was some offering of more scans and monitoring, the mothers noted many occasions where they were denied this facility by administrators and had to go to their doctors and midwives to have the extra scans given. This was not in all cases, but even when they did get their scans, the reassurance was found to be short-lived. Their anxiety was raised once again. The anxiety management throughout the subsequent pregnancy was left to the mothers, and they had to support themselves in most cases emotionally.

As has been loosely explored so far, the mothers experienced limited emotional support. Graham, Stephens and Heazell (2021) also acknowledge the few dedicated clinical services (‘Rainbow Clinics’) who care for women in their subsequent pregnancy following the stillbirth or neonatal death. The clinics use multidisciplinary teams to provide continuity of care. This is also combined with the regular antenatal observation, which is associated with improved clinical outcomes, in particular a reduction in preterm birth and enhanced patient experience. Having such a pathway featured consistently with the additional inclusion of specialised psychology would allow for the planning of a subsequent pregnancy to commence with the investigation of the index stillbirth and follow-up at a postnatal appointment, and allow for beginning appropriate treatment early in the subsequent pregnancy and implementation of screening for SGA with involvement of other relevant specialist services (e.g. maternal medicine clinics, foetal medicine units). Robson and Leader (2009) also found that having a birth plan should be developed as pregnancy progresses, addressing the woman’s wishes and those of her family. Even with this clear layout of supporting the mother during her subsequent pregnancy, this plan still focuses solely on the medical procedures that are needed, but if there were to be the inclusion of an acknowledgement of the psychological, it would be a more rounded approach. Silver et al. (2018) has a combined medical and psychological approach, which ultimately is the nuance of perinatal psychology. There is a great mixture of physical change, emotional distress, and life and death being enmeshed into one experience in stillbirth, as evidenced by Crispus Jones, McKenzie-McHarg and Horsch (2015).

Summary of discussion

Overall, there appear to be links between the findings of this study and the existing literature. There needs to be more consistent support available from a psychological perspective to work alongside the medical expertise that exists in services already; the research on treatment is often focused on specific symptoms or disorders rather than on the more substantial psychological effects of pregnancy loss. However, this study does recognise the broader reality of getting psychology into an already strapped national health service, but there is a need, and the long-term effects of not having support made available earlier will ultimately cost more to provide due to the potential demand for inpatient services. The wider conversation around stillbirth continues to grow, but there is still a great deal of opportunity to develop this topic within psychological research. There is a high level of emotional experience following stillbirth and having the broader focus on the ‘ripple effects’ of stillbirth on areas such as community, family and various societal areas.

4.3 Research and Clinical Implications

This study’s findings have theoretical and clinical implications that are important to consider concerning future research. As part of the critical review of this research, I have outlined recommendations and limitations that are important as part of the discussion of the findings.

This research has been able to highlight various areas that can be developed within this topic. The focus of support after stillbirth has promoted various other areas that can be developed further in research. The first is a further exploration in the acknowledgement of support of partners during such a traumatic time of losing their baby and having the life of their wife/partner be in danger. Awareness is becoming more prevalent in this area, but there is still development needed. One study from Australia came from the fathers’ point of view and how work helped them get through the initial grief period. There was little on this topic from a mother’s point of view, which would be helpful. Work plays a role in some people’s lives and having a more robust understanding of how a workplace can support mothers and fathers in terms of leave and offering support would be an interesting occupational psychology study. Further cases in which fathers have found they have PTSD have been documented both in the interviews with the mothers and in investigations by Hambidge, Cowell, Arden-Close and Mayers (2021).

Another point of research development is that of the use of leaflets. Leaflets played a considerable part in the experience of all the mothers in this particular study, and there is very little research on how best to manage these moments. This research could come from a service development point of view and could include the psychology of loss and other forms of support offered in a more localised area. There could be an exploration of the effectiveness of leaflets during the mother’s time in hospital.

A mother shared that her midwife had told her how to manage these situations and pick and choose when to share her baby’s memory. The anxiety that mothers have during these moments has had little attention in research and could be an area for development, particularly by bringing in cultural elements of how memory-making can be interpreted and what the next stage of development can be in terms of how midwives and doctors or potentially psychologists can support mothers in making sense of their loss. Following on from this point, it is important to acknowledge that the women in this study were all in cisgender male and female relationships, which is a limitation to some level; it would be very useful for future studies to develop further understanding of same-sex or LGBTQ+ couples who are using a surrogate or have had IVF and experience a stillbirth. The levels of support would be helpful to explore as there is little known on what these couples require in terms of psychological support.

Another point noted within this study is social media and support after stillbirth. There is little study on how the various social media pages aid or hinder mothers who have experienced stillbirth but, from the interviews, it came down to the person, how they felt towards social media and how much they engaged with it. This current study recruited through social media, and the uptake was strong. Social media could be used to explore a quantitative methodology that would allow for large-scale data to be collected across the UK.

An area in need of significant development is how to indicate who is most likely to benefit from different types of psychological support, as not all parents will require formal interventions at certain times. There are studies linked with other grief-based treatments that show that, when grief becomes ‘complicated grief’, there are interventions available. However, there need to be studies or developments in therapy to acknowledge the baby’s life and death, as well as the loss of the future that the mother had been envisaging. These mothers need to feel held in the first instance and to have a space to explore the pain of their loss. This is what has been expressed from the interviews in this research. On the other hand, it will also be helpful to explore what it means for people not to seek support, and what they experience in terms of grief management.

A small amount of literature details the emotional connection between couples and loss, but the passionate and intimate relationship would make for interesting studies. It would explore how different couples can weather an intense period and come out the other side a strong unit, thanks to their communication.

The research implications from this study have highlighted a swathe of areas where further research could be developed or implemented, as there are areas within the hospital, in the home or in broader society that will aid mothers emotionally or in adjusting to their new standard of life after their loss. As seen from the previous sections, substantial literature confirms that pregnancy loss is a traumatic event with significant psychological results, including depression, complicated grief, anxiety, PTSD, marital problems and the risk of a negative impact on subsequent pregnancies and children. It is striking, therefore, that the literature on how to help such individuals is scant. There is agreement that careful observation and assessment are needed, and that many patients need access to psychological help, as noted in Wenzel (2016), which also needs to be consistent across the UK.

4.4.1 Theoretical Implications

Based on the literature reviewed for this research project, there could be important implications and considerations beyond this study's scope. These considerations relate to fields linked to support after stillbirth that impacts counselling psychology. Some of these subjects include family systems, relationships, life and death, emotional reactions and the various forms they take as anxiety and depression.

I have found the critical realist exploration of the subjective support experience of mothers following stillbirth to be a good fit with thematic analysis due to its ability to offer a broad overview of the standard narrative concerning the research question. Thematic analysis enabled me to explore decision-making experiences across the mothers and gain a more comprehensive overview of the psychological terrain in terms of support following a stillbirth, with specific attention to experience. This allowed me to situate my perspective against the social and political context of decision-making, while also considering the individual experience. My epistemological and methodological approach in this research provides me with a balance between the macro and micro perspectives. On the other hand, as a consequence of my findings and their implications, the psychology field may benefit from gaining further insight into the support experiences of parents from a hermeneutic angle. In this sense, future large-scale quantitative research on the experiences of support may give more insight into the vast experiences from across the country alongside the qualitative approach, which would allow for the individual nuances of the experience as a consequence of societal norms for that individual as identified by my research by having women from across the UK (excluding Wales).

4.4.2 Implications for Clinical Practice

Based on the findings and implications of my research, I would like to make some recommendations for future research, clinical practice, and training. The clinical and research implications of this study capture a broader perspective in comparison to the theoretical ones. To appreciate the possible clinical implications and areas that may benefit from further research inquiry into support following stillbirth, it is essential to understand how clinical practice can aid the emotional wellbeing of mothers who experience it.

Within clinical practice, there are a few areas in which psychology plays a part in supporting mothers following stillbirth. For example, one mother explained in her interview that, when her twins were born, they expressed a need for consideration and support for mothers and families who find themselves in a situation where life and death coexist. In these cases, there is a live baby and there is the opportunity for the mother to seek help through various services, which will aid some mothers to get the support they need compared to those who don't have a live babe in arms. Psychology can be there as support in the form of empathy, to allow for space where grief and its associated feelings can be held.

Several considerations arise as part of the findings of this research, including the development of how perinatal psychology could be implemented as a topic of counselling psychology training, which would educate trainees on the complexities of pregnancy and the first year of a baby's life. As many trainees work across different settings, it would be prudent to have this knowledge in the back of their minds when working across various settings.

4.4.3 Limitations

There is an important limitation to this study that relates to the diversity of the mothers. A predominance of White and Black women featured in this study. There is no inclusion of other cultures or races, which is a significant shortcoming of this study. It is of great importance for future studies to aim for studies focused on the particular cultural or racial experience of support, or to make sure that inclusion is prioritised within the sampling.

Reflecting that most of my sample has been recruited through a support organisation, this could mean there is a bias from those aware of available support. This was something that was held in mind, and, in planning for recruitment, it was necessary to factor this in and make sure that the questions being asked in the interview covered as many other potential sources of support as possible. Another point to speculate is why people did or didn't take part. There are many reasons why people do or don't participate in research studies, but it is helpful to consider potential points, such as low or high confidence levels. Other reasons include not wanting to come forward for support for reasons such as feeling unworthy of support, or that they weren't on social media at the time of publication, and due to the small numbers needed for this study, the advert was not up for very long. Most people in the UK have a smartphone to access social media but some don't, and I could not access this group of people, so it would be helpful to include other media. There is also the point to consider that those people have had a great experience and may not feel they need to talk about it as they are not having to engage with a support charity or have this type of content on their social media. All valuable points to speculate on, but the fact that I have heard about such a mixture of support experiences from people recruited through the study can hopefully show the opportunities.

There was also the limitation of not having any women who didn’t go on to have children. This would have added another theme and another layer to the study, by showing the levels of support that women need when the subsequent pregnancy doesn’t happen. That experience would have been very different to that of women who have other babies, and it would have made the themes diverse and developed the area of study further.

4.4.4 Reflexivity

Reflexivity is a central component of qualitative research that maintains accountability and reliability (Sciarra, 1999). However, if only done to observe the quality standards of qualitative research, Braun and Clarke (2013) note it can become rigid and even flippant. As a trainee counselling psychologist, I aspired to be curious about my relationship to the research as much as possible – without letting it overtake the focus of my project. Some of these reflections were inherent in my approach to the topic throughout this thesis, and others, I will note here.

Though the relevant literature situates this research within the psychology field, support after stillbirth appears to be a discourse spanning several schools of thought and areas of expertise. The wide attention in literature attests to stillbirth as a phenomenon applicable to various medical forms of literature, social science and psychology, with vast axiological reach. My study looks at specific experiences relating to support after stillbirth, a unique perspective of the phenomena that offers insight into one aspect of loss and how mothers experience or do not experience support.

Initially, I was aware of my arrival at my research question being a challenge. I was interested in a mother’s ability to find support in any form and understand how psychology played a part in this process. Additionally, I was also conscious of my interest in this question, which was to keep the parameters of support broad so that the inclusion of not having support could be factored into the study. My understanding of support involves the subjective experiences and realities of the individuals and the contextual influences and external realities their experiences are situated in. I find balance in a critical realist understanding of the world, recognising the internal and the external (Willig, 2012).

