Baby Loss, grief, and the Quest for Community: A mixed methods study investigating stillbirth bereavement support pathways for ethnically diverse bereaved parents

by

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Abstract

Stillbirth is a silent public health crisis that affects families across the UK. According to a recent NHS figure, one in every 250 births ended in stillbirth, which is approximately eight babies every day (NHS, 2021). While preventative measures have been put into place reducing this silent epidemic, much more action is needed to decrease the number of families experiencing child loss. Year after year, reports (Woods & Heazell, 2018; RCOG, 2020; Widdows et al., 2021) show the national stillbirth rates decrease, however, the stillbirth rate among Black and Asian communities continues to remain particularly high compared to white British families (Garcia et al., 2015; MBRRACE, 2021). Despite the documented disparity of perinatal loss between white British and minority ethnic communities, there is a lack of evidence documenting the best and preferred means to support Black, Asian, and Minority Ethnic (BAME) bereaved families. It is clear that more research is needed to better support minority ethnic families as they grieve the loss of a child and the loss of a future they planned (Campbell-Jackson & Horsch, 2014). Whilst it is important to remember that there will be shared bereavement experiences amongst stillbirth bereaved parents regardless of ethnicity (Garcia et al., 2020), it is imperative to identify how to provide culturally competent bereavement support (Shaw, 2013; Rogers & Greenfields, 2017).

Many baby loss charities across the country have implemented bereavement support programming which may include peer-to-peer support groups and befriending programmes in person and online (Killeen, 2015; Mills et al., 2016; Smith et al., 2020). Despite bereavement support being available across the UK in different formats, not all stillbirth bereaved parents access opportunities provided by these organisations. Within the current literature, it appears that minority ethnic parents are less likely to access this type of bereavement support due to the noticeable gap between minority ethnic parent and white parent participation within the baby loss bereavement support research (Cacciatore, 2007; Kingdon et al., 2019; Garcia et al., 2020). Often parents from minority ethnic communities are underrepresented or go underreported within the literature (Downe et al., 2013; Murphy & Cacciatore, 2017; Heazell et al., 2021). The paucity of research representing minority ethnic bereaved parents' experiences fails to recognise the diverse the narratives of baby loss are within different communities who are high risk for perinatal loss (ONS, 2021; MBRRACE, 2021). The aim of this study is to explore how parents from different ethnic communities seek support through befriending programmes and peer support groups and to examine their experiences in selecting the group that is the most appropriate to support them along their grief journey. This project will also highlight barriers felt by parents that lead to them deciding to not engage with peer-to-peer support.

To carry out this work, I follow a Transformative Paradigm (TP) theoretical framework (Mertens, 2007; 2008; 2010; 2011; 2012; 2017) from which the methodology arises. TP emphasizes the link between

social research and action which calls upon research to further investigate social inequity and social justice (Mertens, 2008). Therefore, TP is an appropriate framework from which to explore the experiences of stillbirth in minority communities. I am using a double qualitative mixed methods approach to collect data for this study which involves a core component and a supplementary component (Morse & Niehaus, 2009). Triangulation of qualitative data through different approaches may generate more significant findings compared to a study employing a single method (Briller et al., 2008). The core component project consists of 16 semi-structured interviews with bereaved parents who self-identify as belonging to minority ethnic communities. I use constructivist grounded theory (Charmaz, 2006; 2014) to generate a theory as to why there's such a disparity between minority ethnic families accessing bereavement support (Murray, 2020).

The secondary component features creative methods approach by facilitating the creation of collages by eight participants analysed through thematic analysis. The purpose of incorporating these different research methods is to generate rich data which will better answer the research question highlight the difference of data that is spoken and that which is visually created (Chilton & Scotti, 2014; Yuen, 2018; Dutton et al., 2019). Themes from the collages are discussed and are applied to the generated theory.

I examine my positionality in this research through collage as a reflexive exercise, documenting my experience of grief and loss during my PhD. Throughout the duration of collecting data, I created a series of collages that reflect my experience as a researcher who has experienced personal bereavement and loss during my studies. Incorporating an autoethnographic lens to this project has facilitated a deeper rapport with the research participants and with the topic (Ellis & Bochner, 2000; Ellis, 2009; Ngunjiri Hernandez, & Chang, 2010).

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To my husband, Rob, thank you for your patience and commitment to this relationship when that meant being 180 miles apart for three years. Never have you once complained about the distance. You held on to me and the promise that one day we would be able to live in the same household. I look forward to beginning our married life together.

Dedication

The entire universe can crumble (and it does) and love itself will never leave.

Love is with you here, even, and especially in this.

Love is what sustains us.

When there is nothing else to hold on to, hold on to love.

Let it carry you forward.

-Megan Devine

I dedicate this thesis to my gma, my mom, and other women in my family who came before me and could only have dreamt of pursuing higher education. This study honours the babies in my family we should have known, including my own.

Glossary of terms

Glossary of terms relating to ethnicity (Bhopal, 2004, pp. 442-444)

Ethnicity: The social group a person belongs to and identifies with or is identified with by others. This is a result from a mixture of cultural factors including language, diet, religion, ancestry and physical features.

Asian: Applied to people originating from the Indian subcontinent

African: People with African ancestral origins who self-identify as African

Afro-Caribbean/ African Caribbean: People of African ancestral origins whose family settled in the Caribbean before emigrating and who self-identify as Afro-Caribbean

Black: People with ancestral origins and who self-identify, or is identified as black, African or Afro-Caribbean

European: People with ancestral origins in Europe. Within public health this is often used as a synonym for white/Caucasian

Majority population: When used in ethnicity studies this term is used synonymously for white or European

Minority ethnic group: Phrase often usually used to refer to a non-white population. Used synonymously with ethnic minority group

BAME: Black, Asian, and Minority Ethnic

BME: Black Minority Ethnic

ABM: Arts-based Methods

HIC: High Income Country

NICU: Neonatal Intensive Care Unit

CPTSD: Complex Post Traumatic Stress Disorder

PTSD: Post Traumatic Stress Disorder

APPG: All Party Parliamentary Group

TP: Transformative Paradigm

WHO: World Health Organisation

1 Introduction

The sudden loss of a child who is stillborn is a tragedy for expectant parents. Stillbirth is a silent public health crisis that affects families across the United Kingdom. Babies who are born without any signs of life at or after 24 weeks of pregnancy are considered stillbirths in the United Kingdom (SANDS 2016; Mistry et al., 2013). In 2020, one in every 250 births ended in stillbirth; which roughly translates to 8 babies every day (Tommy's, 2020; NHS 2021). In 2021, the rate of stillbirths increased in England which results to four per 1,000 births (Office of National Statistics (ONS), 2021; SANDS 2022). This amounts to a 9.5% increase compared to 2020 figures (ONS, 2022). What is more important than the figures and statistics about stillbirth is to remember that 8 families each day are losing a loved one and a life that ended too soon. Babies who are born without any signs of life at or after 24 weeks of pregnancy are considered stillbirths in the United Kingdom (SANDS 2016; Mistry et al., 2013). Health care systems exacerbate parents' feelings of shame and failure when there is an absence of considerate bereavement care. Charities in baby loss, such as national charity Stillbirth and Neonatal Deaths (SANDS) operate to support anyone affected by the death of a baby, and to improve the care bereaved parents receive.

Even as risk factors for stillbirth are identified through prevention research, the psychological consequences of stillbirth and therefore interventions have yet to become a priority. Feelings of failure and hopelessness at having a failed pregnancy exacerbates parents' trauma further, (Flenady et al., 2016). Negative psychological symptoms are often reported because of a stillbirth. The Listening to Parents study in the UK (n=472) (Redshaw et al., 2014) found that 35% of mothers and 13% of their partners who experienced stillbirth reported feeling 4 or more negative psychological symptoms 9 months after the birth. In the same study, 9% of mothers and 5% of the partners reported experiencing difficulties in their relationship at the 9-month mark. Other studies (Gold, Sen & Hayward, 2010; Radestad et al., 2009) determined that parents who have a stillborn child are more likely to experience difficulties in their relationship compared to those who have a livebirth child.

There is a lack of rigorous research and interventions to best support families. While it is important to recognise each family grieves in their own unique way according to their culture and belief systems, interventions to support bereaved parents should still be investigated to assure parents are receiving evidence-based support.

1.1 Purpose of the study

This study's purpose is to improve the access and bereavement care pathways for families who experience the loss of a child to stillbirth. The hope is that this research will provide insight into how baby loss charities can better support families who are grieving. Research shows that families from Black, Asian, and other Minority and Ethnic (BAME) backgrounds are statistically more likely to experience stillbirth, yet there has been little to no research examining how bereaved parents from minority ethnic communities access bereavement support. The rationale for the study is to shine a light on how minority ethnic families interact with bereaved parent support programmes through traditional and creative research methods. This study hopes to address the missing literature and support minority ethnic representation within the baby loss research field. My personal hope is to find answers through which charities who make up the National Bereavement Care Pathway (NBCP) can better adapt and employ measures to meet these families' needs.

1.2 Defining ethnicity in this study

In order to conduct this study, it was important to understand the literature around ethnicity and how to define it within the context of the research. A socially constructed construct, ethnicity is a complex concept that is applied to a group of people who share certain attributes, which includes geographical origins, languages, religion, and cultural customs (Senior & Bhopal, 1994; Bhopal, 2004; Bhopal, 2014). The complexity of ethnicity stems from its fluidity and indistinct nature to describe groups of people (Bhopal, 2004). Although often used interchangeably, race and ethnicity are different and should not be confused (Sheldon & Parker, 1992; Senior & Bhopal, 1994). Within health research, ethnicity is often used to compare health outcomes (Bhopal, 2004) because it is a variable which may predict different health problems and health inequalities (Bhopal, 2014).

Ethnic-minority groups and minority ethnic groups are terms which are often applied to minority populations that are non-white (Bhopal, 2004). Minority ethnic group has replaced ethnic minority because some people may regard the term ethnic minority as imprecise (Bhopal, 2004). The terms BAME (Black, Asian and minority ethnic groups) and Black and Minority ethnic (BME) are commonly used within research to describe minority ethnic populations (Dawson et al., 2018), however; BME and BAME are becoming obsolete (Race Disparity Unit, 2022). BAME and BME emphasise Black and Asian populations and disregard other white minority groups (Race Disparity Unit, 2022). Within research studies, participants should have the right to self-identify what their ethnicity is when taking part in research (Bhopal, 2004, 2014; Flanagin, 2021). Self-identification is based off a person's experience of their ethnic community and the relationships they have with others (Young, 2013), and therefore their ethnicity cannot be assigned by someone else.

For the purpose of this thesis, I refer to the study population as 'minority ethnic' because the study was open to bereaved parents who self-identified as being from minority ethnic backgrounds. I defined minority ethnic background as anyone who did not identify as being white-British. Noting how using BAME may isolate some groups from participating, I wanted to make the inclusion criteria as inclusive as possible to facilitate participation from communities who are often hidden within the research. In total there were sixteen participants who self-identified as Asian, Black, and Polish. Following Bhopal's 2004 work on ethnicity, 'Asian' refers to anyone whose heritage is from the Indian subcontinent. 'Black signifies someone who self-identifies as African and or Afro-Caribbean (Bhopal, 2004). Finally, 'European' suggests the person has ancestral ties to Europe (Bhopal, 2004).

1.3 Research aims

The aim of this project is to explore the role of diversity representation in bereaved parents of stillbirth peer support groups. The research questions which stem from this aim are the following:

1. What are minority ethnic parents' reasons for participating or not participating in baby loss bereavement support groups across England?
2. How do bereaved parents describe their experiences of attending peer support groups, and how do they find community within these services? Additionally, how do bereaved parents find meaning of their loss by participating in peer support services?
3. Why do some parents take on leadership roles within these services? How does participating in leadership opportunities impact their outlook on their loss?
4. What types of support are missing for minority ethnic families? What type of ceremonies and rituals are more culturally appropriate to support them through their grief journey?

1.4 Positioning myself as a doctoral researcher

I am a white, cisgender, heterosexual American woman who was raised in a low-income household in the Midwest in the United States of America. I do not have any physical disabilities. I was raised primarily by my widowed grandmother and a single mother when she was well enough to care for me. Despite only graduating from high school, my grandmother worked hard and studied to advance her skillset to become an executive administrative assistant to the Psychology department at the University of Minnesota from where she retired in 2019 at the age of 82. My mom was naturally artistically gifted and interested in fashion design. She began an art degree at a local university, but she withdrew from the programme before she completed it due to her struggle with her mental health. Since she never completed her programme, she found employment in retail management.

My mom struggled with alcoholism and suffered from bipolar disorder type II for most of my childhood. She had a complex relationship with her mental health and substance misuse. Through my studies and the training, I have received, I now see how the two pregnancies she lost might have caused emotional distress which exacerbated her poor mental health. As far as I am aware, her treatments never addressed her experiences of baby loss. During my childhood, she was frequently misdiagnosed with different psychiatric disorders and often prescribed medication that did not help her. Her addiction increased when I was in high school. Due to the poor situation at home during my adolescent years, I did not have the capacity to concentrate on my studies. For most of my high school career, I was preoccupied and worried about my mom's health and safety and did not focus on most of my school subjects. However, my French language teacher was someone I trusted and in whom I confided about the difficulties I experienced at home. She made the effort to tutor me on the weekends, so I could catch up with my classmates. Her interest in me and my education made me want to do well in French. In fact, it was the only class I did well in throughout my high school career. I hid my emotional distress and shame of being a child of an alcoholic (Lee, Scragg, & Turner, 2001) by becoming the class clown which was a role I played well. I was so convincing; my graduating class bestowed a class clown award on me in the 2005 yearbook. It was easier for me to camouflage my poor academic performance by being disruptive and entertaining in class than it was for me to expose the problems that were occurring at home.

One month before graduating from high school, I had a meeting with the school guidance counsellor and my godmother. He shared his concerns about my future and what my future prospects would be with the low grades I had accumulated throughout my four years in high school. In addition, he told me that my low-grade point average would prevent me from pursuing any form of tertiary education. However, he advised I would be an ideal candidate to become a beautician or a secretary. Although this was a short meeting, his words and lack of confidence in my academic abilities have remained in my memory and have habitually haunted me with each degree I have pursued. I believed I was incompetent and only capable of working in low-income roles like my mother.

Regardless of the poor advice I received from the school guidance counsellor, my grandmother encouraged me to get an undergraduate degree. Initially, my grades were too poor to get into a four-year institution, so I went to a technical college to complete general courses to boost my grade point average. I succeeded in receiving a 4.0 grade point average (the highest-grade point average one can receive) and maintained it to the point where I could apply to a four-year institution. I received acceptance letters to all three of the universities to which I applied. Fortuitously, I was a low-income first-generation university student which meant my undergraduate degree was largely subsidised by a US federal programme. Had I come from a family who was more educated, wealthier, or more stable, I would have not been able to receive as much financial aid as I was given.

University gave me the opportunity to explore what my interests and abilities were. I double majored in French and international studies which fostered my interest in working abroad with people from diverse backgrounds. After working in primary education both in the United States and France, I pursued a Master of Arts degree in International Leadership and Public Policy. This degree led me to an opportunity to be a programme manager within the International Student Services as at my undergraduate university. Whilst recruiting international students in Hong Kong, I met an American professor who taught on a global mental health course. We spoke of international opportunities to work in the mental health field, and he encouraged me to apply for the Master of Science (MSc) in Global Mental Health at King's College London (KCL) and London School of Hygiene and Tropical Medicine (LSHTM). Even though I did not have tangible skills to pursue a degree in mental health research, I received an offer to commence this programme with the 2015-2016 cohort. This opportunity was the beginning of my pursuit to become a mental health researcher. During my MSc programme, I developed a specific interest in women's mental health and knew I wanted to continue studying in the field once I had completed my studies. For my MSc dissertation project, I completed a secondary qualitative analysis on the decision-making process of stillbirth bereaved parents consenting to a post-mortem examination. As a result of the connection between my project's subject area and my family's history of perinatal loss, my interest in the maternal mental health field increased and I decided to pursue doctoral studies in this area.

In 2017, I returned to Minnesota after graduating from the MSc in Global Mental Health. I was estranged from my husband and felt out of place trying to reacquaint myself with my American lifestyle. My husband and I enrolled in marriage counselling to explore whether our relationship could be repaired after living apart from each other for the last two years. Whilst we attended our sessions, I was diagnosed with complex Post-Traumatic Stress Disorder (cPTSD) because of my turbulent childhood. Compared to PTSD, complex PTSD differs: 'the complicated clinical presentation of individuals experiencing recurring trauma, particularly of an interpersonal nature', (Dorahy et al., 2008, pp. 72). Receiving a cPTSD diagnosis helped me make sense of the symptoms related to the trauma I experienced (McCormack & Thomson, 2017). It was the beginning of a journey which has helped me to learn how to heal the inner child in me and to better regulate my physical symptoms of anxiety. Moreover, I began a journey to understand my symptoms in a compassionate way and incorporate this diagnosis as a part of me instead of repeating my learned habit of compartmentalising it deep within my body and hiding my struggles with poor mental health.

Since my initial diagnosis in 2017, I have learnt to accept my cPTSD diagnosis and have discovered ways in which I can use therapeutic exercises that I have been taught to self-soothe my body and calm my dysregulated body (Gerge, 2020). At times, my cPTSD symptoms have felt so severe that it impacted my day-to-day activities, which could be considered a disability under the Equality Act 2010. Since I began my doctoral programme in 2018, I have grieved the dissolution of my first marriage, and the deaths of my mother, uncle, and grandmother who were my primary parental figures. I have had regular bi-weekly counselling sessions to manage some of my cPTSD symptoms, yet there are times where I still struggle to feel well. Within the literature, Djelantik et al., (2019) maintain that bereavement can exasperate PTSD symptoms, and that with each loss, I resume my childhood coping mechanism of suppressing my emotional distress (Smith, Wild, & Ehlers, 2020) which conflicts with the positive coping tools I have learned throughout my years of therapy (Karatzias et al., 2019).

In the summer of 2021, I grew increasingly frustrated in my failed attempts to write my thesis as well as or as quickly as some of my peers. Initially I suspected that it was related to my cPTSD diagnosis. It was possible I was experiencing poor concentration as a cPTSD symptom (Djelantik et al., 2019). I also thought that perhaps it was related to the recent loss of my Uncle Bill because the research has shown that grief can have a negative impact on a bereaved person's academic resilience to focus on their studies (Greene, 2020). My mind felt like there was something *wrong.* I had several conversations with my peers to explore whether they had experienced any of the sensations I described (limited attention span, inability to focus for long, distracted), but no one had. My symptoms were more severe than the stress of writing a thesis. I could not stop making constant comparisons to my peers' progress. It provoked me to seek out advice from my therapist and academic support services to determine whether I had a learning disability. From the results of the Attention Deficit Disorder (ADD) assessments, I was diagnosed with ADD, which is often linked with trauma and a diagnosis of PTSD (Adler et al., 2004; Ruhl et al., 2009; Antshel et al., 2013). Due to my international student status, I was unable to receive a formal diagnosis or formal academic support from the university. Additionally, I was not eligible for the Disabled Students Allowance (Peake, 2016). I was granted a support plan for my cPTSD, so that I could be additionally supported through the recent diagnosis of ADD.

Within the last year, I have tried to understand how to cope with my ADD symptoms to the best of my ability which included ongoing private counselling, and most recently anti-depressants to mitigate some of the ADD symptoms (Hile, 2020). Navigating treatment options felt like a challenging process and this was made more difficult as ADD is viewed differently in the UK and USA. The decision to begin an anti-depressant therapy was a decision I reflected on for several weeks before beginning the medication. I was haunted by my mother's struggle with finding an appropriate medication to help her manage her poor mental health. I imagined the possibility of trying several medications before finding one that would work for me. At times, I have felt that the combination of my cPTSD and ADD symptoms have severely obstructed me from progressing my research, and yet, I'm thankful that I had access to an excellent therapist and compassionate supervisors who see my potential beyond these diagnoses.

Most people I encounter would never recognise that I struggle with poor mental health and a newly diagnosed learning disability. I have learned to hide my mental health symptoms to avoid exposure and potential personal harm that I fear may develop from disclosing this information. As I reflect upon my time within higher education, both in the United States and in the United Kingdom, I recognise my apprehension in terms of disclosing sensitive information about myself within the higher education system, which could be more harmful than helpful. As Rice-Evans and Stella (2017, pp. 26) maintains that 'the double edge is this: disclose and face increased surveillance, policing, and marginalization; attempt to 'pass' and face emotional and psychic exhaustion from constantly performing a more functional, neurotypical- and false- version of yourself". I wrestled with divulging my truth as a researcher with poor mental health and as someone who is researching grief and bereavement as a bereaved person because I did not want to be stigmatised by the University for being 'vulnerable'. Research by Markoulakis and Kirsch (2013) found students with poor mental health felt that they were stigmatised by university policies. For my ethics application, I included a letter from my therapist and two supervisors to demonstrate that I was fit enough to conduct my research despite being someone with poor mental health.

I have fought to be authentic and candid about my mental health struggles in the University which often is ableist and does not accommodate those who are disabled (Horton & Tucker, 2013). Furthermore, traumatic experiences have not been properly addressed by higher education institutions (Rice-Evans & Stella, 2017). I identify with Horton and Tucker (2013) and Rice-Evans and Stella's (2017) work. Whilst I feel vulnerable disclosing my history of poor mental, learning disability, and my grief journey, I prefer to risk revealing my mental and learning disabilities to help to reduce the stigma within the University system and to advocate for other students and staff with mental health concerns (Price, et al., 2017). As someone with lived experience of mental illness, I see the first step to changing the culture within the university is to speak about mental health concerns (Peake, 2016). However, this doesn't go without challenges. As an international student, if I didn't carry on with my studies, I would have lost my student visa. Additionally, my international student status limited the ways in which I could seek support. I resorted to developing a learning support plan with a mental health advisor because I couldn't access learning disability support.

1.5 My journey seeking out bereavement support

Over the course of this degree, I have experienced immense grief and loss. When I began my studies in February 2018, I had just finalised my divorce, and I said goodbye to my hometown and the home I had built with my first husband. At the end of the first year of my degree, my mom died on Christmas Day 2018 from septic pneumonia. Although I had known my mother wouldn't have a long life due to her struggle with substance use, I was unprepared for her death. Whilst alcohol didn't make her catch pneumonia, it did leave her body vulnerable to infections. My world changed in a matter of minutes on 22nd December when I spoke to her doctor, who confirmed she was unresponsive to treatment and unlikely to live. I flew home the next morning to be with my family and to say goodbye to my mom. My sister, grandma, my ex-husband, and I took shifts between the evenings of 23rd December to the late hours on 25th December to spend time and finding ways to reconcile our relationships with her. My mom's death unmasked years of emotions related to my mom and her substance use that I had learned how to disguise as a coping mechanism (Ford et al., 2016). I had internal debates about whether I should return to England to pursue my PhD; her passing made me question my self-esteem (Boelen, van den Hout, & van den Bout, 2006) and my ability to study (Abdelnoor & Hollins, 2004). Ultimately, I did return to the UK to continue my studies in honour of my siblings, and now my mom. I found solace grieving from afar, knowing that the literal distance to my pain was several thousand miles. In the literature, distance which separates the grieving from their grief is a buffer which may protect against prolonged grief (Nesteruk, 2017).

At the time my mom died, I was 30 years old. Emerging adults, people aged 18 to 30 are susceptible to experiencing complicated grief (Sheer et al., 2011; Brent et al., 2012), and I wanted to prevent further complications to my mental health issues. Inspired by this doctoral research project, I decided to seek out bereavement peer support groups to help process my grief. I believed connecting with other bereaved people would help me process my grief. A systematic review of 32 studies by Bartone et al., (2017) found that peer support was beneficial to the bereaved person. Participants of peer support programmes experienced less grief symptoms and found their participation fostered personal growth and reflection (Bartone et al., 2017).

There was only one charity which supported young adults who lost parents to addiction related illnesses. They were based in Oxfordshire and held meetings quarterly. Because of the distance, I didn't attend the peer support group hosted by this charity. Instead, I found my local Cruse Bereavement Care peer support group in Bromley. After reading the literature around baby loss peer support groups, I anticipated receiving the same amount of support. However, I did not feel the experienced had matched my expectations. I was the only female participant, the only member grieving the loss of a parent, and the only person whose loss was connected to alcoholism and substance use. Additionally, I perceived my experience of grief to be more detached compared to the other members' grief because I was grieving transnationally (Nesteruk, 2018). I felt my experience was misunderstood and unrecognised by the group facilitator. It was the only in-person peer support group meeting I attended.

Although I didn't enjoy my one bereavement peer support session led by Cruse Bereavement Care, I believed that I would benefit from being a part of a group meant for grieving people. Eventually I found

Let’s Talk About Loss, which is a charity which hosts a creative writing group designed for bereaved people aged 18-35 in a private online space. The purpose of the group is to help facilitate grieving young adults to use creativity to write about their grief journeys. Since I joined in 2020, I have attended several writing sessions. Usually there are four meetings per year. The writing groups are facilitated by a peer support group facilitator who has writing prompts to guide the two-hour sessions. Leaders guide the group to use these writing prompts as a way for participants to reflect upon their grief journeys. Usually there are two themed time challenges. Once the challenge is finished, people are invited to read their work. Participants are encouraged to publish their pieces, but I prefer to keep mine private. The act of creating a piece of writing is sufficient for me to connect to my feelings related to my grief (Valentine & Walter, 2015).

Being creative is useful to process loss (Valentine & Walter, 2015), and finding a way to use creativity as an outlet for my grief has been beneficial in my grief journey. I appreciate that I can access the group from the comfort of my home. I enjoy virtually meeting young people and emerging adults across the UK who understand what it is like to miss loved ones; I found most people in this group are grieving the loss of a parent. I feel less alone, which is also a sentiment found in the literature on bereavement peer support (Rice, Bennet & Billingsley, 2014). Additionally, attending this writing group has helped me make sense of my mom’s death (Feigelman, Jordan, & Gorman, 2009) by releasing some of my emotions onto paper.