Thus, I found my drive to understand the whole experience of stillbirth a primary motivation due to hearing first-hand accounts before starting training and having a keen interest in developing and pursuing this research question. As the interviews progressed, my reflections on my motivation gave way to a more intimate understanding of the mothers’ narratives, which allowed me to understand the subjectivity of what psychology or other support systems are out there, and how they could be utilised in supporting these mothers as well as just understanding their experiences in general. Similarly, I also aim for this project to provide an opportunity for women to share their experiences and have their babies' names immortalised in a thesis that other people will potentially read. By using the babies' names, there was a realness to the study, and it felt that there was great trust within the interviews, and we were able to talk about their experience in a way that felt very open and genuine, which would only aid the process of the study. Consequently, this approach led me to understand that each mother, from different parts of the country, was able to recall different experiences, but as it turns out, their themes are similar, and there is hope from most that there is going to be an improved understanding of the overall variation in support.

While writing up my findings and discussion, I found the process very linear, which felt slightly at odds with how I process information – especially as it explored such a broad topic from subjective experiences. Eventually, I acknowledged the inherent paradox in this, having been influenced by the literature I have been reviewing over the last three years. I noted that my natural process was to separate the procedural findings from the experiential components of the mothers' narratives, possibly forcing a direct fit. By attempting to write about them separately, I assumed that the mothers' subjective experiences would be independent of their experiences. This was based on the fundamental assumption that nothing was available when it turns out there was, but the consistency was not there to support mothers during the various stages of grief wholly and there was a lack of psychology available in the process. After acknowledging this, I found it helpful to draw on the timeline that the mothers naturally detailed in the interviews to consider my process of researching stillbirth support. This allowed me to return to my initial position when setting my research question, that the process and the experience are interconnected, thus must be considered together. Consequently, I used this realisation to attempt to reflect-in-action (Schön, 1983) as I completed the final drafts of this thesis. This also suggests that the writing stage in thematic analysis is inherently a part of the ongoing analysis (Braun & Clarke, 2013), shaping the presentation of the overall research.

4.4 Conclusion

This study aimed to explore the support experiences of mothers from a critical realist position through thematic analysis to gain an overview of individual experiences against the contextual backdrop of psychological theory. The findings show that, even though there is an element of support available to mothers, it is predominantly given by charities who have limited ability to offer counselling or psychology to aid mothers and fathers in managing their grief. Available literature often misses this dynamic, creating a gap between theory and practice. The findings suggest that having a place for mothers to form a connection soon after their birth is positive support, and that can be with their intimate circle of friends and family or with the medical team to help them during birth. The exploration process to find support themselves was difficult for most and the guidance that mothers need is not consistent across the UK, although new initiatives like the Bereavement Care Pathway can be evaluated and aim to improve this. However, the empirical literature highlighting the benefits of having support and how psychology can be implemented in this process is still in its early days. The mothers had all been able to find ways to support themselves, but it wasn’t until their subsequent pregnancies that their mental health was given priority due to them having a babe in arms, which means there is more opportunity for support. However, mental health support, specifically focusing on birth after loss, is still not widely available. Social media is aiding this drive, but empirical evidence for this unique experience has a long way to go to become accessible. The various considerations for support are experienced as challenging, multifaceted, anxiety-provoking and arduous, but also rewarding when support is found. This is the human aspect of the mother as an individual who also exists within a context that may help or hinder decision-making. Some recommendations are drawn from recommendations of other studies, where there is a lack of diversity in what support is available and what modality would work well with this presentation. These recommendations call attention to the ongoing mental health challenges that women experience after they have had a stillborn baby and to the fact that, even though it takes a village to raise a child, it also takes a robust support system to bring the mother back to a liveable reality.

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Appendices

Ethics ETH1920-0631: Mrs Charlotte Squires (Medium risk)

Date Created : 13 Nov 2019

Date Submitted : 24 Dec 2019

Date of last resubmission : 13 Feb 2020

Date forwarded to committee : 22 Jan 2020

Date of committee meeting : 05 Feb 2020

Academic Staff : Mrs Charlotte Squires

Student ID: [redacted]

Category: Doctoral Researcher

Supervisor Dr Aylish O'Driscoll

Project: An Exploration of Mother's Experiences of Support following their Baby Being Stillborn.

School : School of Arts and Social Sciences

Department : Psychology

Current status: Approved after amendments made

Ethics application

Risks

R1) Does the project have funding?

No

R2) Does the project involve human participants?

Yes

R3) Will the researcher be located outside of the UK during the conduct of the research?

No

R4) Will any part of the project be carried out under the auspices of an external organisation,

involve collaboration between institutions, or involve data collection at an external organisation?

No

R5) Does your project involve access to, or use of, material that could be classified as

security sensitive?

No

R6) Does the project involve the use of live animals?

No

R7) Does the project involve the use of animal tissue?

No

R8) Does the project involve accessing obscene materials?

No

R9) Does the project involve access to confidential business data (e.g. commercially sensitive data, trade secrets, minutes of internal meetings)?

No

R10) Does the project involve access to personal data (e.g. personnel or student records) not in the public domain?

No

R11) Does the project involve deviation from standard or routine clinical practice, outside of current guidelines?

No

R12) Will the project involve the potential for adverse impact on employment, social or financial standing?

No

R13) Will the project involve the potential for psychological distress, anxiety, humiliation or pain greater than that of normal life for the participant?

No

R15) Will the project involve research into illegal or criminal activity where there is a risk that the researcher will be placed in physical danger or in legal jeopardy?

No

R16) Will the project specifically recruit individuals who may be involved in illegal or criminal activity?

No

R17) Will the project involve engaging individuals who may be involved in terrorism, radicalisation, extremism or violent activity and other activity that falls within the Counter- Terrorism and Security Act (2015)?

No

Applicant & research team

T1) Principal Applicant

Name

Mrs Charlotte Squires

Provide a summary of the researcher's training and experience that is relevant to this research project.

The lead researcher will be conducting the interviews with participants who have met the criteria of participation. The high standards of City, University of London are evident during the various placements where the necessary skills to supply high-quality therapeutic skills are demonstrated and through academic assessment. Before joining the course, previous work and life experience highlighted positive regard for others in an empathetic and caring way.

The lead researcher has also been compiling experience through various training given by baby loss charity Simba who is based in Scotland; Child Bereavement UK entitled 'supporting parents through pregnancy loss and the death of a baby', which the Royal College of Midwives accredits; as well as online training supplied by the NHS. All these pieces of training covered the areas of exploring and developing self-awareness concerning loss, grief and bereavement, and being able to recognise physical and emotional reactions to grief and understand what mothers may need when faced with their baby's death.

Before this training, the researcher has various experiences of meeting clients in several locations through work and volunteer roles. These included buddy systems and making sure that safety and professionalism was always the focus.

T2) Co-Applicant(s) at City

T3) External Co-Applicant(s)

T4) Supervisor(s)

Dr Aylish O'Driscoll

T5) Do any of the investigators have direct personal involvement in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

No

T6) Will any of the investigators receive any personal benefits or incentives, including payment above normal salary, from undertaking the research or from the results of the research above those normally associated with scholarly activity?

No

T7) List anyone else involved in the project.

Project Details

P1) Project title

Experiences of Support Following Stillbirth for Mothers in the UK using a Thematic Analysis Approach.

P1.1) Short project title

P2) Provide a lay summary of the background and aims of the research, including the research questions (max 400 words).

Counselling psychologists cover broad areas of services, which means their potential clients could have experienced stillbirth themselves or may know someone who has.

This study will be focusing purely on the experiences of mothers who have had a stillborn baby over two years ago in the UK. This focus is because women who have suffered stillbirth are more likely to have anxiety and depression afterwards. This can be evidenced in a US study by Hogue et al. (2015) that of 800 who had a stillbirth were two times more likely to have depression compared to those how had live births. This effect increased when they have studied again two years later, showing that stillbirth has a long-term impact on mental health. Another study (Gold, Leon, Boggs and Sen, 2016) of 609 women who had experienced a stillbirth found that women with loss were four times more likely to have depression and seven times more likely to have post-traumatic stress disorder.

As the above studies have evidenced, stillbirth is a distressing experience that can result in high psychological symptoms, including anxiety, depression, distress, and negative well-being.

Symptoms appear to be peak in the first few months post-loss, although evidence suggests that symptoms may persist up to three years for some. Social support was identified to be beneficial for women post-loss.

This study aims to improve the awareness of what support is required to mothers following stillbirth experience using interviews and thematic analysis. The study also aims to provide a full account of the participants interviewed through inductive, bottom-up analysis of individuals responses.

The specific objectives include:

- It is recognising barriers or facilitators that could hinder mothers from accessing support after stillbirth.
- Exploring what opportunities there are in seeking support after stillbirth.
- The primary outcome is to increase awareness of the potential limiting or positive experiences of support after stillbirth. The secondary outcome is to have counselling psychologists review this research and become more knowledgeable of how to support clients who have experienced stillbirth; by noting the pathways their clients have been through and the best lines of therapy to take.
- Current research within this area from a counselling psychology perspective shows a need for this specific topic to be investigated.
- The following question will be explored: What are mothers' experiences of support in the UK following stillbirth?

P4) Provide a summary and brief explanation of the research design, method, and data analysis.

The study will employ cross-sectional research and a small sample design incorporating a qualitative methodology. Data will be collected through semi-structured interviews (Newcomer, Hatry, & Wholey, 2015). The research is hoping to have a heterogeneous sample to capture a range of experiences. The study is looking to recruit a minimum number of ten participants. The target population for this study are individuals living in the UK who have experienced stillbirth. Interviews will be held in the participant's homes to have a comfortable space for the interview to take place. If this should not be suitable, then an alternative location, e.g. a local library or community centre, will be sought depending on the geographical location. Due to these locations being in the public domain, the research will make sure that a private room is used so that confidentiality can be upheld.

The initial contact with all participants will be via email to exchange introductions, and a copy of the information sheet will be included to introduce the study. A pre-interview phone call to make sure that the participants are not potentially triggered and so the researcher can gauge if the potential participant is meeting the inclusion and exclusion criteria of the research and the participation procedure. If both parties are happy to proceed, the participant will be formally recruited and follow up conversations will be had to organise logistics for the interviews. On the interview day, the participant will be given two copies of the consent form to sign. The researcher will retain one and the other by the participant, a demographic questionnaire, and a debrief sheet of support networks with contacts for the participant should they feel they need it.

Thematic analysis will be employed to explore the comprehensive descriptions and personal accounts of the experience. Braun, Clarke, Hayfield, and Terry (2018) highlight that thematic analysis may provide a rich and detailed yet multifaceted account of data, which is the aim of this research.

P4.1) If relevant, please upload your research protocol.

P5) What do you consider are the ethical issues associated with conducting this research and how do you propose to address them?

When researching bereaved mothers, there are numerous ethical considerations because of the possible vulnerability due to their baby dying. However, research suggests that bereaved individuals value bereavement research and even appreciate the opportunity to participate in it. Many women welcome the chance to give their views about their experience in confidence, knowing that this information may be used to help improve stillbirth awareness. However, it is understood that thinking about taking part in this study may be upsetting for them or raise other issues or concerns about their care. Participants will receive information about organisations they may like to contact for support.

Informed consent will be attained from participants before the interviews. Participants will have a phone call with the researcher to discuss the study overall and allow the researcher to screen whether the participant will be suitable for the study. However, it will be confirmed that the participant meets the inclusion/exclusion criteria.

So, the study will allow for the potential of participants becoming distressed during the interview. All participants will be made aware of their right to stop the interview altogether or to have a break from the interview and resume when they feel able to do so. The researcher is a Trainee Counselling Psychologist with experience in responding to people in distress and knowledge of safeguarding issues.

Participation and the right to withdraw is highlighted in the information sheet and the consent form.

Participation in this research is voluntary and at the participant’s discretion, and confidentiality will be maintained. All research data will be treated confidentially. All interview recordings, transcripts and notes will be kept in a secure location in the form of a hard copy and a secure encrypted online drive (OneDrive) which the university provides with access, permitted only to the researcher. There will be pseudonyms given to each participant so that confidentiality is upheld.

Participants will be informed through the information sheet that the thesis will be available to them if they consent to hold their details until the final version is completed. No names or identifiable characteristics will be used in any future publications.

As this topic can be deemed emotionally distressing and the researcher will be embedded in the research for a long time, supportive supervision and breaks is vital. There will be contact with the researcher supervisor during the whole process, and personal therapy will be in action at this time too.

P6) Project start date

The start date will be the date of approval.

P7) Anticipated project end date

01 Oct 2021

P8) Where will the research take place?

Due to the research being open to participants across the United Kingdom, the researcher will need to travel to the participant's local area or they can go to London. These options mean that there will be a choice for the participant so they can feel as comfortable as possible during the interviews:-

1) The participant's home or a mutually agreed upon location in the community, e.g. community centre or local library. NB: due to these locations being in the public domain, the research will make sure that there is the use of a private room so that confidentiality can be upheld

2) The City, University of London campus (private room, booked in advance).

As this study is open to people across the UK, the researcher is attempting to make it as inclusive as possible by providing two options for interviews. If the participant would prefer the interview to be at their home, the researcher will adhere to City, University of London's lone working policy and take the appropriate steps to ensure the safety of both the participant and herself.

P10) Is this application or any part of this research project being submitted to another ethics committee, or has it previously been submitted to an ethics committee?

No

Human participants: information and participation

The options for the following question are one or more of: 'Under 18'; 'Adults at risk'; 'Individuals aged 16 and over potentially without the capacity to consent'; 'None of the above'.

H1) Will persons from any of the following groups be participating in the project?

None of the above

H2) How many participants will be recruited?

10

H3) Explain how the sample size has been determined.

Studies using thematic analysis tend to be small because of the commitment to a detailed and in-depth account of the interview content (Braun and Clarke, 2006). However, a small sample is expected to be standardised so that recruited individuals belong to a carefully defined group and feel that the research question carries a personal meaning for them. The current study plans for a minimum of ten participants to be interviewed so that there is enough data to form a picture of support.

H4) What is the age group of the participants?

Lower Upper

20

H5) Please specify inclusion and exclusion criteria.

To ensure the homogeneity of the sample using the following inclusion/exclusion criteria will be followed when recruiting participants:

1) The exploration of gender is beyond the focus of this study, only mothers will be recruited.

2) Only women that experienced a stillbirth (as defined by the NHS – a stillbirth is when a baby is born dead after 24 weeks pregnancy) of their baby will be included in the present research project. Therefore, for the nature of this specific study the inclusion of miscarriage (a miscarriage is the loss of a baby before 24 weeks (NHS, 2020).

3) No age restrictions are to be applied to the upper age limit since there is no evidence to suggest that age is a factor affecting the process of finding meaning and growing after a perinatal loss. However, a minimum age of 20 years old has been applied due to the participants potentially being younger than 18 years old at the time of their stillbirth. Being under 18 years old will mean a different type of support to that over 18 years.

4) The same principle was followed to include women from any socioeconomic, ethnic, religious, or educational background. Specifically, age and religious views and ethnic background will be included in the demographics questionnaire to assist the researcher in an accurate description of the sample.

5) Pre-birth factors and other maternal characteristics such as the method of conception (natural or IVF), relationship with the father of the baby, or medical history, are not considered as inclusion criteria.

6) Whether the mother has had therapy during the bereavement period has not been considered as an inclusion criterion because individuals can be helped to process their grief and find meaning in their child's death by their own strengths and support networks.

7) This is because the interviews could interfere with any current treatment. During the initial phone call with a participant the question 'are you currently in therapy or seeking treatment for a mental health condition' will be asked. An exclusion criterion will be if participants are currently having treatment for a severe mental health condition such as psychosis or extreme levels of post-natal depression. This will be assessed on an individual basis.

8) Mothers participating in the study will have experienced stillbirth at least two years before the interview and not more than ten years. The researcher preferred to exclude the mothers during the first year of their grieving or around the first anniversary because it is more likely for them to be in an acute grieving phase and not to be fully able to engage in a search for meaning or benefit from their loss.

9) All participants will be considered on an individual basis.

H6) What are the potential risks and burdens for research participants and how will you

minimise them?

So that the participant is as comfortable as possible, choosing the location of the interview will help them feel comfortable and safe within the setting. Being a counselling psychologist, the researcher will utilise her therapeutic skills, such as expressing warmth, communicating empathy, establishing a good rapport, listening actively, summarising and paraphrasing what is said to help the participants feel contained, respected and safe in the context of the interview. Participants would have adequate time before, during, and after the interview to ask further questions or reflect on the interview process.

Should some of the mothers feel upset and cry during the interviews. They will be encouraged to say if they wish to stop the interview and will be offered the opportunity to stop at any time. The researcher will also use her clinical judgment to monitor participants' levels of distress.

A debrief will be given to the participant after the interview has finished. The researcher will check in with the participant and make sure that gratitude is shown. If there are any signs of distress or a need for any grounding exercises, there will be time for this.

Further support will be supplied in the form of a crib-sheet with several national and (if possible) local charities and associations who can offer support should the participant feel they need it.

H7) Will you specifically recruit pregnant women, women in labour, or women who have had a recent stillbirth or miscarriage (within the last 12 months)?

No

H8) Will you directly recruit any staff and/or students at City?

None of the above

H8.1) If you intend to contact staff/students directly for recruitment purpose, please upload a letter of approval from the respective School(s)/Department(s).

H9) How are participants to be identified, approached and recruited, and by whom?

Participants will be recruited via the social media and newsletters of various baby loss charities, including SANDs, Tommy's, SiMBA Charity, Abigail's Footsteps, Beyond Bea, Our Missing Peace, Petals and Aching Arms, and others should contact be made. After ethical approval has been granted from City, University of London, the research proposal will be submitted electronically to each charity so that full clarity of the study can be gained. The email correspondence between the charities and the researcher has been friendly, and the study's details have been well received.

The charities will post the flyer or a specially-designed social media post on their platforms and encourage their subscribers to participate in the study. The researcher's contact details will be on these posts, and the opportunity to get in touch will be made clear.

The initial contact with all participants will be via email to exchange introductions, and a copy of the information sheet will be included to introduce the study. Due to the target population requiring the experience of stillbirth, there will be a pre-interview phone call to make sure that the participants are not potentially triggered and so the researcher can gauge if the potential participant is meeting the inclusion and exclusion criteria of the research and the participation procedure. If both parties are happy to proceed, the participant will be formally recruited and follow up conversations will be had to organise logistics for the interviews.

H10) Please upload your participant information sheets and consent form, or if they are online (e.g. on Qualtrics) paste the link below.

H11) If appropriate, please upload a copy of the advertisement, including recruitment emails, flyers or letter.

H12) Describe the procedure that will be used when seeking and obtaining consent, including when consent will be obtained.

The participant will receive an information sheet before the initial screening phone calls to introduce the study and get a clearer idea of what they are going to be doing within the study. The information sheet will note the need for signed consent, and this will prepare them for the need to sign a consent form. At the phone call, the participant will be informed of the need to sign the consent form to proceed.

The researcher will obtain consent in person when meeting face-to-face with the participant at the interview before any recording has taken place. The participant will be asked to complete a very brief demographic information sheet and the consent form. They will keep a copy of the consent form and support debrief sheet that details available support resources for bereaved mothers and their families. The researcher will retain another copy.

The time between receiving the information about the study and conducting the interview will depend on the availability of the participant and the researcher. Ideally, within 1-2 weeks after initial contact, the interview will be held so that the participant is not left waiting too long to talk about a potentially emotive subject. Should there be a long wait for the interviews to begin, a conversation will be sought between the participant and the researcher to make sure that this is suitable for both parties. There will also be conversations sought between the researcher and their supervisor so guidance can be given in how to proceed.

H13) Are there any pressures that may make it difficult for participants to refuse to take part in the project?

No

H14) Is any part of the research being conducted with participants outside the UK?

No

Human participants: method

The options for the following question are one or more of: 'Invasive procedures (for example medical or surgical)'; 'Intrusive procedures (for example psychological or social)'; 'Potentially harmful procedures of any kind'; 'Drugs, placebos, or other substances administered to participants'; 'None of the above'.

M1) Will any of the following methods be involved in the project:

None of the above

M2) Does the project involve any deceptive research practices?

No

M3) Is there a possibility for over-research of participants?

No

M4) Please upload copies of any questionnaires, topic guides for interviews or focus groups, or equivalent research materials.

M5) Will participants be provided with the findings or outcomes of the project?

Yes

M5.1) Explain how this information will be provided.

The consent form provides an opportunity for the participants to request a copy of the final research report should they select the ‘YES’ box next to the corresponding question.

M6) If the research is intended to benefit the participants, third parties or the local community, please give details.

M7) Are you offering any incentives for participating?

No

M8) Does the research involve clinical trial or clinical intervention testing that does not require Health Research Authority or MHRA approval?

No

M9) Will the project involve the collection of human tissue or other biological samples that does not fall under the Human Tissue Act (2004) that does not require Health Research Authority Research Ethics Service approval?

No

M10) Will the project involve potentially sensitive topics, such as participants’ sexual behaviour, their legal or political behaviour, their experience of violence?

No

M11) Will the project involve activities that may lead to ‘labelling’ either by the researcher (e.g. categorisation) or by the participant (e.g. ‘I’m stupid’, ‘I’m not normal’)?

No

Data

D1) Indicate which of the following you will be using to collect your data.

Questionnaire

Interviews

Audio/digital recording interviewees or events

D2) How will the privacy of the participants be protected?

De-identified samples or data

D3) Will the research involve use of direct quotes?

Yes

D5) Where/how do you intend to store your data?

Data to be kept in a locked filing cabinet

Password protected computer files

Storage on encrypted device (e.g. laptop, hard drive, USB

Storage at other site

D5.1) If stored at another site, please provide details.

The records of transcription, audio recording and any other notes taken will be stored within City,

University's OneDrive system is encrypted.

D6) Will personal data collected be shared with other organisations?

No

D7) Will the data be accessed by people other than the named researcher, supervisors or examiners?

No

D8) Is the data intended or required (e.g. by funding body) to be published for reuse or to be shared as part of longitudinal research or a different/wider research project now or in the future?

No

D10) How long are you intending to keep the research data generated by the study?

Although City guidelines state a minimum of 10 years, it is recommended to keep their data until after graduation. Therefore, research data shall be kept on the encrypted platform for at least five years following the researcher's graduation, following which it will be destroyed.

D11) How long will personal data be stored or accessed after the study has ended?

Personal data will be destroyed along with the research data after the study and when the participants who have wanted a copy of the study's results have received them.

D12) How are you intending to destroy the personal data after this period?

All files which are to be kept on the City University encrypted One Drive will be permanently deleted.

Health & Safety

HS1) Are there any health and safety risks to the researchers over and above that of their normal working life?

Yes

HS2) How have you addressed the health and safety concerns of the researchers and any other people impacted by this project?