Below is a poem I wrote upon during a group meeting in early 2022. It was a poem to my grandmother who passed in autumn 2021 (her death and my uncle’s death will be discussed in chapter 12). The theme for the session was astronomy and space. Participants were challenged to write a poem on the topic of astronomy. This poem reflects upon my experience of grieving the loss of my loved ones whilst I’m not in my home country.

No Outer Space, Just Space

Distance . . .

Distance is calculated in miles

But how can it measure space that no longer exists.

The building that's technically a house remains, and yet it's no one's home anymore.

Google can estimate the length of time for me to cut through each time zone and go from day to night back to day in a return flight

And yet why do I try to convince myself I want to go backwards in time. I'm better in the present.

Location . . .

You joined mom and Bill; the three of you are out there.

There, where space isn't a precise point on a map

Every evening, I walk back home in dusk and look up to the night sky as if it's a portal that helps me speak to you directly

It's as real as Facetime and Skype.

Those, too, after all were conversations in space.

Do you hear me when I speak? Do you notice how I designate which sunsets are for you and which are mom?

A promise to remember you and a habit I want to observe for myself

Periwinkle, violets, navy, too. Those hues of blue remind me of all the clothes still left in your closet that I'll have to sort sooner than later.

These colours are your spaceship back to me

They can reach you before any smart phone feature can.

And yet . . .

I can hear your voice cut through the nightfall saying 'oh hi, honey' through distance and space between us.

1.6 Positioning myself to the research topic

Within qualitative research, it is critical for the researcher to recognise the position she holds by examining her position in relation to the research topic and data (Pitard, 2017). Cromby & Nightingale (1999) write that reflexivity can be separated into two facets: the personal and the epistemological. Reflexivity examined through a personal lens is defined as examining how the researcher's values and life experiences impact the research, conversely, epistemological reflexivity questions how the researcher's identity may have influenced the research (Pitard, 2017). Charlene Haddock Seigfried, who was a pragmatic feminist researcher, wrote "the researcher is not a neutral observer, but on the same plane as the subject matter" (Haddock Seigfried, 1996 as cited by Tarver, 2007 pp.279).

My understanding of grief and bereavement was strongly influenced by a childhood where I knew I had siblings and cousins who were not living. My upbringing was veiled in my family's experiences of grief and bereavement; I understood how death impacted on a family at a young age. I had experience of the concept of loss way before some of my peers at school. Despite the sequence of losses which I have endured over the past four years, I found working on a research project on pregnancy loss has enabled a positive understanding of my family's intergenerational pain of disenfranchised grief of child loss (Gajdos, 2002). Whilst my siblings and cousins were named and openly discussed within our familial system, I am conscious of the stigma related to discussing their grief outside my family (Pollock et al., 2020). The exposure to grief at a young age and caring for a mother with poor mental health equipped me with the skills to work in a sensitive field such as baby loss. Whilst multigenerational grief has shaped me as a person, I have tried not to repeat the same patterns (Gajdos, 2002) of concealing my grief within the boundaries of my family, particularly when we were collectively grieving the deaths of three prominent people in our family. I speak openly of my grief to destigmatise it and to honour the changes I have experienced within myself because of my own grief journey (Clarke, 2020).

From an epistemological perspective, I am a white American woman from a working-class background who is a first-generation doctoral student and the first member of my family to pursue an advanced degree. I have never experienced interpersonal discrimination nor systemic racism as some of my participatants in this study have. Whereas I am a person who has experienced multiple losses of varying degrees, I consider myself to be an "insider" in the context of the research topic (Mannay, 2010; Berkovic et al., 2020). Furthermore, I am a sibling to two stillborn children, and have experienced the impact of baby loss on a family's structure. As an 'insider' this identifies me as being a researcher who is familiar with the experiences of their participants (Browne, 2003). However, I am an "outsider" in relation to understanding the experiences of grief through the lens of people from minority ethnic communities (Acker, 2000). I cannot understand how systemic racism has impacted on the healthcare I access and the care I receive from healthcare workers (Ahlberg et al., 2019).

It is important to note that positioning oneself in the research goes beyond the demographics of the researcher and acknowledges the researcher's beliefs (Pitard, 2017). Throughout this thesis, I maintain my position as a pragmatic feminist researcher and acknowledged my identity as a researcher to understand how I have practised reflexivity throughout the course of this doctoral study. Pragmatic feminist researchers argue that traditional philosophies tend to prefer logic which reduces the obscure nature of the human experience (Whipps & Lake, 2020). Nevertheless, to be reflexive requires the researcher to engage in more abstract ways of thinking (Doyle, 2013).

Within feminism and pragmatism, there is room for multiple experiences to exist rather than one formal reality (Feeley, Thomson, & Downe, 2020). Within this combined paradigm, it's necessary to include multiple individual experiences so that different perspectives may be employed which enables the development of practical solutions to problems (Whipps & Lake, 2020). Pragmatic feminist researchers advocate for change within unjust social and political systems (Whipps & Lake, 2020) by integrating theory into practice (Tarver, 2007). In the context of this research project, as a pragmatic feminist researcher I have acknowledged the existence of the multiplicity of stillbirth bereaved parents' perspectives when accessing baby loss peer support programmes. As such this pluralistic model seeks to find solutions for this issue (Franks, 2002). Within pragmatic feminism the focus is on achieving certain objectives (Klages, 1997 as cited by Franks, 2002) which appeals to me. I did not merely want to conduct research which would produce knowledge; I wanted my work to contribute to what is known about the topic and to provide a voice to bereaved parents so that bereavement support could be enhanced for this community.

Whilst there is more that I could write from my personal and epistemological viewpoints, it would be outside the scope of this thesis. As Franks (2002) writes: the practice of research and methodologies in which research is conducted originates from the circumstances in which the researcher finds themselves. Had I not had a lived experience of baby loss within my family, I might not have had the enthusiasm or skills to carry out this research project despite overcoming the challenges I have faced personally.

1.7 Collaborating with professionals in the maternal health field

The findings from this study add new knowledge to the perinatal loss field and to the existing literature on baby loss. This study intends to expand the field to be more inclusive and equitable to populations who are most at risk of experiencing perinatal loss, yet whose experiences are often ignored in qualitative research. Collage is used to explore grief and bereavement creatively which will add a new outlook on baby loss through arts-based methods. Additionally, I have added input to the field through the following contributions:

I have published an article about using creative methods in baby loss research in The British Psychological Society so that my research extends its reach to professionals who work with bereaved parents. I plan to publish the collage findings and the reflexivity chapter. The following reference is the article I published with my first supervisor, Dr Jacqueline Wier in 2020.

McCloskey, E. & Wier, J. (2020). Implementing creative methods in baby loss research: Exploring stillbirth bereaved parents' journeys through collage. *QMiP Bulletin,* 30 (Autumn), pp. 51-61

I was invited to join the All Party Parliamentary Group (APPG) on Baby loss in 2019 which is comprised of members of parliament, clinicians, charities, researchers, commissioners, and bereaved parents. I promoted my study to boost recruitment efforts in 2019, and I plan on presenting findings of my study later this year. I have been an active APPG member as a doctoral student and I intend to maintain my status once my programme has finished. At the APPG meetings, I met several key contacts who have helped me disseminate my recruitment flyers. With the support of the bereavement midwives who are active members of the APPG, I presented twice at the national bereavement midwives forum.

During my time at Canterbury Christ Church University, I led several qualitative research methods seminars with midwifery and nursing students during my course. In addition, I have led seminars to healthcare practitioners on the importance of delivering trauma-informed care to bereaved parents.
In March 2022, I co-led a creative methods workshop with another doctoral candidate to nursing and nursing associate faculty.

To disseminate my findings, I submitted an autoethnographic collage for a poster competition for the 2019 Social Research Association conference. Although I was accepted to present at the 2020 Qualitative Research on Mental Health Conference, this occasion was cancelled due to the pandemic. In 2021, I presented early findings from the collage data at the School of Nursing, Midwifery, and Social Work Annual Research Conference. In May 2022, I presented my study at the Post Graduate Research Association conference where CCCU postgraduate research students present their doctoral projects.

To give back to the bereaved parents who participated in this study, I will produce an executive summary which will be sent to them and to the community partner organisations which assisted recruitment efforts. Building relationships with baby loss charities and the bereaved parents who support their efforts has been a meaningful experience.

1.8 Summary of thesis

This thesis offers a unique contribution to the health sciences by applying the traditional method of semi-structured interviews and the creative method of collage. Data were collected in March 2020 to November 2020. There was a total of sixteen participants who participated in semi-structured interviews: thirteen mothers and three fathers. Eight mothers took part in the collage-making activity. I applied constructivist grounded theory to the semi-structured interviews (Charmaz, 2006;2014) to develop a theory on how minority bereaved parents access baby loss peer support groups. For the visual collage data, I analysed the data under thematic analysis (Braun & Clark, 2006).

Table 1 provides a summary of this thesis. It highlights the titles and purpose of each chapter to guide the reader on how this thesis is constructed.

Table 1: Thesis structure

Chapter	Title	Purpose of the chapter
Chapter 1	Introduction	Provides the reader background of the research topic and introduces the doctoral candidate as a researcher and her personal experience of grief and bereavement.
Chapter 2	Defining my theoretical framework	Introduces the researcher's outlook on theoretical positions
Chapter 3	Literature review	Gives an account of the available literature on stillbirth and current resources available to grieving families. This literature review underscores the missing literature on minority ethnic families' experience of pregnancy loss.
Chapter 4	Methods	Offers a detailed description of the methods used in this study and how the research was conducted

Chapter 5	Results of the semi-structured interviews	Presents the results of the semi-structured interviews. Quotes are imbedded within the chapter to provide context to the findings.
Chapter 6	Results of collage-elicitation exercise	Presents the results of the collage-making activity and presents the themes from the thematic analysis
Chapter 7	Generating a constructivist grounded theory	Provide an account of how the constructivist grounded theory was developed
Chapter 8	Explanation of Road to Hope through Grief Theory and discussion of the theory	Detailed account of how the RTHTG theory is discussed. Explains the different stages of the theory.
Chapter 9	Researcher Reflexivity	Presents findings of the researcher’s reflexivity collage-making exercise and how it contributes to new knowledge
Chapter 10	Conclusion	Provides an explanation of the overall findings of the study and how this piece of work contributes to the field. Discusses the strengths, limitations, and recommendations for future work in the perinatal loss field

2 Defining my theoretical framework

2.1 Introduction to the chapter

The following chapter will discuss my ontological, epistemological, axiological positions.

2.2 Ontology: Nature of reality

Ontology seeks to define what reality is on a conceptual level by asking the question: what is real, and, by extension of this question, what is truth? (Mertens, 2009). The transformative lens in answering this question is grounded in acknowledging the role of power and how power grants which version or reality is recognized as "real", (Mertens, 2009). Mertens argues the ontological assumption of this framework argues "what we can know of what exists, or the reality that we accept as true, is socially constructed", (2009, p.53), from which she argues there are some individuals who hold positions that can influence power and control over individuals who are likely to be excluded from decisions about what the accepted definition says of what exists. Exploring and eventually understanding how "various viewpoints within a political, cultural, and economic value system to understand the basis for the differences' give way to revealing how certain perspectives on reality become privileged over others" (Mertens, 1999 as cited by Romm, 2015, p. 413). Under the transformative paradigm (TP) umbrella, the ontological assumption rebuffs cultural relativism because cultural "relativism allows multiple definitions of realities to be true (Mertens, 2009, p. 48)", which would permit variations of discrimination and oppression to coexist within the realities they perceive as true. However, TP does acknowledge that multiple realities are socially constructed and contributing factors related to those experiences that keep those in power in place do need to be investigated.

The influence of privilege and power impact reality and determine what is real in the context of society (Mertens, 2003). Power is implicit and permeates the research and evaluation world by determining what experiences and realities are perceived as "researchable" (Mertens, 2009). Indoctrinated into the culture, the role of power under the transformational lens is evident in what area of work receive funding; what communities participate in the research; and what product of change comes as a result from the research (Mertens, 2009). Further examining the role of power in the stillbirth research field, one can argue that the academic literature is skewed towards clinical work focusing on preventative measures than there is for psychosocial support for families who have had a stillborn.

2.3 Deficit perspective

Within the social science research realm, it is important to consider how the research question is phrased. Historically, social science research has supported deciphering and explaining deficits within the community being researched (Mertens, 2009, p. 18). Chiu (2003) argues that much of the research conducted in minority ethnic communities arrives from a destructive theoretical and methodological stance where studies focus on community deficits which derive inconclusive and contradictory results. As a researcher in the field of minority ethnic women and health care, Chiu (2003) argues that researchers tend to focus solely on communication and cultural deficits without acknowledging the greater social context. “The narrow focus on language and culture as barriers to uptake of services has not only hindered a wider theoretical understanding of the problems, but also has had the effect of perpetuating ineffective health promotion practice”, (Chiu, 2003, p. 167). When research is conducted in this manner, the strengths in that community are not recognized. “The need for transformative research and evaluation is evident in scholarly research literature that addresses experiences of marginalized groups from a perspective of access to appropriate services” (Mertens, 2009, p. 25).