There will be an option for the interviews to be conducted at the participant's home. In the event this occurs, the researcher will adhere to the City University Lone Working Policy. In previous volunteer positions, the researcher has conducted home visits as part of her role. She is well versed in the potential risks that could arise. She will ensure that all visits are conducted during social hours (9am to 5pm) to minimise these. She will perform a google maps search to assess the outside area for potential risks. Before the interview, the researcher will ask for a list of other home inhabitants, including pets. Upon arrival at the house, the researcher will conduct an informal risk assessment examining the home for potential physical risks such as stairs, wires, etc. The researcher will note all possible exits and ensure that she sits near an exit door. The researcher will have a 'buddy' that she can contact twice via text, one before the interview and once immediately following exiting the participant's home. She will give her buddy a timeframe, following which if no contact is made, the buddy is to call the researcher's mobile phone. The buddy and researcher will have a code to alert the buddy if the researcher is feeling unsafe. At this point, the researcher will make an excuse to leave the participant's home. If the participant blocks this, the researcher will use another code phrase to alert the buddy to contact emergency services. The location of the interview will be shared with the buddy. The Buddy will be the study's supervisor Dr Aylish O'Driscoll. The researcher also has a professional indemnity policy with Howden Insurance.

HS3) Are there hazards associated with undertaking this project where a formal risk assessment would be required?

No

APPENDIX B – Ethics Approval Email

Dear Charlotte

Reference: ETH1920-0631

Project title: A Thematic Analysis Approach to Explore the Experiences of Support Following Stillbirth for Mothers in the UK

Start date: 20 Feb 2020

End date: 1 Oct 2021

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- Change or add a new category of participants;
- Change or add researchers involved in the project, including PI and supervisor;
- Change to the sponsorship/collaboration;
- Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research participants;
- Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;
- Change to the insurance or indemnity arrangements for the project;
- Change the end date of the project.

Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d) should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

Kind regards

[redacted]

Psychology committee: medium risk

City, University of London

Ethics ETH1920-1826: Mrs Charlotte Squires (Medium risk)

Date Created: 17 Jun 2020

Date Submitted: 17 Jun 2020

Date of last resubmission: 06 Jul 2020

Date forwarded to committee: 08 Jul 2020

Academic Staff: Mrs Charlotte Squires

Student ID: [redacted]

Category: Doctoral Researcher

Supervisor: Dr Aylish O'Driscoll

Project: An Exploration of Mother's Experiences of Support following their Baby Being Stillborn.

School: School of Arts and Social Sciences

Department Psychology

Current status Approved

Ethics application

Amendments

SA1) Types of modification/s

Change the design and/or methodology of the project, including changing or adding a new research method and/or research instrument

Change project documentation such as protocol, information sheets, consent forms, questionnaires, recruitment materials (please upload the relevant files with highlighted changes)

SA2) Details of modification

I am requesting that an amendment is made in how I will be conducting my interviews.

Instead of holding the interviews face-to-face in the participant's home, I will instead be doing the interviews virtually. The platform I will be using to do this is Zoom. This change to how the interviews will be conducted can be seen in the consent form and participant information sheet.

Consent Form Changes are:

- in the table, on the first page, I have also included the acknowledgement within the form that the client is to sign to state they are happy to interview over Zoom.

- my signature is already featured, which means that the client needs only to add theirs. They will then return the document to me via the chat function on Zoom. This will allow for the real-time signing of the document.

Participant Information Form Changes are:

- the information sheet explains in detail the amendments to the process. There is no mention of meeting physically with each other or me visiting them in person.

- in the following sections, there have been changes made to detail the practicalities of how the online interview will affect the participant - what will happen if I take part? What are the possible disadvantages and risks of taking part? What should I do if I want to take part? What happens if I want to withdraw? What happens to my data?

- There has also been an addition of a how-to guide for the participant who has not used Zoom

before. It explains the process of logging into Zoom and how the interview will work.

These points have all been highlighted in yellow on the attached documents.

Minor amendments to the debrief document and the interview schedule have been made. This is mainly in terms of language and clarity, due to the movement to online interviews. There was a need to make sure the language would work online. These have been uploaded for full transparency to the panel. I have also decided to not use a demographic questionnaire as I can obtain this information organically during the interview.

SA3) Justify why the amendment is needed

On 23rd March 2020, the UK went into lockdown due to Covid-19. This meant that there was limited opportunity to meet with people outside of your household. Government guidelines at this time are still imposing a 2m social distancing and limited travel opportunities. It was deemed by the course leaders and the university that research is moved to virtual methods where possible.

My study can move to online easily, and I have suspended my interviews until August 2020. This is so the interviews can occur online allowing this project to continue and keep all parties safe from contracting the virus.

I will acknowledge that there are that need to be managed effectively as part of this change to the style of interview. These points have been noted in the information sheet under What are the possible disadvantages and risks of taking part? The points highlight to the participant that if there become emotionally distressed, I will use my counselling skills to support them. I will also confirm before starting the interview that they are in a safe and comfortable place. There is also the consideration for the internet not working where I will endeavour to reconnect, try calling them on the telephone or rescheduling.

SA4) Other information

SA5) Please upload all relevant documentation with highlighted changes

Project amendments

P1) Project title

P2) Principal Applicant

Name

Provide a summary of the researcher’s training and experience that is relevant to this research project.

P3) Co-Applicant(s) at City

P4) External Co-Applicant(s) P5) Supervisor(s)

APPENDIX D – Email confirmation of changes due to pandemic

Dear Charlotte,

Reference: ETH1920-1826

Project title: A Thematic Analysis Approach to Explore the Experiences of Support Following Stillbirth for Mothers in the UK

Start date: 20 Feb 2020

End date: 1 Oct 2021

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

The approval was given with the following conditions:

· add your email address on the debrief at the location referred to

Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

· Change or add a new category of participants;

· Change or add researchers involved in the project, including PI and supervisor;

· Change to the sponsorship/collaboration;

· Add a new or change a territory for international projects;

· Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research participants;

· Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;

· Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;

· Change to the insurance or indemnity arrangements for the project;

· Change the end date of the project.

Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d)

should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant

institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

Kind regards

[redacted]

Psychology committee: medium risk

City, University of London

APPENDIX E – Ethics Amendment for Participant Numbers

Ethics ETH2021-0982: Mrs Charlotte Squires (Medium risk)

Date Created: 09 Jan 2021

Date Submitted: 09 Jan 2021

Date forwarded to committee: 15 Jan 2021

Academic Staff: Mrs Charlotte Squires

Student ID: [redacted]

Category: Doctoral Researcher

Supervisor: Dr Jacqui Farrants

Project: An Exploration of Mother's Experiences of Support following their Baby Being Stillborn.

School: School of Arts and Social Sciences

Department: Psychology

Current status: Approved

Ethics application

Amendments

SA1) Types of modification/s

Other

SA2) Details of modification

I had originally submitted to the ethics committee that the project would recruit a maximum of 10 participants.

I am requesting that this number be increased to a maximum of 20 participants.

SA3) Justify why the amendment is needed

I am requesting that the number of participants is increased because of the high level of interest that has been shown during recruitment. I have easily reached my current maximum of 10 participants and there are some participants who currently can't be involved. I hope to include the rest of the interested participants because I believe hearing their story will add to the research and that it took them great courage to reach out and participate which is an important element to this research.

SA4) Other information

SA5) Please upload all relevant documentation with highlighted changes

Project amendments

P1) Project title

Experiences of Support Following Stillbirth for Mothers in the UK using a Thematic Analysis

Approach.

P2) Principal Applicant

Name: Mrs Charlotte Squires

Provide a summary of the researcher's training and experience that is relevant to this research project.

The lead researcher will be conducting the interviews with participants who have met the criteria of participation. The high standards of City, University of London are evident during the various placements where the necessary skills to supply high-quality therapeutic skills are demonstrated through academic assessment. Before joining the course, previous work and life experience highlighted positive regard for others in an empathetic and caring way.

The lead researcher has also been compiling experience through various training given by baby loss charity Simba based in Scotland; Child Bereavement UK entitled 'supporting parents through pregnancy loss and the death of a baby' which is accredited by the Royal College of Midwives. As well as online training supplied by the NHS. All this training covered the areas of exploring and developing self-awareness concerning loss, grief and bereavement. Recognising physical and emotional reactions to grief; gaining an understanding of what mothers may need when they are faced with the death of their baby.

Recently the lead researcher has become an accredited member of the BACP, which demonstrates proficiency of counselling skills.

P3) Co-Applicant(s) at City

P4) External Co-Applicant(s)

P5) Supervisor(s) - Dr Jacqui Farrants

Dear Charlotte

Reference: ETH2021-0982

Project title: Experiences of Support Following Stillbirth for Mothers in the UK using a Thematic Analysis Approach.

Start date: 20 Feb 2020

End date: 1 Oct 2021

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- Change or add a new category of participants;
- Change or add researchers involved in the project, including PI and supervisor;
- Change to the sponsorship/collaboration;
- Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research participants;
- Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;
- Change to the insurance or indemnity arrangements for the project;
- Change the end date of the project.

Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d) should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

Kind regards

[redacted]

Psychology committee: medium risk

City, University of London

APPENDIX G – Consent Form

CONSENT FORM

Dear Participant,

Thank you for agreeing to contribute to this research which aims to explore the experiences of support following stillbirth for mothers in the UK.

Please read and initial the following before signing this form and agreeing to participate in the study fully.

		Please initial box
1.	I confirm that I have read and understood the participant information sheet dated [INSERT DATE AND VERSION NUMBER] for the above study. I have had the opportunity to consider the information and ask questions that have been answered satisfactorily.	**I agree**
2.	I agree with City recording and processing this information about me. I understand that this information will be used only for the purpose(s) explained in the participant information, and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	**I agree**
3.	I understand that I am free to withdraw from the study at any point during the interview and up to 2 months after the day of the interview. After this point, I acknowledge that I will be <u>unable to withdraw</u> as the analysis has begun.	**I understand**
4.	I agree with the interview being audio recorded via the video conferencing platform Zoom.	**I agree**
5.	I understand that this interview will be recorded for analysis purposes and that the researcher will keep notes during the interview.	**I understand**
6.	I understand that any direct quotes will be anonymised using pseudonyms.	**I understand**
7.	I understand that I can stop the recording at any point to take a break during the interview.	**I understand**
8.	Having read the above, I agree to take part in the above study.	**I agree**

APPENDIX G – Consent Form

	Yes	No
• I have taken the opportunity to ask questions about the interview process and the research.	☐	☐
• I have read and fully understood the requirements of the research.	☐	☐
• I would like to be informed of the results of this study once it has been completed and understand that my contact details will be retained for this purpose	☐	☐

Please note that two copies of this form need to be signed both by you and the researcher.

A fully signed copy will be retained by both the researcher and the participant.

Name of participant	Date	Signature
Name of researcher	Date	Signature

Thank you very much for agreeing to take part in this research.

Please do not hesitate to contact my research supervisor or me if you have any further enquiries.

Charlotte Squires
Trainee Counselling Psychologist, City, University of London
[redacted]

APPENDIX H – Participant Debrief Sheet

Participant Debrief

Thank you for participating as a research participant in the present study exploring the support you received after your baby was stillborn.

This study has sought to learn more about your experiences of support to develop this under-researched area further. The interviews will be analysed to help form a picture of what support is available and support mothers need. The experience you have shared will help build this picture, and once the study has been completed, the potential publication will allow other professionals to further their knowledge of the support needed.

If you would like access to the final research report, please make sure you have stated 'YES' on the consent form so that a copy can be sent to you when the study is completed.

PLEASE NOTE: If you feel distressed after the interview, please get in touch with the organisations found on the page below to offer support specifically to those who have experienced stillbirth or baby loss or contact your GP.

If this is not possible, please get in touch with a 24-hour telephone hotline such as Samaritans (call 116 123) or Sane (call 0300 304 7000).

If you have questions about your participation in this study or about the study itself, you are encouraged to contact the principal researcher Charlotte Squires via the email above.

Thank you again for your participation.

Kindest Regards,

Charlotte Squires

APPENDIX H – Participant Debrief Sheet

Stillbirth Support Contacts

Sands Helpline

The Helpline is for anyone affected by the death of a baby and wants to talk about their experience.

- Call: 0808 164 3332
- Email: helpline@sands.org.uk

Tommy's Advice Line

The advice line has experience in talking about pregnancy loss and has had bereavement training.

- Call: 0800 0147 800. The line is open Monday to Friday, 9-5pm.

Child Bereavement UK

- National Helpline 0800 02 888 40 (Monday – Friday, 9 am – 5 pm) - freephone, confidential helpline for people affected by bereavement and professionals supporting bereaved families.
- Email for bereavement support: support@childbereavementuk.org.
- Live chat (Monday - Friday, 9 am - 5 pm) - Offering bereavement support and information.

The Lullaby Trust

If you would like the opportunity to talk freely, for as long as required, with a sympathetic and understanding listener, please call the bereavement support helpline.

- Call 0808 802 6868 (Mon to Fri, 10 am – 5 pm | Weekends and Public Holidays, 6 pm – 10 pm)

Child Death Helpline

A caller to the helpline may be anyone affected by a child's death, from pre-birth to the death of an adult child, however recently or long ago and whatever the circumstances of the death.

- Call: 0800 282 986 / 0808 800 6019
  (Every evening between 7- 10pm | Mon/Thur/Fri, 10am – 1pm | Tue/Wed, 10am – 4pm)

Baby Loss

This voluntary organisation is available to anyone affected by the loss of a baby during pregnancy, at birth or shortly afterwards.

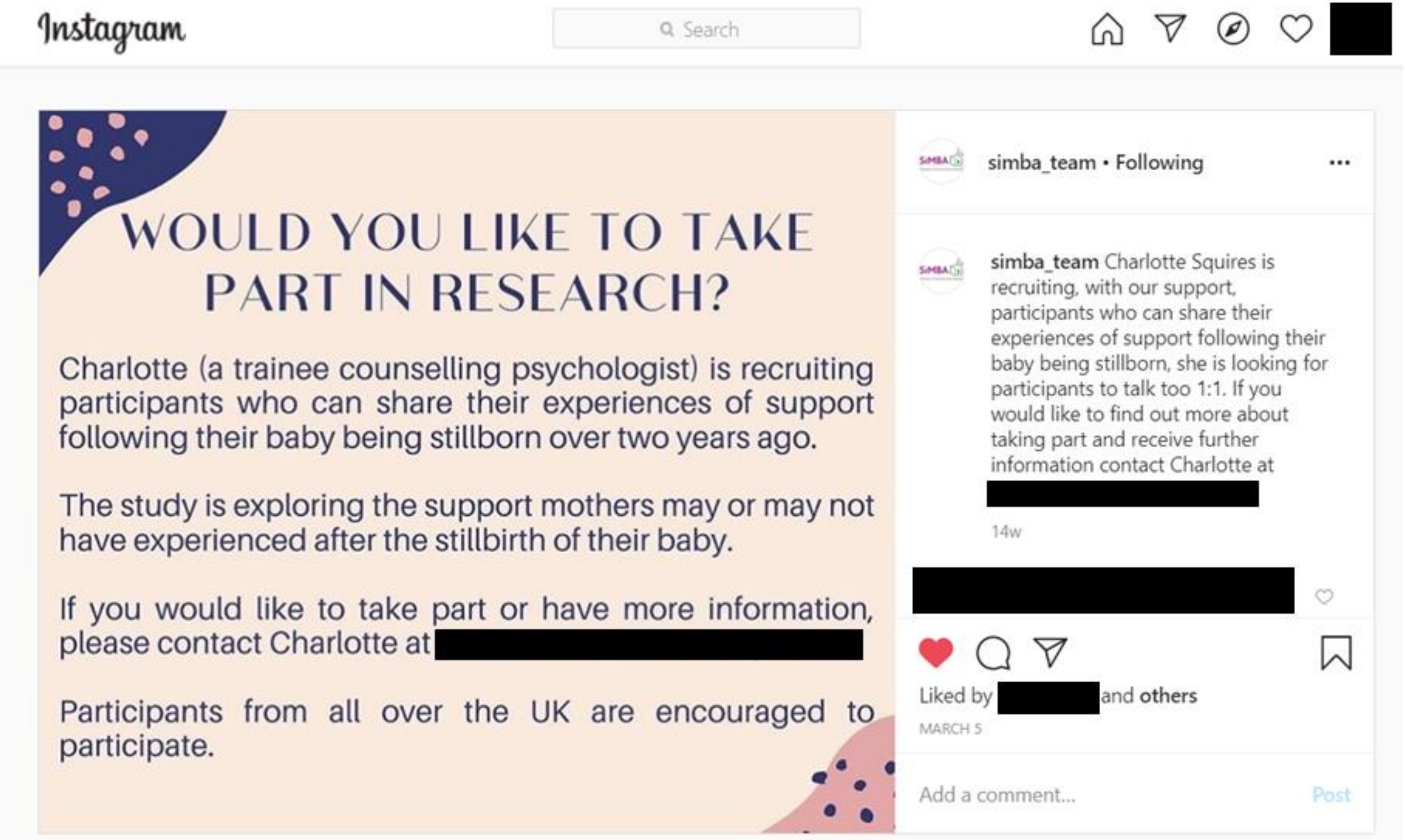
- Website:www.babyloss.com
- Email:support@babyloss.com

Lily Mae Foundation

This great charity provides resources for hospitals across the Midlands and also provide monthly support meetings. Website:www.lilymaefoundation.org

APPENDIX I – Social Media Advert

SOCIAL MEDIA POST - Instagram post via Simba Charity page and on my colleague's page



[redacted]

WOULD YOU LIKE TO TAKE PART IN RESEARCH?

Charlotte (a trainee counselling psychologist) is recruiting participants who can share their experiences of support following their baby being stillborn over two years ago.

The study is exploring the support mothers may or may not have experienced after the stillbirth of their baby.

If you would like to take part or have more information, please contact Charlotte at [redacted]

Participants from all over the UK are encouraged to participate.

simba_team • Following

simba_team Charlotte Squires is recruiting, with our support, participants who can share their experiences of support following their baby being stillborn, she is looking for participants to talk too 1:1. If you would like to find out more about taking part and receive further information contact Charlotte at

[redacted]

14w

[redacted]

Liked by [redacted] and others

MARCH 5

APPENDIX J – Participant Information Sheet

Participant Information Sheet

REC reference number, date and version of information sheet: Reference: ETH1920-0631, 26/02/2020, V3

Title of study - An exploration of a mother's experiences of support following their baby being stillborn.

Name of principal researcher: Charlotte Squires

This study is conducted in partial fulfilment of a Doctorate in Counselling Psychology at City University and is supervised by Dr Aylish O'Driscoll, [redacted]

In the event of any concerns, comments or complaints arising from this study, you may contact [redacted] Research Integrity Manager, City, University of London, [redacted]

What is the purpose of the study?

Since 2001, stillbirth has increasingly been a topic of study, which this study will aim to expand. Stillbirth experience research focuses on the mother's experience, midwives and health practitioners experience and broader family experience.

Counselling psychologists cover broad areas of services, which means their potential clients could have experienced stillbirth themselves or may know someone who has. Understanding the impact of this life event is needed within this realm of psychology and not purely from a clinical or health psychology view.

This study aims to improve the awareness of mothers' experience in terms of support following stillbirth using interviews. The interviews will then be analysed to find themes within the content.

From a counselling psychology perspective, current research within this area shows a need for this specific topic to develop. The following question will be explored:

- Following stillbirth, what is a mother's experience of support?

What will happen if I take part?

- If you decide that you would like to be involved in this research project, you will be asked to complete a consent form which will have been electronically signed by Charlotte already. You need to sign this document which we will do over Zoom electronically.
- The interviews will be held over Zoom, the video-conferencing application. Please make sure that this is in a quiet and comfortable place that allows privacy.
- You will participate in a one-to-one interview with Charlotte. The interviews are expected to last around 1hour, 30 mins, and no longer than 2 hours.
- The interview will be audio-recorded, and Charlotte might also keep notes during this interview.
- The interviews will then be transcribed by Charlotte and then analysed.
- You will keep a copy of the consent form and be given a debrief sheet that details available support resources for bereaved mothers should you need any further support after the interview.

What are the possible disadvantages and risks of taking part?

The possible risks and disadvantages that could occur while taking part in this study could be:

- There is the potential for difficult or painful feelings surrounding the stillbirth could surface.
    - As we are unable to meet physically, the interview will be paused. Before the interview, make sure you are comfortable and feel safe is very important.

What are the possible benefits of taking part?

The possible benefits that could occur while taking part in this study could be:

- You will be able to share your experiences of seeking support after your stillbirth.
- To contribute to the advancement of research surrounding stillbirth and help psychologists understand what mothers need concerning support once the study is completed.

What should I do if I want to take part?

If you wish to participate in this research, please get in touch with the principal researcher Charlotte Squires by email ([redacted]). You will receive a copy of this information sheet which you will need to review.

Following this, a phone call will be arranged with Charlotte to answer any questions you may have. During this call, Charlotte will be making sure that you meet the inclusion criteria to proceed with arranging a time for the interviews. An email invitation will be sent to you, confirming when the interview will begin.

You will be given consent forms that will be signed in real-time via the use of Zoom Chat. I will go through this with you on the day. You will need to read, sign and return to Charlotte and keep a copy for yourself.

At the confirmed time and date, the interviews will take place over the video conferencing application Zoom. Zoom will allow us to meet ‘face to face’ via video link where the interview will take place. Charlotte will be recording the interview and will only be using the recorded audio from the interview to analyse. Zoom allows us to have a secure interview which will keep confidentiality intact.

Once the interview has been completed, there will be time to debrief, and you will be given a document which informs you of potential support networks.

Please see below the areas that you need to consider when taking part in the study :

1) Only women who lost their babies after 24 weeks of pregnancy will be included in the present research.

2) No age restrictions are to be applied to the upper age limit. However, a minimum age of 20 years old has been used due to the potential of participants being younger than 18 years at the time of their stillbirth.

3) Women from any socio-economic, ethnic, religious or educational background will be included in the study.

4) If you are currently having treatment for a mental health condition, you will not be able to participate.

5) Mothers participating in the study will have experienced stillbirth at least two years before the interview and not more than ten years.

What happens if I want to withdraw?

If you want to withdraw from the study, please get in touch with Charlotte by email ([redacted]) to raise any concerns you have. Once you have indicated you wish to withdraw your data will be destroyed.

> **Please Note: there is a cut-off point for being eligible to withdrawal** – you are free to withdraw from the study at any point during the interview and up to 2 months after the day of the interview. After which point, you will be unable to withdraw as analysis will have begun.

What happens to my data?

- Charlotte and her supervisor only will have access to personal data.
- Confidentiality will be ensured, e.g. names will not be used but given a pseudonym; quotes will be anonymised/ to protect your identity.
- There will be audio recordings made at the interviews via Zoom, which will then be transferred to an encrypted laptop where it will be transcribed.
- Confidentiality will be broken should you report imminent harm to yourself or another, a safeguarding threat to a minor, or terrorist activity.
- The records of transcription, audio recording, and any other notes taken will be stored within City, University's OneDrive system, which is encrypted. The length of time records will be kept at City, University is usually ten years. The records will be destroyed should you withdraw from the study.

Any information you give will be handled as confidential. Your name will not be attached to the transcripts of the digitally audio-recorded interviews or the notes kept by Charlotte during the interview. Charlotte and her supervisor, in the immediate research process, written reports, or future publications, will treat this information following the Code of Conduct, Ethical Principles and Guidelines published by the British Psychological Society (www.bps.org.uk).

What will happen to the results?

The results of this study will be included in Charlotte Squires' Doctoral Thesis. It is possible that in the future, additional publications may arise as a result of this research. In this event, confidentiality would be maintained in any publication.