Following Mertens’ and Chiu’s work on deficit research, researching this specific research question would look like the following: The government, medical community, public health and social science researchers have published papers stating that BME communities are more susceptible to poor birth outcomes including the increased risk of stillbirth (Cacciatore, 2007; Heazell et al., 2016; Mistry et al., 2013; ONS, 2013). Publications have been made calling for more psychological support for bereaved parents (Cote-Arsenault and Donato, 2011; Flenady et al., 2011; Heazell et al., 2015), however the few studies that are within the literature focusing on peer support groups for parents do not include enough representation or voices from BME participants (Cacciatore 2007; 2010). Good representation and a change of focus from deficit to resiliency research is needed because there are people’s health and wellbeing at stake. “The voices of those who are disenfranchised on the basis of gender, race/ethnicity, disability, or other characteristics remind us of the issues of power that surround so much of the public sphere, even those supposedly neutral and objective worlds of research and evaluation”, (Mertens, 2009, p. 29).

2.4 Epistemology: Nature of knowledge

Epistemology is a part of philosophy concerned with the theory of knowledge, and how the researcher uses her philosophical paradigm in guiding her own philosophical assumptions about the research and the way in which she selects the tools, instruments, participants and methods to employ in the study (Mertens, Holmes, & Harris, 2009; Willig, 2008). Mertens explains that the epistemology of TP defines the nature of knowledge through the collaboration between researchers and the participants of the study to achieve an understanding of what appropriate knowledge is within the transformative change, rooted in social justice and change (2009, p.56,). “Knowledge is socially and historically located within a complex cultural context”, (Mertens, 2009, p. 48). For researchers to access knowledge of a community’s reality, it is necessary to establish an interactive link between the researcher/evaluator and the participants in the study (Mertens, 2003). The relationship between researcher and communities are interactive and empowering; relationships are developed and nurtured with appropriate cultural sensitivity and awareness (Mertens, 2008).

Developing trust with participants is critical in the transformative epistemological lens (Mertens, 2009). TP supports culturally competent relationships between the researcher and the community members. A mean through which trust is established is being cognizant of power relations (including but not limited to race, gender, sexual orientation, class, nationality, etc.) between the researcher and participants (Mertens, 2008). Maintaining active awareness of power calls upon the researcher to question her unearned privilege: the superiority of whiteness (Kendall, 2006). Kendall argues that although the power of whiteness was created by some white men, it affects all white people as a social construct and the world we live in and the systems we perpetuate. Kendall (2006, p.63) writes:

"We must be aware of how the power holders oppressed all people of colour to shape the country as they wanted it. Racism is one of several systems of oppression. Others are class, sexism, heterosexism, the institutionalised primacy of Christianity, and able-bodiedism. These systems work toward a common goal: to maintain power and control in the hands of the wealthy, white, heterosexual, Christian, able-bodied men. Examining the intersections is essential to understanding the intentional and finely crafted nature of the system"

Despite the immensity, whiteness is as a social construct, Kendall (2006, p.62) argues that the system is not impervious to change. By using the white privilege in a way to dismantle the system that maintains whiteness superiority in place, the goal to create change can be achieved. Researchers serve a dual purpose in that they can play a role as a supportive activist in the community in which they conduct their work, and in the academic world where they challenge the prevailing research establishment (Dillard, 2000, as cited by Mertens, 2009, p.59).

2.5 Axiology: Nature of human knowledge

TP's axiological assumption is rooted in human rights and social justice (Mertens, 2009). The three main ethical principles are: respect, beneficence, and justice (Mertens, 2009). These values go beyond showing a commitment to an ethics committee at a university, in that researchers should pursue active quests to further social justice initiatives within the context of the research and incorporate those themes into the research agenda (Romms, 2015). Respect can be achieved and maintained through critically examining their interactions with the diverse communities in which researchers work with and across cultural lines (Mertens, 2008). Researchers risk perpetuating both discrimination and oppression by not thoroughly spending time understanding the communities in which they work to contest the societal processes that allow the status quo to exist (Mertens, 2009, p.48). Mertens defines beneficence as the act of promoting human rights and an increase in social justice through research

(2009, p. 49). Under the TP, research is expected to remain active after its collected and disseminated; the connection between the process and the outcomes of research should be developed under the social justice agenda (Mertens, 2005; 2008; 2009). Research ethics under this paradigm should include space for other knowledge systems, those outside the Eurocentric epistemologies, and acknowledge communities' cultural knowledge and to legitimize the research findings, (Chilisa, 2005, as cited by Mertens, 2009 p. 62).

Ethical accountability is central to the transformative paradigm, and "drives the formulation of the three other belief systems (ontology, epistemology, and methodology)", (Mertens, 2010 p.470). While some mixed-method authors associate mixed-method research with pragmatism to explain their underpinning of using more than one method, Mertens prefers to use the essence of TP as the philosophical basis for using mixed methods, which asks researchers how mixed methods might serve as medium to achieve some form of social justice (Romms, 2015).

3 Literature review

3.1 Introduction to the chapter

A health system's response to the care of families who experience stillbirth and the health professionals who attend those affected is a marker of a health system's overall performance. SANDS and other parent led campaigns have called for the increased need in research for prevention and care after stillbirth (SANDS, 2016). There have been two stillbirth series published in The Lancet (Froen et al., 2011 and Froen et al.,2016). Both series call upon the international community to reduce risk factors, increase research within the area, provide better bereavement care for parents and to include stillbirths in reporting health systems. The first Series' success led to the recognition of stillbirth as a vital part of the 2015 Global Strategy for Women's Children's and Adolescents' Health, which makes maternal and child health a priority in the ongoing sustainable development goals. The second Series calls to end preventable global stillbirth deaths by 2030, which would result in 21 million stillbirths prevented (Chou et al., 2015). Authors of the series argue prevention is realistic, cost-effective, and more importantly will have long term effects on child-development while reducing maternal and baby morbidity outcomes (Horton & Samarasekera 2016; de Bernis et al., 2016). Although the first Series garnered global attention, the slow progress in reducing the number of stillbirths shows that there has been only minor headway (Goldberg et al., 2011; Mullen & Horton 2011), especially in the UK where the rate of stillbirth is higher compared to other high-income countries (Draper et al., as cited by Kingdon et al., 2019).

3.2 Defining stillbirth

Globally, 2.6 million stillbirths happen per annum, of which nearly forty percent occur during labour (UN-IGME, 2020). Stillbirth, or foetal death, is defined as a baby born with no signs of life. In fact, stillbirths account for twice as many deaths as due to HIV/AIDS but have failed to receive as much attention and action, causing it to be an unrecognized global health issue (Scott 2011). Efforts to reduce stillbirths lag those for maternal or neonatal deaths (Blencowe et al., 2016). Despite figures that show 98% of stillbirths occur in south Asia and sub-Saharan Africa, the rates of stillbirth in high income countries (HICs) have remained consistent. Current literature estimates that 1 in 200 pregnancies result in stillbirth in HICs (Hennegan, Henderson, Redshaw 2015). Most HIC stillbirths occur in the antepartum period (Goldenberg et al., 2011; UNGA, 2015). In the *Lancet* 2016 stillbirth series, high-income countries accounted for around 3.5 per 1000 births that end in stillbirth (Smith et. al, 2018).

However, defining which births qualify as stillbirths versus a late term miscarriage is difficult, because there is not a homogenised definition recognised by the international community which clearly states at which week of gestation the loss of a baby is recognized as a stillbirth. The burden of stillbirth has generally been underestimated due to the World Health Organisation (WHO) putting forth guidelines which recognise a gestational age cut-off of 28 completed weeks for comparing international rates of stillbirth, despite WHO also recommending states document that 22 completed weeks of gestation qualifies as stillbirth for in country documentation purposes (WHO, 2017, Smith et al., 2018). Within this discrepancy of accountability and guidance lies inaccurate and unreliable international comparisons for research, prevention efforts and more importantly sufficient bereavement care for families (Flenady et al., 2016, Zeitlan et al., 2016).

WHO defines stillbirth according to the 10th edition of the International Classification of Diseases (ICD-10), which was created several decades ago before gestational age assessment was measured (Blencowe et al, 2016). ICD-10 defines stillbirth as a birthweight of 1000 grams or more. If the birthweight is not available, a gestational age of 28 weeks or more, or a measurement of 35 centimetres or more. For miscarriage, the corresponding values are 500 grams of weight, 22 weeks of gestation completed, or 25 centimetres or more. Research conducted by Mahangoo et al. (2013) argues that defining stillbirth through a gestational age threshold is more appropriate because it serves as a better predictor of maturity and therefore viability than using birthweight, considering many foetuses at risk of stillbirth or preterm birth experience preceding foetal growth restrictions (Mahangoo et al, 2013). Information about gestational age is more widely available than birthweight for many stillbirths using ultrasounds, which is now a standard of care in high-income and middle-income countries.

Smith et al. (2018) argued that the accurate rate at which stillbirths are recorded in each country could be missing as stillbirths that occur in earlier pregnancy are not being recognised. Quantifying stillbirths has a major influence on reported stillbirth rates at early gestations; especially those at 22 weeks to less than 24 weeks (Smith et al., 2018). There has been little international comparison of stillbirths by WHO under 28 weeks gestation. Smith concluded that 32% of stillbirths would be excluded by only reporting deaths at 28 weeks of gestation or more. Excluding earlier gestations, especially those between 22-28 weeks, could mean that the stillbirth rate in high-income countries could be gravely underestimated. In terms of providing parents with emotional and mental support, failure to count earlier gestation stillbirth also dismisses the heartache and pain suffered by many parents and families who have experienced earlier gestation foetal death or stillbirth (Heazell et al., 2016). To families who experience this type of loss, a second trimester stillbirth is no less a tragedy than a stillbirth at 28 completed weeks and onward. In the 2011 *Lancet* series on stillbirth, Mullan and Horton emphasised that "to a mother and father, a stillbirth is no less a tragedy than the death of a newborn baby or child", and that parents deserve the "recognition of their loss and reassurance that an accurate record of it will add to the global knowledge required to prevent future ones", (Mullan & Horton, 2011).

3.2.1 Stillbirth in the United Kingdom

In the United Kingdom, stillbirth is defined as an infant born with no life signs at or after 24-week gestation. In 1992, the Still-Birth (Definition) Act became law, which transformed the definition of a stillbirth from 28 or more weeks complete gestation to 24 or more weeks completed gestation (UK Government, 1992 SEE HARVARD REFERENCING BOOK). The change in law permitted bereaved parents to register their baby's birth, file for a stillbirth certificate, and organise a formal cremation or burial for the baby (UK legislation, 1992). The UK has one of the highest stillbirth rates in high-income countries and has decreased slower compared to other countries (Flenady et a.l., 2016). Stillbirth rates have varied from the 1980's which supports the argument that further efforts to reduce stillbirth is achievable (Flenady et al., 2016). In 2020, the number of stillbirths in England and Wales decreased 6% (3.9 stillbirths per 1,000 births) to 2,371 (ONS, 2020). However, there was more than a 7% increase (4.2 stillbirths per 1,000 births) (ONS, 2021). The Covid-19 pandemic negatively impacted the rates of stillbirth and maternity services (Khalil et al., 2020).

Over half of stillbirths (52%) in England and Wales are unexplained (Parliamentary Office of Science & Technology, 2016). Most expectant parents are uninformed about stillbirths, and ill prepared to process warning signs to seek medical attention. More importantly, proximal risk factors such as smoking, obesity and advanced maternal age may increase their odds of losing their baby (Flenady et al., 2011). Research shows that despite many guidelines to improve care in the UK existing, there is little implementation of these guidelines (Parliamentary Office of Science & Technology, 2016). Still, the UK government has implemented a plan which aims to reduce the rate of stillbirth by 2025 (O'Connor, 2016). Even with an overall low stillbirth burden in wealthier countries, families still endure differing rates of stillbirth based upon social factors and the location within a country where the child is born.

3.2.2 Health inequalities pertaining to minority ethnic populations in the United Kingdom

Social and racial inequality are major risk factors of stillbirth. Across the UK, inequalities of perinatal loss continue to persist and are attributed to a range of factors. Black and Asian families continue to be more at risk of perinatal loss compared to white British families (Garcia et al., 2015; Matthews et al., 2022). Extensive inequalities in infant mortality rates exist between white and minority ethnic groups in both England and Wales (Gray et al., 2009). In fact, an ONS report which reviewed infant mortality between 2007 to 2019 showed that as stillbirth rates fell for white ethnic groups, Black and Asian continued to rise (Maddox, 2021). Currently, Black babies born in the UK are more than twice as likely to be stillborn compared to white babies; rates of stillbirth and neonatal mortality in Asian babies is nearly 60% more likely to occur compared to white babies (Waters, 2022). Although the rate of stillbirth per ethnic communities is known, there is limited research in identifying the causes of stillbirth among these ethnic groups (Matthews et al., 2022).