What if there is a problem?

This study has been approved by City, University of London Psychology Research Ethics Committee.

If you have any problems, concerns, or questions about this study, you should speak to a research team member. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone [redacted]. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the project's name is: *Experiences of Support Following Stillbirth for Mothers in the UK using a Thematic Analysis Approach*.

APPENDIX J – Participant Information Sheet

You can also write to the Secretary:
[redacted]
Research Integrity Manager
City, University of London, Northampton Square
London, EC1V 0HB
Email: [redacted]

Further information and contact details

For more information about this study or to volunteer for this study, please contact: Charlotte Squires, Principle Researcher [redacted]

Data privacy statement

City, University of London is the sponsor and the data controller of this study based in the United Kingdom. The legal basis under which your data will be processed is City's public task. This means that we are responsible for looking after your information and using it properly.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further details https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-thegeneral-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/).

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the study results, your contact details will also be kept for this purpose. The only people at City who will have access to your identifiable information will be Charlotte Squires. City will keep identifiable information about you from this study for ten years after the study has finished.

You can find out more about how City handles data by visiting https://www.city.ac.uk/about/governance/legal. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (IOC) https://ico.org.uk/.

Thank you for taking the time to read this information sheet.

APPENDIX J – Participant Information Sheet

How to Access Zoom

1. **I will email you an e-invitation which will have the Meeting-ID and password detailed so you can access the interview.**
    a. The time and date of the interview will also be included (this will be pre-agreed).

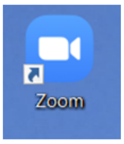
How to Join the Interview if you have…

Not Downloaded Zoom Software

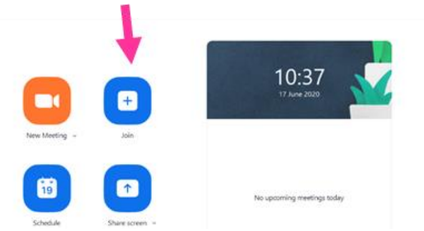
If you do not have Zoom on your device already - click this link and join the interview via the Zoom webpage https://zoom.us/join

Downloaded Zoom Software

a. On the day and time of the interview click on the Zoom icon which will be on your device if you have downloaded the program.



b. When this opens, Click join



1. **Enter the meeting ID, which you will find on your email**

2. **Then, click join**

3. **You will then be asked for a password**
    a. this password is also on the email invitation you will have received.

4. **Click join**

5. **If you are early to the meeting, you will be put in a 'waiting room', and I will let you in once I have logged in.**

Please Note:

- As previously mentioned, these interviews will be recorded from beginning to end.
- I will be transcribing the audio and using this within the research.
- If you need to pause during the interview, I will stop all recordings and resume when we are ready.
- Consent forms will be signed in real-time via the use of Zoom Chat. I will go through this with you on the day

APPENDIX K – Interview Schedule

Interview Schedule

Before we begin to discuss your experience of support after the loss of your baby (*insert name if they gave their baby a name – check with them how they would like you to refer to their baby throughout the interview*), this research aims to highlight this to help us better understand how to help people who gave experienced the stillbirth of their baby.

I want to remind you at this time that all information is confidential, and personal details will be changed to preserve anonymity. I also want to highlight that we can skip any questions that make you feel uncomfortable and add in anything you think should be added. Is that ok with you?

I want to try and focus this interview on the time after you lost x. I hope to focus most of our discussion on your experience of the support you received (or did not receive). Please understand that this is a flexible interview. However, if you want to tell me something, or if you feel one of these questions triggers something, please share this with me and/or we can take a break.

Preamble – what promoted you to take part in this interview?

1. Can you tell me a bit of your experience / your story of losing x?
    a. Can you give examples of your thoughts, memories, mood, etc.?
    b. Did you make any memories with (name of baby) such as a photograph?
    c. What was that like?
    d. Have these feelings have changed over time?

2. Support means many things to different people; what does support mean to you in general terms?

3. Can you tell me a bit about the support you received after you lost x? I mean all forms of support, such as professional, family, friends, other networks

4. Were you ever offered/did you seek any professional support (e.g. bereavement midwife, counselling, other forms of therapy)?
    a. Can you tell me a bit more about this?

5. If you had access to some support in the first year after X died, can you tell me what might have been helpful for you to experience?
    a. What was and wasn't helpful – with the professional support and what was different to only having a family?

6. What is missing for women who have experienced a stillbirth in the way of support?
    a. Specifically, for your mental health?

7. Is there anything you think I have missed or would want to be asked at this point?

We have come to the end of the interview, and I would like to check if you are ok and need to go over any points we have discussed?

I would also like to express my sincerest thanks for sitting with me and telling me your story. I realise that it is very difficult to do so. I really do appreciate you trusting me and sharing this experience with me. I will now be taking the audio recording and analysing our conversation to find themes with other stories I am hearing. If you have no further questions, we can end the interview. Thank you again for your time and honesty.

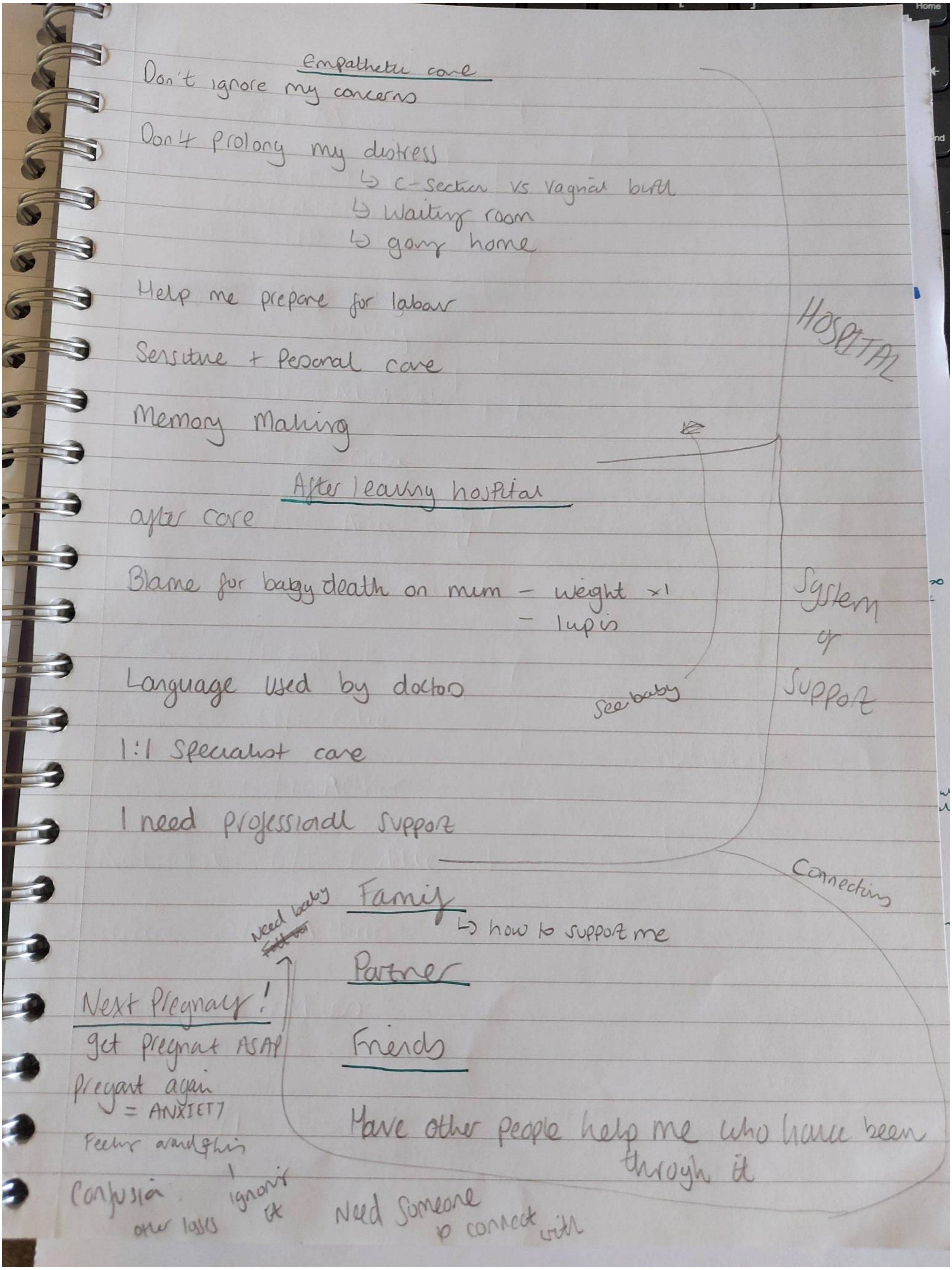
APPENDIX L – transcript coded and notes taken (stage 3)

Needing a connection to the hospital and event via midwife	it was quieter I would go into the hospital and take in the stuff and we had a few meetings like that umm I don't know if she would have felt like she was supporting me but it was because it was providing this link and I remember her saying – that – and giving me the opportunity to back and just talk to her about what had happened because there was so much that I was confused about and didn't remember umm and I had this real need to go back there and be back in that building
Husband not wanting to go back to hospital	whilst my husband didn't want to go within like 30miles of it he was quite happy to go nowhere near it so she sort of fulfilled that need for me.
No bereavement midwife	Umm – they didn't at that time have a dedicated bereavement midwife or bereavement midwifery team I believe they do now at the hospital
Community midwife	um but my community midwife who's name was Marion um --- was very, very good.
Continuity of care is needed	So, we had moved – the village we live in we'd moved when I was 7months pregnant with Maeve um so had carried on linking with the hospital which was in Glasgow. Umm for birth and everything cause it just seemed easier but I did connect with the community midwife and that I had met with her twice I think just for those late pregnancy checks umm and there was (sigh) there was some issue because we were then in different health boards so Maeve was born in one health board but we were living in another one and they weren't told what had happened so I got in touch with her and she came out
After birth support	um and they ordinarily – you know a midwife visits in the first 10days after a baby is born and um but she kept coming back long after that

APPENDIX M – overarching codes (stage 3)

Column 1	*Column 2*
Overall Code	**Codes**
Anxiety	Anxieties pre birth IVF Baby Anxiety around scans / stress Support whilst pregnant to help with anxiety offered
What I needed	Just wanted someone to sit with her and listen to her grief and not fix it Relentless desperation to get help Desperation for help PAIN IN NO SUPPORT I need more personal support but it was helpful Not having to repeat my story is helpful Having someone who gets it is important Honouring the memory of her baby Saying the baby's name was really vital for her Inclusion is important for memory Support whilst pregnant to help with anxiety offered Just needed someone to grab on to Longing for reassurance To be told You will survive this Reassurance Empathy needed

APPENDIX N – overarching codes and organisation (stage 3)



Empathetic care

Don't ignore my concerns

Don't prolong my distress
↳ C-Section vs Vaginal birth
↳ Waiting room
↳ going home

Help me prepare for labour

Sensitive + Personal care

Memory Making

HOSPITAL

After leaving hospital

after care

Blame for baby death on mum – weight ×1
– lupus

Language used by doctors

See baby

1:1 Specialist care

I need professional support

System of Support

Connecting

Family
↳ how to support me

Partner

Friends

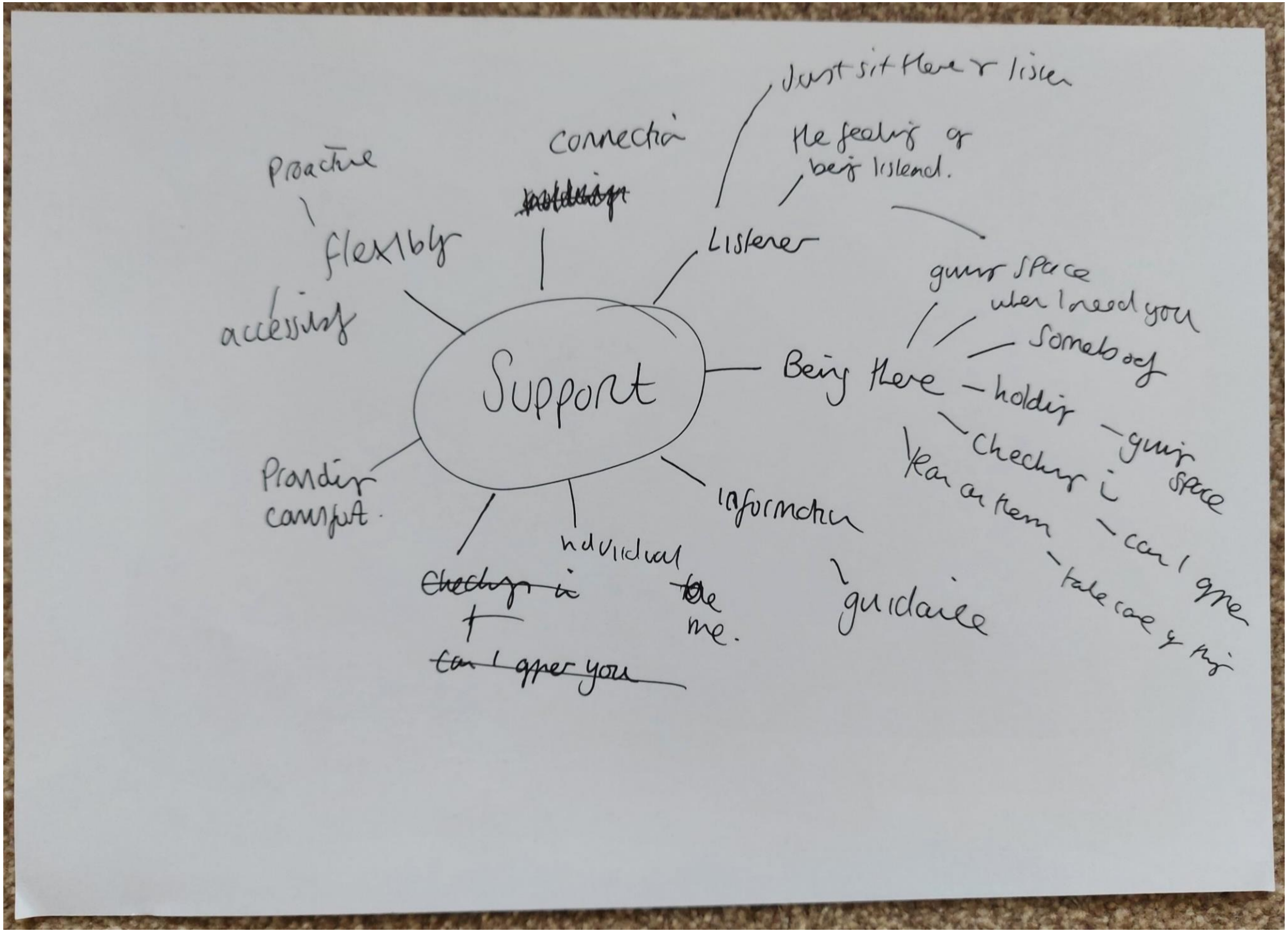
Have other people help me who have been through it

Need baby
~~[illegible]~~

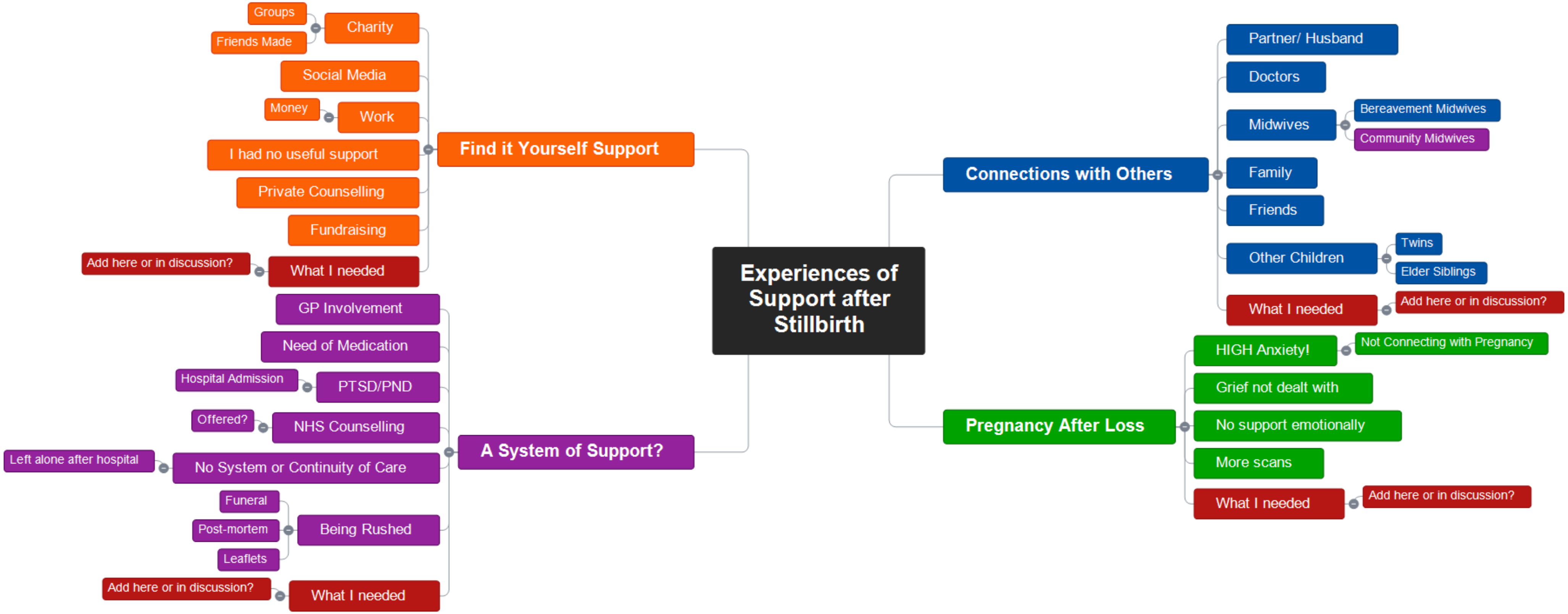
Next Pregnancy!
get pregnant ASAP
Pregnant again
= ANXIETY
Feelings around this
Confusion
other losses
ignoring it

Need someone to connect with

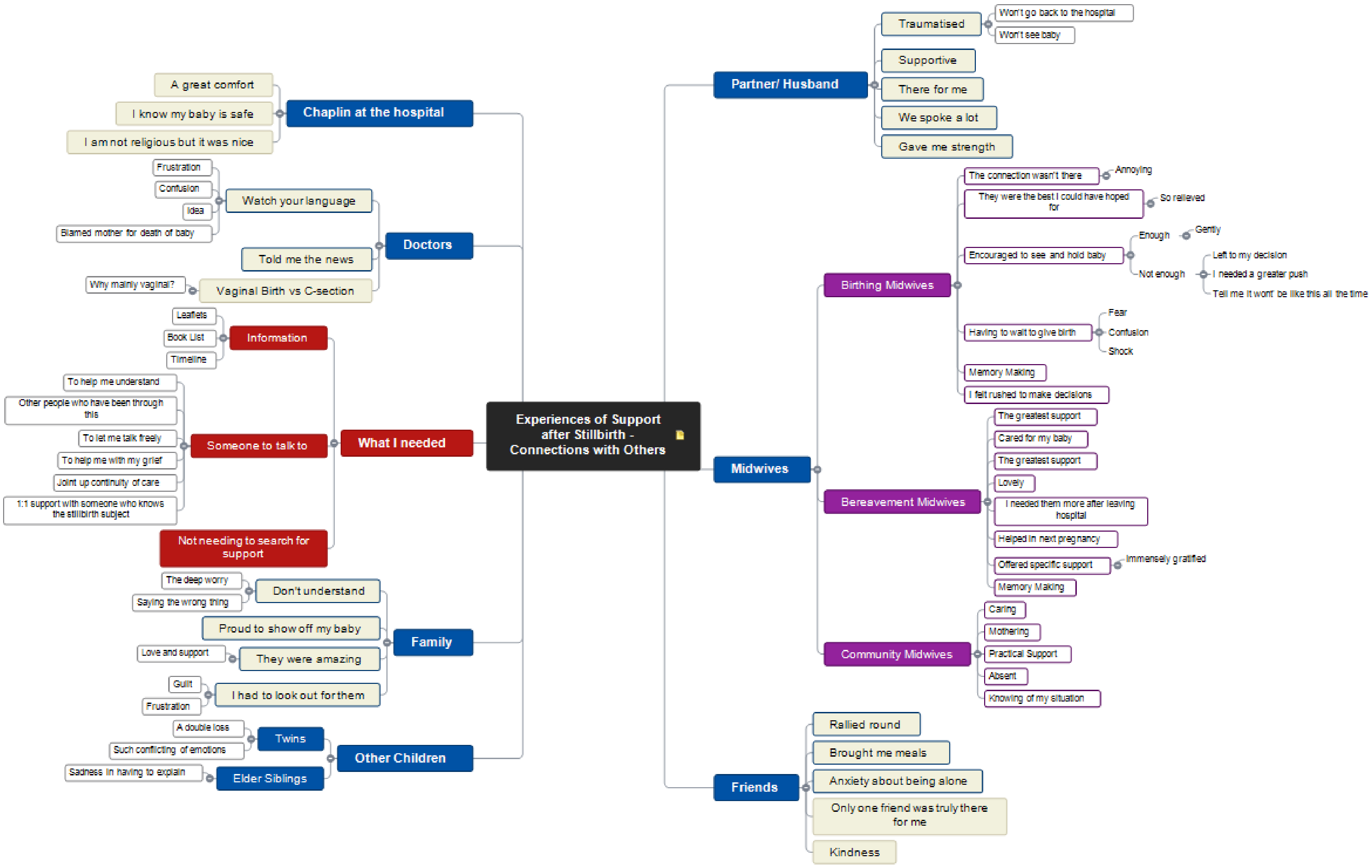
APPENDIX O – grouping of codes – representative example