One explanation is that minority ethnic families in the UK experience more socioeconomic hardships and may experience more health problems compared to their white counterparts (Oakley et al., 2009; Matthews et al., 2022). Furthermore, women from minority ethnic backgrounds from lower socioeconomic groups have higher risk factors of teenage pregnancy, obesity, smoking, mental illness, and are more likely to have stillbirths caused by infection (Parliamentary Office of Science & Technology, 2016; Jardine et al., 2021). Obesity defined as a body mass index >30, pre-existing diabetes, smoking, and mental health issues were associated also contributed to the increased risk (Denison et al., 2018; Public Health England, 2019). Within the research published by the ONS (2013), Pakistani, Black African, Black Caribbean and Bangladeshi babies were more likely to be raised in areas of high deprivation compared to white British and white other babies. Additionally, it is these communities who are more likely to experience stillbirth related to congenital abnormalities (Matthews et al., 2022). "The risk of stillbirth and infant mortality is higher in communities where marriages occur between couples with at least one shared ancestor (great grandparent or closer), such as some UK born Pakistani communities", (Parliamentary Office of Science & Technology, 2016, p.3). Other possible factors include variation in the lengths of gestation and in birthweight, and the ability to access antenatal and postnatal care. Although there is limited research, it is possible that minority ethnic communities experience poorer pregnancy outcomes due to pollution (Jardine et al., 2021).

A 2005 study conducted by the Fawcett Society (Dustin, 2005), a charity campaigning for gender equality and women's rights, minority ethnic women were poorer, less educated, less healthy than both white women and the rest of the UK population. The report found glaring inequalities; one of which being babies born to immigrant Pakistani mothers were more than twice as likely to die in their first weeks of life compared to babies born to British-born mothers (Fawcett Society, 2005). The Fawcett Society (2005) also reported that two-fifths of Asian and black women live in poverty, twice the rate of white women. Minority ethnic women were found to be underrepresented in positions of power, suggesting minority ethnic women experiences are often overlooked and often not included within research.

A 2013 population study conducted by Garosi and et al. evaluated the main risk factors associated with stillbirth in an unspecified multi-ethnic English maternity population within the West Midlands. Their work investigated the role of demographic, social and medical risk factors and how that could contribute to the incidence of stillbirths. African, African-Caribbean, Indian and first-generation migrants from Pakistan were significantly associated with higher stillbirth rates. This meant that each of the main minority groups within this population-based study had an increased risk of stillbirth. Women who were or had a partner who was unemployed along with women who lived in disadvantaged areas also had an elevated risk of stillbirth. Experiencing mental health issues was a considerable risk factor reported by over 11% of the mothers. Garosi et al. (2013) attribute it to research that has found a link between poor mental health and poor lifestyle choices such as substance use in pregnancy and poor antenatal health seeking behaviours (King-Hele et al., 2009). However, the highest risk of stillbirth was found in pregnancies with foetal growth restriction. Often, foetal growth restriction doesn't begin to show until the third trimester which illuminates that within this population early detection has the potential to reduce the leading risk factor (Gardosi et al., 2013). Gardosi et al.'s (2013) findings matched the findings of Flenady et al., (2011), however foetal growth restriction, which is difficult to predict and recognize in pregnancy, was determined to be the single largest contributor to an increased risk for stillbirth

A population-based retrospective study by Seaton et al. (2012), socioeconomic inequalities in overall and cause-specific stillbirth rates in England were examined over an 8-year period. Rates of stillbirth were twice as high in the most deprived area compared with the least deprived area, showing no evidence of a change over time. Despite emerging research, little is known about differences in the deprivation gap by specific causes of stillbirth within the UK (Seaton et al., 2012). The study's findings concluded that antepartum haemorrhage, congenital anomalies, and pre-eclampsia were main risk factors for deprived areas which confirmed trends in stillbirth rates that have been found around the world (Guildea et al., 2001; Centre for Maternal and Child Enquires, 2010).

The absence of antenatal education has been shown to heighten the risk of stillbirth (Flenady et al., 2011; Yudkin, Wood & Redman, 1987). Work by Heazell et al., (2021) found that attending antenatal care classes was a way in which mothers could actively reduce the risk of stillbirth because they were more aware of risk factors and preventative measures. However, minority ethnic women face additional barriers in accessing these services (Garcia et al., 2015) compared to their white-British counterparts. For example, pregnant women may not have access to interpreters which prevents them from addressing their healthcare needs (El Ansari et al., 2009). Expecting mothers may feel uncomfortable being cared for by male healthcare staff (Garcia et al., 2015). For some families, they might be unaware how they access antenatal care within the NHS which may lead to late bookings in maternity services and therefore increase the odds of perinatal loss (Tucker et al., 2010). In contrast, a shortage of government funding into maternity services has meant there are fewer midwifery staff and therefore decreased antenatal education provision (RCOM, 2022).

3.3 The financial burden of baby loss

The cost for caring for the emotional and physical health consequences of stillbirths are 10-70% greater than for livebirth infants (Mistry et al., 2013; Gold et al., 2013). In the second Lancet Series, Heazell et al. (2016) assessed bereavement care in economic and social costs to the family unit. Costing and care for subsequent pregnancies also increase after a stillbirth to closely monitor the foetus' progress. Heazell et al. (2016) estimate that the price of a stillborn in the health system in HICs is between £3499 to £4057 depending on whether the cause of death was known or unknown. The economic cost of stillbirth on the country is unknown due to the value in varying health metrics, such as quality-adjusted-life-years (QALYs) and disability-adjusted-life-years (DALYs) not being given for the stillbirth's loss of life nor for the parents' loss (Heazell et al. 2016). Instead, the cost of preventing stillbirths has been a more favoured means of costing in most economic analyses. Emotional factors of grief are often described as intangible costs (Ogwulu et al., 2015). Bereaved families feel the economic effects of the death in terms of funding funeral arrangements; acquiring medical expenses for counselling and financial loss due to time off from their employment and reduced productivity (Heazell et al. 2016). In fact, in the Listening to Parents study by Redshaw et al. (2014) through which a survey was completed by 473 responses, only 59% of bereaved fathers reported taking time off from work; on average the leave was for 10 days.

Considering the stark inequalities faced by BAME groups compared to white British families, the increased financial impact of the loss of a baby on families of colour has been underestimated. A lack of research regarding the cost of baby loss to different ethnic groups singularly fails to accurately portray the actual cost felt by families going through a devastating time. Research has been found to show Black Caribbean women are more likely than the rest of the UK population to be single parents and are more prone to live in socio-economically deprived areas (Edge, Baker & Rogers, 2004). The burden of being the head of a single parent and a bereaved mother would negatively impact a family's quality of life. However, given there is no research to support the researcher's claim, the absence within current research that investigates the cost of stillbirth according to different ethnic groups remains unknown.

3.4 Psychological impacts after stillbirth

The psychological impact of stillbirth on parents is profound (Henley & Schott 2008; Schott, Henley & Kohner, 2007). In the 2011 Lancet series, Goldenberg et al. provided evidence that women who had stillbirths are often marginalized and stigmatized in their communities. Series Two calls for noticeable action to reduce stillbirth stigma and to support women and their families who want to share their stories and remember their lost child. Although there are evidence-based guidelines and interventions to help support bereaved families, evidence shows that some families continue to feel ashamed for losing their child (Flenady et al. 2016; Bhutta et al., 2014).

Mothers are often left searching for answers, wondering if there is anything they could have done differently, which leads to internalizing feelings of guilt and shame (Cacciatore, 2013). Studies conducted in Australia and the US determined that negative psychological indicators were frequently expressed as depression, anxiety including panic and phobia symptomatology, post-traumatic stress disorder (PTSD), and suicide ideation (Lee 2012; Kavanaugh & Hershberger, 2005). PTSD is associated with occupational instability, parenting complications, and difficulty in social functioning (Cacciatore, 2007). Women who have a history with depression are vulnerable to further depressive episodes after a stillbirth (Hogue et al., 2015). Depression in women has been shown to adversely affect their personal health and wellbeing, this is also true for their partners and their children (Edge, 2007).

Beyond the acute crisis of birthing the baby, the effects of stillbirth echo throughout the family structure. Spouses can be a valuable source of support to one another following a baby's death, yet research shows that the lack of partner support can increase the risk of negative mental health outcomes for mothers (Cacciatore, 2013). It is understandable that the death of a child would have a significant impact on a marital relationship. Parents of stillborn babies have an increased risk of marital dissolution (Shreffler et al., 2012). Alcohol and other substance abuse increases after the loss of a child (Deahl & Srinivasan et al., 2001). One study reported that bereaved fathers feel unacknowledged and insignificant in the grieving process, which made them susceptible to chronic grief as these men kept their feelings to themselves (Avelin et al., 2013). Men may find it difficult to offer emotional support in times when they are also experiencing a crisis (Hutti, 2006). Couples who feel they cannot express grief equally have reported relationship challenges which range from intimacy issues to marital breakdown (Dyregrow & Gjestad, 2011). When controlled for known risk factors, couples who had a stillbirth were at a greater risk of their relationship ending compared to those who had a livebirth, which suggests a significant amount of stress is generated from the experience of losing a child, which could end the relationship (Gold et al., 2010).

Other children in the family may be affected by stillbirth. Research indicates that children whose sibling was stillborn may be vulnerable to experiencing psychological problems related to maternal anxiety (Hughes et al., 2002). Furthermore, infants who are born after a stillbirth show insecure attachment behaviour to the mother. Hughes et al. (2001) argue insecure attachment to the mother is not related to maternal depression or anxiety but stems from unresolved maternal mourning for the stillborn.

Insecure attachment in young children is associated with increased vulnerability to adverse psychosocial development later in life (Van IJendorn, Schuengel, & Bakermans-Kranenburg, 1999).

The Listening to Parents study (Redshaw, Rowe & Henderson, 2014) has been the most applicable piece of research in terms of identifying poor mental health outcomes for bereaved parents in the UK, as it had 16% of respondents who were from minority ethnic groups. Upon reviewing the research, it is uncommon to have a large survey that encompasses more than ten percent of respondents from minority ethnic backgrounds. Nearly a third of the women in the total population (n=473) who had a stillborn reported depression symptoms and a quarter of the same population self-reported suffering from anxiety. Fathers also experienced poor mental health, with one in ten reporting feeling anxious, depressed or both. Figures detailing which ethnic populations experienced depression and/or anxiety symptoms were not listed. Nine months after the stillbirth, a third of the mothers and a fifth of the fathers still reported feeling depressed and anxious.

Compared to their partners, women were more likely to attend a support group (24% to 9%). The survey found that bereaved mothers were more than twice as likely (29% to 11%) to seek a counsellor of some kind compared to their partners, but also reported that partners are the main support for mothers after the birth. Religious advice and support were important for some couples. Tense relationships between partners was also reported with 5% of men and 9% of women reporting difficulties.

Although some parents may find comfort and support in relationships already established, there is research to show that parents may find themselves feeling socially isolated (Burden et al., 2016; Fernandez-Sola et al., 2020). When a baby is stillborn, social support systems of many bereaved mothers weaken (Cacciatore, Schnebly & Froen, 2008). Mothers have reported feeling isolated and marginalised (Michon et al., 2003; Goldenberg et al., 2004; Cacciatore, 2007). Often parents feel missing legitimisation of grief after the death of a stillborn child versus that of a live-born child that other people had the opportunity to know (Cacciatore, 2007). They may feel as if their communities don't understand the significance of their loss (Jones, 2019). Psychosocial support can significantly improve a family's outcomes after stillbirth (Davis, Steward & Harmon, 1988). Research into parent support groups has been growing in recent years. The role of social support in bereaved parents' lives is found consistently in researching interventions for families (Stroebe et al., 1999, Silver, 2007).

3.5 Peer-to-peer parents support groups

There is a shortage of intervention research and evidence-based practice relating to perinatal death (Murphy et al., 2018). Reports on social support and impact that parents receive after loss is mixed. To this researcher's knowledge and upon investigating current literature, there is no standardized structure and efficacy of these groups. What is clear is that cultural norms and attitudes within Western society play a major role in diminishing the value of a stillborn baby in society (Cacciatore & Bushfield, 2008). Women who have a stillborn child need an abundance of unconditional and social support (Cacciatore, 2007). Having social support has been linked to improvement in health outcomes since the 1970s (Hutti, 2006).

As women can feel estranged from their existing relationships following loss, the establishment of new relationships is important for women (Erlandsson et al., 2011). For parents who are unable to attend groups, the advent of the internet serves as a medium for bereaved parents, grandparents, and other family members to find support through online forums (SANDS, 2018). Findings from Murphy (2013) have found that becoming involved in awareness raising and fundraising for stillbirth related causes with healthcare professionals have been useful for mothers to use their bereavement to empower themselves. When considering social support that parents receive following a stillbirth, it would be valuable to have more insight on the attitudes that feed into people's beliefs and behaviours attending parent support groups.

Despite the gap in the literature pertaining to stillbirth bereavement support groups, research shows that support groups offer partial support to both men and women by providing a sense of community for the bereaved (Boivin, 2003; Neukrug, 2004; Boyle et al., 2015). However, Social support differs from professional support. Professional support in the context of pregnancy loss is derived from mental health care providers that often focuses on finding supportive interventions that come from counselling and problem solving (Hutti, 2006). Peer support groups do not intend to replace the expertise of a health professional. Yet, research shows that follow-up care of women experiencing loss result in them feeling forgotten by the health system (Boyle et al., 2015). Support groups are distinguished from self-help and treatment groups as support groups serve as a medium in helping people deal with stresses related to a common crisis or life event (Cote-Arsenault & Mason Freije, 2004). A support group's goal is to create an environment where members feel encouraged and able to cope more effectively with the common issue that is shared. For mothers, support groups can be a valuable way of making connections with people who understand and can provide the right amount of support and help (Willer et al., 2019). Bereavement peer support groups help fulfil needs not being addressed by other social systems (Reilly-Smorawski, Armstrong, & Catlin, 2002).

One key piece of literature is a 2007 mixed methods study by Cacciatore which focused on support group participation and post-traumatic stress symptoms. Based on both the quantitative and qualitative responses, she found that American women who attended bereaved parent support groups reported fewer symptoms of post-traumatic stress compared to women in the study who did not attend support groups. The qualitative questionnaire component shed light onto the importance of attending groups for bereaved mothers. Several women who attended support groups for more than two years reported that that their involvement in the group made them feel like they were "making a difference for others and doing things in honour of the deceased child", (Cacciatore, 2007, p.84). Cacciatore's study did not break down the ethnic backgrounds of the participants. However, the following quote illustrates a valuable perspective when looking at BAME parent participation in stillbirth bereavement groups:

"There are so many African American families in denial about infant and child death because they refuse to trust the traditional thinking regarding therapy and support groups […] Mistrust still exists because of history. There have been so many racial barriers broken but mental healthcare and support groups are still considered taboo among our culture. I still struggle and feel isolated by my own culture, but I also know the life changing advantage of therapy and support groups", (Cacciatore, 2007, p.83). Although there hasn't been a study like this conducted in the UK, it is plausible that Black British families would experience similar feelings of going against one's cultural expectations. Bereaved parents might feel judged by their community (McLeish & Redshaw, 2017).

An ethnographic study, by Cote-Arsenault and Mason-Freije (2004), investigated the culture of two American support groups during a subsequent pregnancy following a perinatal loss and examined the impact of the groups on women who sought them as an intervention. Attending a support group made mothers feel supported and normal. Many women stated that they felt stronger in their own emotions and developed new coping strategies as a result of attending meetings.

The authors did record that the population of this study was 90% white and 10% diverse minorities, mainly Asian and Pacific Islanders (p.653), however there were no specific qualitative extracts that showcased the importance of attending support groups from a minority ethnic perspective. Within the research on baby loss peer support programmes, it is evident that the voices of minority ethnic communities are missing. Ethnic inclusivity within research is essential to generalise research findings (Rooney et al., 2011), and fails to meet the NHS' 2010 policy on tackling health inequalities is a form of social justice (Marmot, 2010).

Whilst most research on peer support has been about in-person groups, it is important to note peer support may be successfully implemented online and over the phone. This is significant considering the impact of the COVID-19 pandemic and how it has changed social support for expecting families (Zhou et al., 2021). With stay-at-home orders in place around the world, communicating and engagement became virtual (e.g., video calls) (Wiederhold, 2020). Bereaved parents can still make meaningful connections through online baby loss peer support (Gold et al., 2012; Carlson et al., 2012)

An Australian study examined the perceptions and experiences of parent support group volunteers who deliver a 24-hour telephone support service for the Australian Stillbirth and Newborn Death Support (SANDS) organisation (Boyle et al., 2015). As this study took place in Australia, phone support and online forums facilitate avenues of support that may be blocked due to geographical distance. Boyle et al. (2015) recommended SANDS organisations address the needs of people from culturally and linguistically diverse background by recruiting peer supporters from different backgrounds. This was the first recommendation in the literature that I found which suggested that diverse ethnic and geographical representation in parent peer support programming is important when connecting to parents experiencing perinatal loss.

Much of the research considered focuses on the experience of white, middle-class families. Whilst there has been a considerable increase in the volume of research into stillbirth prevention and therefore public awareness, aggregated data may mask the differences felt between parents from different ethnicities among whom little research has been undertaken (Edge, 2007). It is unclear how perinatal loss is experienced by parents from minority-ethnic groups as well as those who are considered from lower socio-economic groups due to the lack of representation in the literature (Neimeyer & Currier, 2009; Carlson et al., 2012). Carlson and colleagues (2012) suggest that there is limited research on baby loss peer support groups because these programmes are often run by volunteers within the bereaved family community. These volunteers lack funding and skillset to conduct scientific research (Carlson et al., 2012).

3.6 National Bereavement Care Pathway

When a life is lost, the absence of medical professionals who have a competent knowledge of bereavement practices may cause more distress (Buckley et al., 2022). Standards of care for bereaved parents in the United Kingdom have differed over time (Hennegan, Henderson & Redshaw, 2015). The care parents receive following a stillbirth can vary considerably regionally (ONS, 2015). Inconsistencies across the country can lead to further distress for parents and families, which impact physical and emotional well-being (Wakefield et al., 2020). Distress from not receiving adequate care after a stillbirth can have adverse effects on future pregnancies (Harder, 2015). Several studies (McCreight, 2004; Gijzen et al., 2016; Inati et al., 2018) estimate that half of families of stillbirth receive insufficient bereavement care (Flenady et al., 2011). While parent support groups are available, the network of stillbirth organizations are under resourced and disengaged from one another which results in multiple fragmented efforts that could be combined into a greater network (de Bernis et al., 2016). In the absence of a clear pathway to support parents, care is likely to vary according to the interest and the skill level of individual clinicians (Mills et al., 2016).

In 2016, the National Bereavement Care Pathway (NBCP) for pregnancy and baby loss was created by a core group of principal stakeholders which comprised itself of representatives from baby-loss charities and relevant professional bodies in the UK. Members include SANDS, ARC (Antenatal Results and Choices), Bliss, Lullaby Trust, Miscarriage Association, Neonatal Nurses Association, Royal College of Midwives, Royal College of Nurses, Royal College of Obstetricians and Gynaecologists, NHS England, Institute of HEALTH Visiting and University of Bristol. The purpose of the pathway is to improve the overall quality of bereavement care parents receive after pregnancy or baby loss and train professionals how to best support grieving families (Donaldson, 2019). The overarching aim of the NBCP is to overcome inequalities and to increase the quality in provision and experience of baby loss bereavement care (Donaldson, 2019). Five experiences of pregnancy or baby loss included in the pathway are: miscarriage, termination of pregnancy for foetal anomaly, stillbirth, neonatal death, and sudden unexpected death of an infant up to 12 months (SANDS, 2018). These representatives work with a wider group of parents, researchers, and the All-Party Parliamentary Group (APPG) on Baby Loss to include as many perspectives as possible. Feedback from parent focus groups highlighted the following areas that need to be improved upon communication, continuity, consistency, and parent-centred care (Harder, 2015).

Since the onset of the NBCP in 2016, there have been two evaluations. The most recent evaluation (2019) of the NBCP reported interesting results (Donaldson, 2019). A major qualitative theme which is related to this study, suggests newly bereaved parents feel largely unsupported once they leave the hospital (Donaldson, 2019). Supporting parents in their communities is outside the scope of the NBCP (Donaldson, 2019), however; it is a significant finding within the evaluation that parents are requesting more emotional and psychological support which corresponds to the literature and to the results of this study (Murphy, Shevlin, & Elkit, 2014). Instead of providing psychological support in the community, the pathway signposts people to organisations who can help parents through their grief journey. The evaluation included over 1,200 healthcare practitioner participants (Donaldson, 2019). 76% of professionals surveyed felt that the NBCP improved bereavement care thanks to consistent bereavement guidelines (Donaldson, 2019). These guidelines may have impacted the ways in which parents access bereavement support; over 85% of parent participants said they were informed about relevant bereavement organisations which suggests healthcare staff are referring parents onto charity services (Donaldson, 2019). Efforts to improve the quality and access to adequate bereavement care are crucial for families who experience baby loss. However, after reading the literature published relating to the NBCP (Harder, 2015; Donaldson, 2019) there is no emphasis on providing care to families from minority ethnic backgrounds nor disadvantaged communities. I suspect the two evaluations largely consisted of white participants, because of the lack of quotes from the qualitative data that suggested parent or healthcare provider were from certain ethnic communities. Considering ethnicity and socioeconomic status are risk factors relating to pregnancy loss, it is disheartening to not see attention paid to communities who experience perinatal loss compared to the overall population (Kavanaugh & Hershberger, 2004).

3.7 SANDS

SANDS (Stillbirth and Neonatal Death Charity) was founded in 1978 by a group of bereaved parents who experienced the death of their babies. They felt isolated by the lack of acknowledgement and understanding of the significance of their loss and the impact on their lives of losing a child. Since its formation, SANDS has played a key role in raising awareness surrounding baby death across the UK. Supporting parents is SANDS' primary goal (SANDS, 2021). Thousands of parents have been supported by the organisation through research and peer parent support groups. SANDS provide free support to anyone affected by the death of a baby through a national helpline, online forums, and support groups and in person groups for parents who want to have face-to-face contact with people who have also experienced the similar loss. Healthcare Professionals have also benefited from trainings and research into ways in which care for bereaved parents receive. The aim of the organisation was to reduce the number of babies dying by at least 20% by 2020, but it is unknown if that aim was achieved. Their 2022-2025 strategy calls upon the UK to halve the rates of stillbirths and neonatal deaths (SANDS, 2022). The strategy report also calls upon the charity to be equitable and accessible in its support programmes (SANDS, 2022).

Many parents find connection with other bereaved parents who have also experienced the death of a baby; finding that they can offer real understanding in peer support programmes (Obst & Due, 2019; Robinson & Pond, 2019). Across the UK there are 104 local SANDS support groups who are run by bereaved parents and family members. Meetings are often held once or twice a month, and offer parents the chance to meet other parents, gain support and to share their experiences. Outside of larger group meetings, leaders encourage members to telephone or email each other as means of interim support (SANDS, 2018). The SANDS bereavement support app was launched in September 2018. It aims to assist families by giving them the power to access information and support at their convenience. The app contains information and support resources for family members beyond parents. In addition, it links to the SANDS website and provides information to support groups across the UK. Health professionals can benefit from using the app by accessing SANDS best practices for bereavement care resources as well as work currently being done in research and prevention.

It's necessary to acknowledge SANDS as a national organisation that supports parents through several peer support initiatives and is an active charity to call upon change (SANDS, 2022). Whilst there over

90 baby loss organisations who serve bereaved families across the UK (Baby Loss Awareness Alliance,2022) these charities are often regional and unable to conduct large research and have the impact like SANDS. SANDS was the most frequently mentioned charity in the semi-structured interviews. All of the participants in this study had heard about the organisation after the loss of their babies which shows the national reach SANDS has within maternity and baby loss fields.

3.8 Background to creative methods in grief and bereavement research

A loved one's death may provoke intense symptoms of grief and loss which manifest in emotional, physical, and psychological pain (Arnold, 2019). Literature suggests the use of creativity within one's grief journey may facilitate the body to release complex feelings (Brennan, 2015; Franks, 2016; Coenen, 2018) when the words to express grief feel as if they've been taken away (McCloskey & Wier, 2020). This section of the literature review is introduced here and is explored further in a publication in the British Psychological Society's special interest edition of creative qualitative methods. The article is featured in the appendix of this document.

The act of being creative helps a grieving person heal and make sense of their loss (Frants, 2016). In fact, implementing creative arts in bereavement counselling can help therapists facilitate clients to process multi-faceted emotions of grief (Buser et al., 2008). The use of creative qualitative methods has increased in health research (Bell, 2010). Creative modalities used in therapy range from visual forms such as painting, collage, and drawing to performances such as creating music and participating in drama (Torres, Neimeyer, & Maryl, 2014; Illiya, 2015; McCloskey & Wier, 2020). The use of visual art in practice has been documented to be especially helpful in healing (Gabora & Kaufman, 2010; Arnold, 2019). By creating something to express grief allows the bereaved person to process and make sense of their loss (Edgar-Bailey & Kress, 2010). Using creative therapeutic techniques may be particularly healing for bereaved parents who feel they can't openly discuss the loss of their baby (Flenady et al., 2014).

Creative modalities stemmed in art therapy can be used in qualitative research to bring creativity to social science (McCloskey & Wier, 2020). Researchers who use creative methods are inclined to value alternative ways of thinking which contradicts the more Western positivist outlook (Vaughan, 2005). As a feminist researcher (Finley, 2001), I accept that my researcher identity prefers to use methods that call for action and change; this is the way that I see this piece of research and use creative methods to take on an active role in calling for social justice (Mullen, 2003 as cited by Vaughan, 2005). Arts-based methods (ABM) stem from creative methods (Van der Vaart, van Hoven & Huigen, 2018). McNiff (1998, 2011) writes that art-based research takes place when a researcher implements a method of making art as a primary form of exploration. McNiff's (1998, 2011) definition has influenced my interpretation of how to include creative methods into this research project. Arts-based methods (ABM) have been used across social sciences but has largely contributed to the psychology and education fields (McNiff, 2011). Researchers benefit from using ABM because these methods bring about new approaches of understanding a phenomenon (Dunn & Mellow, 2017), and bring new awareness to intricate subject areas that would have been missed in traditional research methods (Eisner, 2008). In addition, ABM offer participants ways in which they can express themselves outside of interviews and questionnaires which focus on verbal and written skills (Dunn & Mellor, 2017). Using a visual item like collage may help participants recall details of their experience that would otherwise go unnoticed (Butler-Kisber, 2008). When ABM and traditional research methods work conjointly, research is enhanced in that there is a range of results and therefore a breadth of meaning that exists within the studied phenomenon (Coemans & Hannes, 2017; Van der Vaart, van Hoven & Huigen, 2018).