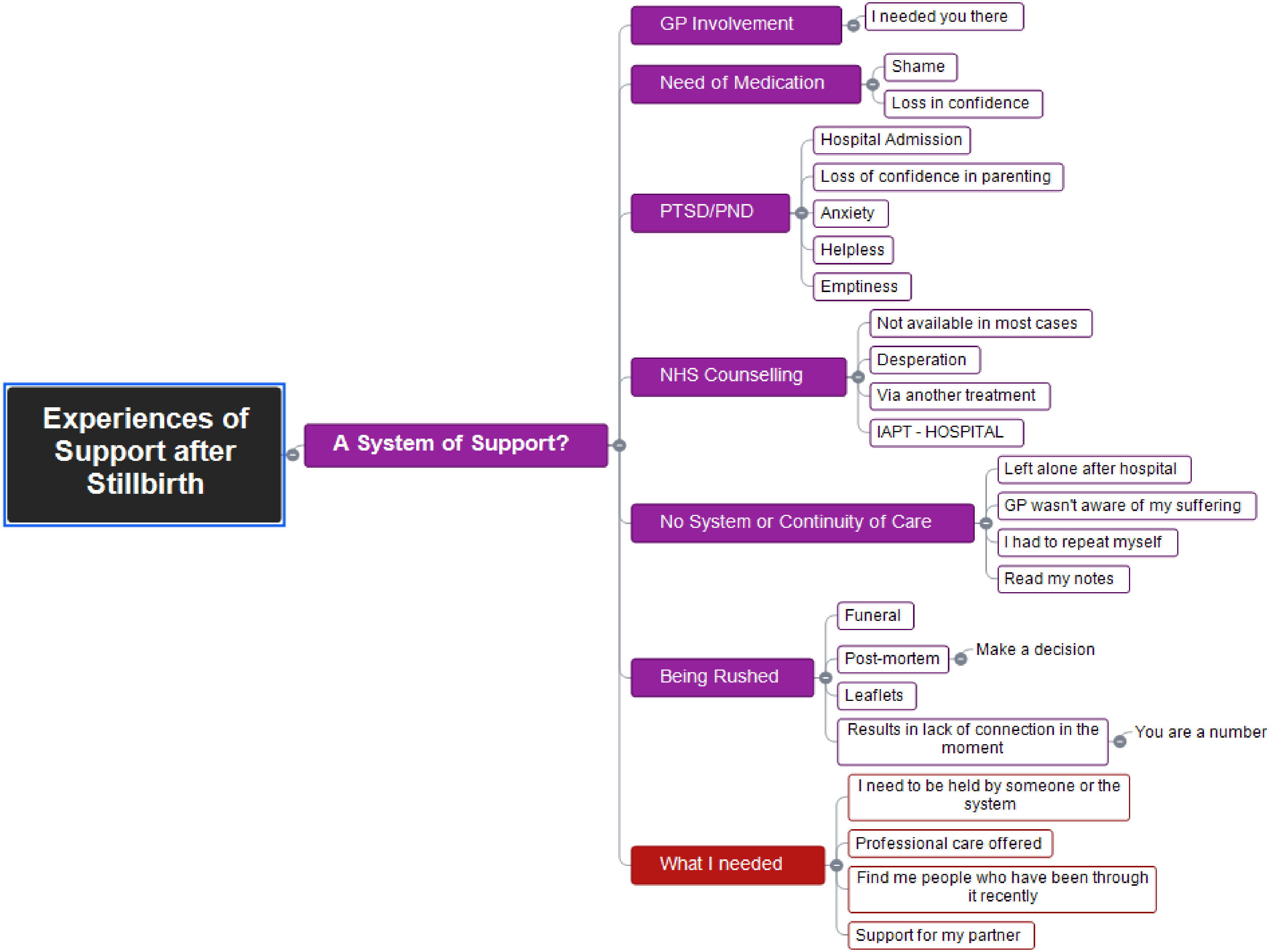
APPENDIX P - Table of Themes and Subthemes



APPENDIX Q - Theme 1 – Connections with Others

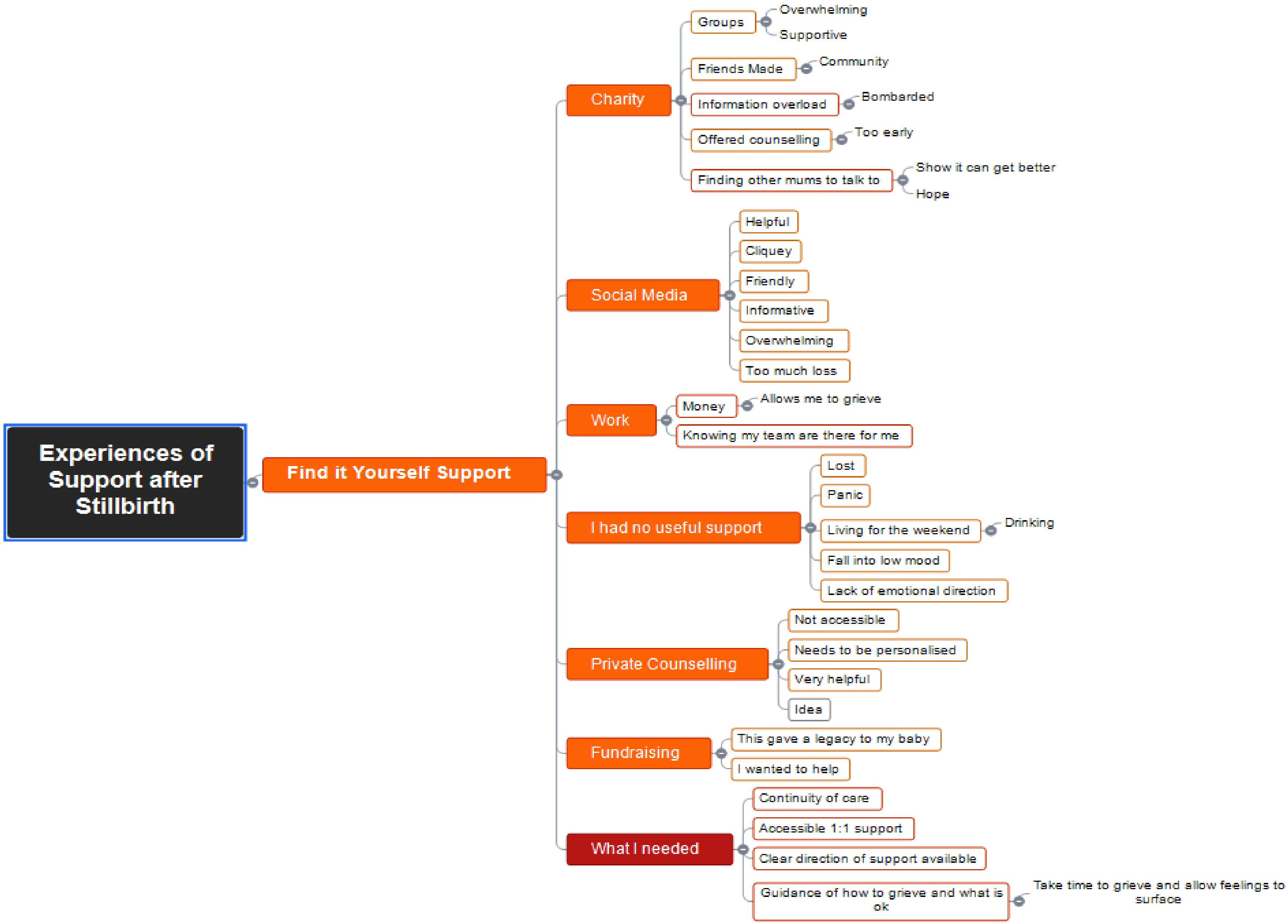


APPENDIX R - Theme 2 – A System of Support

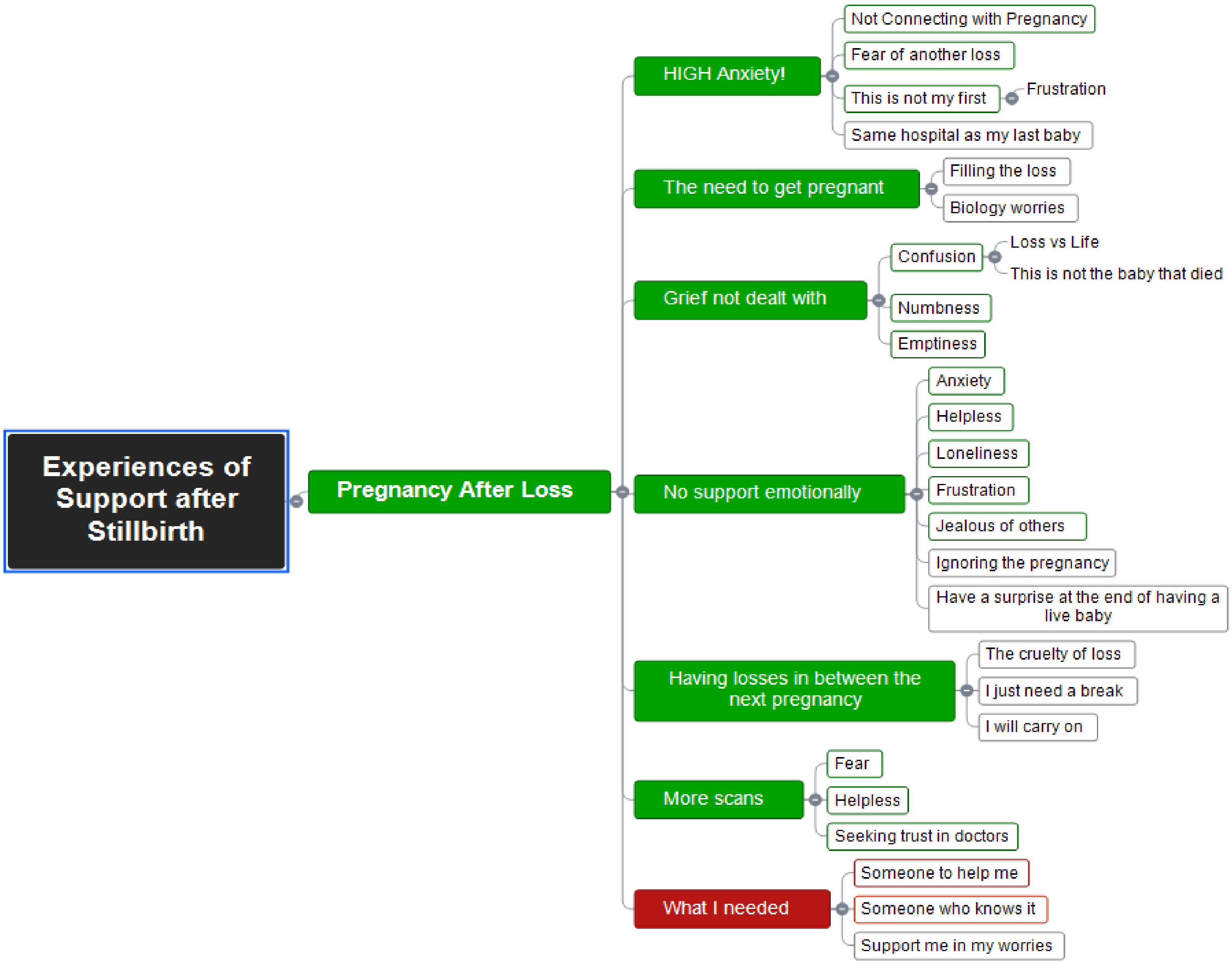


- Experiences of Support after Stillbirth
  - A System of Support?
    - GP Involvement
      - I needed you there
    - Need of Medication
      - Shame
      - Loss in confidence
    - PTSD/PND
      - Hospital Admission
      - Loss of confidence in parenting
      - Anxiety
      - Helpless
      - Emptiness
    - NHS Counselling
      - Not available in most cases
      - Desperation
      - Via another treatment
      - IAPT - HOSPITAL
    - No System or Continuity of Care
      - Left alone after hospital
      - GP wasn't aware of my suffering
      - I had to repeat myself
      - Read my notes
    - Being Rushed
      - Funeral
      - Post-mortem
        - Make a decision
      - Leaflets
      - Results in lack of connection in the moment
        - You are a number
    - What I needed
      - I need to be held by someone or the system
      - Professional care offered
      - Find me people who have been through it recently
      - Support for my partner

APPENDIX S - Theme 3 – Find it Yourself Support



APPENDIX T - Theme 4 – Find it Yourself Support



SECTION TWO

CASE STUDY AND PROCESS REPORT
Eating Disorder Treatment using CBT-E

Charlotte Squires

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SECTION THREE

PUBLISHABLE PAPER

An Exploration of Mother’s Experiences of Support following their Baby Being Stillborn.

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