Stillbirth is an under-researched area within the perinatal health field (Budd et al., 2018). Collage is an ABM that stems from the French word 'coller' which means to glue and is the act of selecting images or materials and pasting them onto a flat surface (often paper) to depict a phenomenon (Butler-Kisber & Poldma, 2010). Generally accessible to the majority of people, magazines, newspapers and other texts are often used to make a collage, however; the creator may incorporate photographs, painting, and drawing (McCloskey & Wier, 2020). As a method, collage has increased in popularity because it facilitates ways of arranging photographs, text, and other materials from an intuitive perspective (Butler-Kisber, 2010). It's more approachable than painting or drawing because the task of creating a collage is relatively straightforward (Chilton & Schotti, 2014; McCloskey & Wier, 2020).

Within grief and bereavement research, collage has been implemented in a variety of subject areas. For example, this method has been carried out in research on trauma (Homer, 2015), dis-enfranchised grief in older adults with dementia (Olsson, 2022), grief and bereavement peer support groups (Grebin & Vogel, 2007), and addressing ways in which support can be provided to hospice caregivers (Kaimal, Mensinger & Carroll-Haskins, 2020). Collage has been used in maternity research looking at the experiences of parents facing periviable delivery (Tucker Edmonds et al., 2019). However, the paucity of literature on collage as a research method in perinatal loss research suggests this study is making an original contribution to the ABM and bereavement fields.

3.9 Summary of the literature

Stillbirth is an invisible loss to the outside world. Losing a baby is a life changing experience that may severely impact parents' physical and mental wellbeing. Parents may experience silence, whether it be their own or other people's, around pregnancy loss (de Costa, 2011; Binnie, 2020); the grief that is experienced by parents of stillbirth is now well-documented in research. Despite ongoing research and public health measures being put into place, HICs like the UK continue to experience stable numbers of losses per year (Flenady et al., 2016). Ethnic disparities in perinatal loss are well known, especially among women of African and South Asian origin (Esegbona-Adeigne & Olayiwola, 2020; Gardosi et al., 2013; Kingdon et al., 2019; Garcia et al., 2020). Evidence shows that minority ethnic families in the UK are proportionately more likely to experience a stillbirth due to social and racial inequalities (Matthews et al., 2022).

Support groups play a role in reducing the trauma of stillbirth (Cacciatore, 2007), and can be an effective strategy for parents who do not want to/ or unable to seek the help of a professional therapeutic relationship. Despite this the lack of research in diversity within baby loss, research has shown that peer support groups are helpful for bereaved parents. Coming together with peers offers parents an opportunity to socialise with others with similar experiences. The purposes and benefits of parents coming together extend beyond emotional support. Participants in Cacciatore's study reported that they could resource share, ask clinical questions and network with other parents. Parents can have their feelings and beliefs validated in a safe space whether it be in person, over the phone or online. Having community to support bereaved parents benefits their mental health by promoting social interaction.

What is notable within the current literature is the overarching theme of gaps, specifically regarding how minority ethnic families experience stillbirth, their grief journeys, and whether they have access to participate in parent peer support groups. In general, minority ethnic populations are underrepresented in health research (Smart & Harrison, 2016). Research that is available often explores minority ethnic populations risk factors of stillbirth which focus on population figures and are quantitative in nature (Drysdale, Ranasinha, & Kendall, 2012; Norris, et al., 2017; Connelly, Gayle, & Lambert, 2016). Qualitative research documenting minority ethnic parents' experiences of baby loss in the UK is the largest gap in the stillbirth bereavement field. This suggests that qualitative studies on minority ethnic families' experience of perinatal loss is needed (McCloskey & Wier, 2020). By intentionally or unintentionally excluding marginalised communities in research, health inequalities continue to thrive (Memon et al.,2016).

Whilst conducting this literature review, I did find a few American studies about minority ethnic communities grieving the loss of a child (Whitaker, Kavanaugh & Klima, 2010; Hawthorne, Youngblut, & Brooten, 2016; Fenstermacher & Hupcey, 2019). Whilst these studies diversify grief narratives and broaden the field of grief and bereavement studies, it is important to remember that although the US and the UK are similar, they are not the same. Both countries have different healthcare systems (Loury, Modood & Teles, 2005) and therefore offer different pathways of bereavement support to grieving families. The lack of UK research in this area prevents the field from diversifying and advancing, also impedes the creation of best practices for clinicians and charities to mitigate the grief journeys of bereaved parents (Gillespie & Lopez). To Western societies, the discussion of grief is only tolerable if it is a collective loss by the majority group (Gillespie & Lopez). People who belong to minority populations are often considered 'others' (Kamenova, 2014; Chauhan & Foster, 2014; Strani & Szczepaniak-Kozak, 2018) are often considered to be outside of the dialogue about grief (Gillespier & Lopez 2019).

This piece of research contributes to the discussion currently taking place across academia to break down silos that exist between higher education institutions and the real world. Additionally, this doctoral project supports minority ethnic voices and experiences to be heard in a time where representation is health research is vital (Mannay, 2013; Adebiyi, Ghesae, & Mustafa, 2021). To do this, I use semi-structured interviews and a collage-elicitation exercise to incorporate verbal and visual data. Implementing collage as a creative method may facilitate a more inclusive approach to research by making the process easier for research participants to contribute (Kramer-Roy, 2015; McCloskey & Wier, 2020). I hope to offer valuable insight into how charities can improve accessibility to better include minority ethnic bereaved parents in their support groups, interventions, and best practices.

4 Methods

4.1 Introduction to mixed methods

When thinking about which research design is more appropriate for a research project, it is essential to choose one that is compatible with answering the research questions (Creswell, 2014). Qualitative research is used in social research by observing individuals in their natural environment to explore their realities and perspectives (Trumbull, 2005). It shows how individuals' behaviours and attitudes are constructed by the environment and situations they live in. (Hennink et al., 2010). Qualitative research is useful for understanding social phenomena and exploring participants' perspectives, motivations, and beliefs on the matter of interest (Gill et al., 2008). When applied to this study, the qualitative nature of the study focused on BAME parents' perspectives and experiences attending bereaved parent support groups.

In addition, the research questions must work in tandem with the chosen methods. I chose to use a mixed methods approach to conduct my research. The mixed methods approach is an emerging methodology within health research that usually "mixes" quantitative and qualitative data within a single investigation (Mertens, 2013). Although mixed-method projects are complex, (Hanson et al., 2005), I appreciate the flexible nature of mixed methods and how it complements a range of philosophical perspectives including a transformative and pragmatic position (Creswell et al., 2011; Morgan, 2007; Mertens, 2009). Furthermore, mixed methods research can be implemented to explore real-life situations from numerous perspectives which enhances the validity of the research (Creswell et al., 2011). Appropriate for this particular study, implementing mixed methods better communicates the perspectives of underrepresented communities (Hanson et al., 2005). in social sciences, mixed methods research has increased in popularity within health and medical sciences including mental health and social work (Windom & Creswell, 2013) and has risen in popularity throughout the early 21st century (Morse, 2010). Mixed methods research has supported the development of policy (Caracelli, 2006), health services (Johnstone, 2004), health promotion (Campbell et al., 2000; Milburn et al., 1995), and psychiatry (Wittink, Barg, & Gallo, 2006). Due to its integrative design and structure, mixed methods support a variety of research questions (Creswell, Plano Clark, 2011) and is suitable to researchers who are trained in different approaches (Morse & Niehaus, 2009) due to the complexity of managing a core component and supplementary components within the same project.

Mixed methods' strengths lie in understanding inconsistencies between quantitative results and qualitative findings; giving a voice to research participants to ensure findings are grounded in their experiences; offering flexibility to study designs and gathering comprehensive data (Windom & Creswell, 2013). Employing a mixed methods design may be stronger than a single method study because the multiple components can create enriched data and shed light on results from a different perspective that may be missed when only one method is used (Morse & Niehaus, 2009; Onwuegbuzie & Johnson, 2006). Mixed methods may also enhance the research impact (Sndelowski, 2000; Gilbert, 2006). Greene & Caracelli (1997, p.7) argue mixed methods research produces “a complex picture of a social phenomenon” which is what this project aspires to generate, so advancements can be made in bereavement support.

Creswell (2003) recommends selecting a systematic framework when using mixed methods for research. The field has largely centred on combining qualitative and quantitative methods, missing the option of combining two qualitative or two quantitative methods under the rubric of mixed methods research designs (Morse, 2010). Creswell (2014) makes the case that researchers should understand both quantitative and qualitative research to use mixed methods design. According to Morse, (2010 p.485): “in the mixed method continuum, there is certainly a grey area”. Researchers who are affiliated more closely to qualitative research have a more flexible view of mixed methods research (Morse & Niehaus, 2009). However, researchers remove the difficulties of mixing numerical and textual data when working under the same paradigm (Morse & Niehaus, 2009). After careful consideration, I decided the best framework to answer my research questions was to utilise two-pronged qualitative methods approach under the theoretical guidance of Morse’s extensive work in nursing education and research (1995, 2002, 2009, 2010, 2012, 2016), and her detailed guide on mixed methods design (Morse and Niehaus, 2009).

4.2 Morse’s mixed method design

Following Morse’s work on mixed methods within paradigm research, this study will be a QUAL-*qual* mixed-method design. This mixed methods design is the easiest to conduct since both the core and supplemental components are housed within the same paradigm (Morse & Niehaus, 2009). A main qualitative project supplemented by a smaller qualitative project, also referred to as QUAL-*qual* methodology, is the least common type of mixed methods study because it goes against the popular mixed methods model which combines both qualitative and quantitative paradigms in the same study (Morse & Niehaus, 2009). Although there has been a debate between scholars in the field (in 2007, Johnson, Onwuegbuzie, and Turner made an attempt to discuss what defines a mixed methods study), Morse and Niehaus (2009) argue that their definition of a mixed methods design may include two qualitative methods or two quantitative methods as long as the study comprises of “a qualitative or quantitative core component and a supplementary component which consists of qualitative or quantitative research strategies but is not a complete study in itself”.

Morse and Niehaus (2009) and Morse and Cheek (2014) instruct researchers to think carefully to differentiate between multiple methods and mixed method design. In their handbook (2009), Morse and Niehaus articulate further that it is essential to distinguish the main project from the supplemental projects; the supplemental component that is incomplete and cannot answer the research question(s) by itself. The core component is the main study within the research project and should be able to stand alone to be published by itself if the supplementary components fail because it is scientifically rigorous (Morse, 2003; Morse & Cheek, 2014). However, the supplemental arm is somewhat separated and unable to stand alone (Morse & Niehaus, 2009). The supplemental strategy is usually comprised of a separate design and produces a different type of data (Morse, 2010). As such the additional component adds a different perspective to complement the core project, by adding another facet which may have gone unnoticed by the core method (Morse & Cheek, 2014). Although the supplemental component adds depth to the overall aim of the project, it is considered too weak to be published on its own (Morse & Niehaus, 2009).

Qualitative research's exploratory nature generates information about unknown aspects of a phenomenon (Teddlie & Tashikkori, 2009), and seeks to understand how individuals make meaning of their social world (Hesse-Biber, 2010). Qualitative approaches address the multilayers of social realities through which a transformative quality can identify issues of power and authority (Hesse-Biber, 2010 p. 456). The QUAL-*qual* design is the most appropriate for my study which explores BAME stillbirth bereaved parents' experiences and decision making into how to access peer support groups or befriending services. The intent of this project is not to generalize all minority ethnic bereaved parents' experiences of stillbirth bereavement, but to develop an in-depth exploration of their experiences accessing support. My intention in using this design was to generate a richer understanding of the different facets of baby loss and bereavement support. Perinatal loss, grief, and accessing services to support one's mental health are highly emotive and sensitive areas of study (Kennedy & Gardner, 2021). I wanted to use a multi-layered research design to explore the complex phenomena of the parents' experiences. Often multiple qualitative methods are needed to capture phenomena (Morse & Niehaus, 2009).

Semi-structured interviews are a trustworthy method used by many researchers, and yet there may still be data that goes literally left unsaid in a verbal interview. (Brayda & Boyce, 2014). The use of collage within the context of the wider field of creative methods, added an additional layer to create more meaningful and personal data (Dutton et al., 2019; Vachelli 2018). Collage, as the supplemental component, allowed participants to express themselves in an artistic manner which is often not permitted in their daily lives. Not only did it supplement the greater understanding of this phenomenon, but it also encouraged participants to have agency over their contribution to research through the physical embodiment of the research process (Vacchelli, 2017) through the acts of selecting images that fit their experience of baby loss, cutting these images out, and pasting them in a specific order onto their board.

4.2.1 Theoretical Framework

Morse (1991; 2003) urges researchers to identify the theoretical perspective that will guide the course of the research project. This will confirm whether the research study confirms a hypothesis (deductive process) or discovers something unknown (inductive process) (Morse & Niehaus, 2009). By distinguishing the theoretical stance of the project, the 'overall purpose' (pp 24, 2009) becomes clearer. Situated between the inductive approach and the deductive approach is abduction; a process that allows the researcher to move between induction and deduction (Blaikie, 1993; Morse & Niehaus, 2009). However, Morse and Niehaus (2009 pp. 40) reason that abductive mode is more aligned to an inductive process as it "works in a stepwise fashion, but more slowly and deliberately than in an inductive mode". Abduction can be applied to people's everyday interactions to then expand their accounts to which the approach can be utilised to generate social scientific theories to explain the phenomenon (Gilbert, 2006). This approach is used in different qualitative research methods such as grounded theory (Reichertz, 2019). I applied abduction during the interview process for which data was collected for the core component of my project. Using grounded theory, I conducted preliminary analyses between the sets of participants to assess the validity of the data which will lead to the formation of my theory. Morse and Niehaus (2009) advise researchers to pay close attention to their chosen theoretical drive. If the focus of the research direction becomes too vague and loose there may be errors which could compromise the study's validity.

4.2.2 Simultaneous versus sequential method design

I intend to use a simultaneous mixed method design inspired by the work of Morse & Niehaus (2009) and Morse's work (2010). According to Morse (2010), simultaneous study designs are projects where the main component and supplementary components are conducted at the same time. This is different from a sequential mixed method design which dictates the core portion of the research project must be complete before supplementary components could begin (Morse & Niehaus, 2009). This research is a qualitative study as its nature is primarily exploratory. Within a simultaneous design, the core method tends to be a standardised qualitative method (Morse, 2010). This is applicable to this study, because I am implementing grounded theory (Charmaz, 2006, 2014) for the semi-structured interview portion with bereaved parents. Morse (2010) writes the supplementary component may be implemented when there are different varieties of data being collected. The supplementary project prompts additional information about the phenomenon which may be unavailable if only the core method was used (Morse, 2010). The collage-making portion of this study will be implemented immediately after the interview. The use of collage produces visual data which is different compared to the verbal data that arises from semi-structured interviews.

4.3 Facet Methodology

I chose to incorporate Facet Methodology (Mason, 2011) to guide the course of my research methods. Developed as an alternative to conventional mixed methods practices at the Morgan Centre, University of Manchester, Facet Methodology is an innovative approach and orientation to research rather than a set of tools to carry out research. Whilst it may appear that Facet Methodology resembles mixed methods in the sense there may be more than one modality or method used to answer the research question (Mason, 2011), Facet Methodology cannot be limited to simply being another way of conducting mixed method research, and yet it is also not an "anything goes" approach. I will explain the differences between Mixed Methods and Facet Methodology in the following section.

Facet Methodology (FM) is a novel approach to examining the "multi-dimensionality of lived experience", (Mason 2011, p.75). It encourages researchers to be open and inquisitive, to maintain a level of curiosity throughout the duration of the project (May 2021). In her introductory article about FM, Mason (2011), advises researchers to imagine FM as a gemstone, and like a gemstone, there are multiple and different facets of the gemstone depending on how the light penetrates each side. The facets of the gemstone that are illuminated serve as a metaphor to represent how researchers can view a research query (Mason, 2011). Mason (2011 p. 79) describes seeing facets as means of "investigating something that is theoretically interesting in relation to the overall enquiry, and each seeks out particular instances or versions of the kinds of entwinements and contingencies that are thought to be characteristic of the object of concern in some way".

Researchers who choose to implement FM in their work seek to see the connectivity in the real world; the lived world is dynamic and ever evolving (Muir, 2022). FM attempts to highlight the links between the facets and how these facets interact with each other (Mason, 2011; 2018). The goal of using FM is to strategically choose which facets of the gemstone to examine, to identify how the facets are interlaced, and to seek out how the facets came to be entwined (May, 2021). Each selected facet must be chosen carefully, which is why this method relies on imagination and skill (Mason, 2011; May 2021). Furthermore, a researcher's ontological and epistemological perspective must match Facet Methodology; meaning there is a curiosity and eagerness to see what social phenomena are connect and how this lived world experience is connected (May, 2021). The essence of who that researcher is affects what they choose to investigate. It's the *what* and the *how* we look at the facets. Due to FM's nature of being an orientation, FM is exploratory and permits researchers to experience the research process like an adventure by letting the project unfold along its way (Mason, 2011).

Applied to this study, my ontological and epistemological perspective rests in transformative paradigm (Mertens,2007), and it influences how I perceive the topic of baby loss peer support programmes and how I carry out this piece of research. Because FM does not rest in one research paradigm, it can be applied across ontologies and epistemologies (Mason, 2011), and therefore complements the use of transformative paradigm (Mertens, 2007). Like FM, TP doesn't instruct researchers how to carry out data, but offers a framework to guide researchers on how to view the phenomenon differently (Mertens, 2007). Transformative Paradigm assumes that reality is socially constructed and consists of multiple reality which corresponds to Mason's (2011) development of facet methodology and the different sides of a gemstone. The 'facets' chosen to be investigated are related to the researcher's ontological and epistemological perspective (Mason, 2011) Mertens' (2007) work argues that the transformative epistemological outlook places importance of trust between the researcher and the participants. Research should be carried out in a cyclical nature (Mertens, 2007); participants should be offered the opportunity to contribute at different stages of the research process. Transformative paradigm is implemented in mixed methods to tell the stories of people who are experiencing injustices (Mertens, 2007), which is align to facet methodology which selects the facets to investigate instead of investigating an entire phenomenon (Mason, 2011). As a researcher, I am interested in exploring the perspectives of minority ethnic bereaved parents accessing baby loss support instead of exploring baby loss bereavement pathways for all bereaved parents. Demonstrated in the literature review, minority ethnic parents in the UK experience a higher risk of perinatal loss compared to their white counterparts (Stacey et al., 2021). This form of social injustice deserves to be further investigated. I see transformative paradigm and facet methodology complementing each other in this investigation.

This methodology is valuable in resolving the tension between micro and macro phenomenon as it acknowledges that facets are "mini-investigations that involve clusters of methods focused on strategically and artfully selected sets of related questions" (Mason 2011, p 79). Facets can't be reduced simply to the areas of study (May, 2021). These "mini-investigations" are not chosen at random. Instead, the facets are specifically sought out to be examined regarding what Mason (2011) calls "the object of concern" (pp.76), but I have applied the concept to the study aim. It's important to note is that Facet Methodology requires people to be strategic. Mason tells researchers it is important to have some sense or background knowledge of the topic in some ways. This is unlike grounded theory in the traditional sense in that researchers are advised not to have any kind of background on the research problem (Kelle, 2007). However, similar to grounded theory, there still is a requirement to generate theories as to why the phenomenon is happening the way it is (May, 2021).

What the facets produce should be considered more as a personal narrative rather than a comprehensive knowledge of the phenomenon (Mason, 2011; Muir, 2022). As a social scientific researcher using FM, I understand that it is not possible to observe the entirety of the gemstone, or in the case of this research thesis, how all minority ethnic stillbirth bereaved parents in England access peer support. It is also unlikely that each baby loss charity across the country has access to support bereaved parents through peer support programmes. The facets selected are not dependent on the size of the study (Mason, 2011). However, the facets that are selected for exploration and examination can provide innovative ways to develop perspectives of the problem (May, 2021).

This thesis seeks to tell the stories of bereaved parents seeking baby loss bereavement support in hope of making practical changes to bereavement support in England. Mason (2011, pp. 80) writes that FM "requires a blend of scientific and artistic or artful thinking" which allows researchers to experiment with different methods to answer the research question. She encourages researchers to be playful and inventive with their thinking and reasoning (Mason, 2011) by experimenting with different methods. When FM is applied to this project, it is clear to see there is a blend of both ways of thinking through the more traditional method of interviews, and through a creative lens by way of implementing collage-making. Mason (2011, 2018) encourages researchers to not only be creative, but to also see the situation inventively. Using collage, participants were active creators in the research process. The creation of art enabled participants to visually tell their stories of loss and grief. They participated in a craft that is largely accessible to people and an activity that participants enjoyed doing. FM facilitates both researcher and participants to be imaginative contributors to science (Mason, 2011).

What I appreciate most about Mason's work on FM, is her suggestion that researchers should use their intuition within the research process (Mason, 2011; May, 2021). This encouraged me to use the intimate knowledge I have personally had with grief and bereavement. I used my experience to build a candid rapport with the participants which was empowering to not hide my grief. I had direct feedback from participants that knowing about my loss made them feel they could be straightforward with their responses in the interview and the creative methods process. Likewise, I feel this method acknowledges that researchers cannot see the totality of the situation, and that the selected facets to be researched may be perceived differently through the paradigm lens of other researchers.

4.4 Guiding theories

Transformative paradigm is my guiding theoretical framework where I aligned my philosophical underpinning as a researcher (Mertens, 2005; 2007). Merten's (2007) work on TP focuses on how mixed methods research and social justice intersect to bring change by challenging the status quo in acknowledging there are injustices and inequity among society. TP acknowledges the role of the research industry and how it has historically excluded communities in participating in research (Mertens, 2007). It is no secret that racism has flourished in scientific research which led to abhorrent mistreatment of minority ethnic communities, such as the Tuskegee experiment, and sterilization of Puerto Rican women (Duster, 2006). Marginalised communities, who are largely underrepresented in research (Shevlin & Rose, 2022), may not know they can participate in research and change the narrative (Risa Briggs, 2004 as cited by Mertens, 2007). Facilitating marginalized communities to share their experiences is the first step to make change in society (Shevlin & Rose, 2022). I argue TP is my philosophical position, however; there are guiding theories which are associated with my research identity and with the research topic. Two prominent guiding theories Critical Race Theory and Meaning Making influence my understanding of the topic. Because I am investigating a multifaceted issue, it is imperative to incorporate theories that are applicable with working with minority ethnic bereaved parents (Wu and Volker, 2009). I will use these theories to structure the interview schedule and questions I ask and to further guide how I will analyze the data.

As the literature review demonstrates, racial inequalities are a fundamental cause of ethnic disparities in health outcomes (Smith, Bambra, & Hill, 2016). Scholars in this area argue that racism produces rates of morbidity, mortality and overall well-being (Nazroo, 2003; Razai et al., 2021) which are dependent on how race is socially assigned. Critical Race Theory (CRT) originated in socio legal studies and is grounded in social justice (Ford & Airhihenbuwa, 2010). The application of CRT in public health has grown to become its own field; scholars in the area are called 'healthcrits' (Ford & Airhihenbuwa, 2018). Public health theorists who use CRT have made meaning contributions to the field by highlighting how racism impacts health research (Ford & Harawa, 2010; Obasiguem 2013) It's clear that research plays a critical role in confronting racism by understanding how it impacts on the health and well-being of minority populations (Butler et al., 2018). Eliminating racism is central to achieving health equity (Ford & Airhihenbuwa, 2010). This theory acknowledges the intersections that reside within the differences that occur in race, class, gender and sexuality in the social world of ethnic minorities (Graham et al., 2011), which aligns with Merten's (2007) transformative paradigm. Furthermore, CRT seeks to name and understand the causes of racial hierarchies as does TP (Ford & Airhihenbuwa, 2018). What I appreciate is that CRT offers public health researchers a new paradigm for investigating health disparities and urges scholars to transform the hierarchies they identify through their research (Ford & Airhihenbuwa, 2010).

Bereavement is a personal and family issue (Neimeyer et al., 2011). Stillbirth takes away the hope and expectations from families, friends, and communities expecting a new life (Mills et al., 2014; Meaney et al., 2017). As humans are social animals, bereavements easily disrupt the social systems of which they are a part (Neimeyer, 2011). Neimeyer & Sands (2011, p. 9) maintain that: "To a far greater extent than other animals, we as human beings are distinguished by living not only in a present, physical world, but also in a world populated by long-term memories, long-range anticipations, reflections, goals, interpretations, hopes, regrets, beliefs and metaphors, in a word, *meanings*." Making meaning from loss is not always a straightforward process (Neimeyer, 2001). Davis et al., (2000) suggest that when traumatic losses occur, the search for making sense is more common than when a loss is expected. Research which examines the experiences of bereaved parents emphasizes the role of meaning making in predicting bereavement outcomes (Buckle & Fleming, 2011). In a study comprised of a large group of mothers and fathers whose children had died in infancy and childhood, Keesee et al. (2008) found that for participants, the degree of sense making proved to be a primary predictor of the severity of grief they experienced. Participants who reported having made little or no sense of their loss were more likely to report greater intensity of grief (Keesee, Currier & Neimeyer, 2008). Therefore, meaning making using a psychotherapy lens will be applied to the findings of the research to serve as a means of understanding and valuing the bereaved parents' participation in the group (Neimeyer, Baldwin, & Gillies, 2006; Uren & Wastell, 2002; Lichtenthal et al., 2010).

Equally, bereavement is experienced within a cultural framework (Klass & Chow, 2011). In bereavement and grief studies, culture and ethnicity are used interchangeably (Klass & Chow, 2011). However, Klass and Chow's (2021) definition evolved to describe an ethnic group as a shared bond of ancestral ties, religion, language, place of origin, history, or appearance. Culture however is how "people or groups of people represent their experience and is the basis for their actions; literally a picture of our world", (Klass & Chow, 2011, p.342,). All cultures regulate the mourning rituals of its members, whether it be subtly or overtly, implicitly, or explicitly (Neimeyer, 2001). Culture provides the template for how people represent their grief and therefore serves as a basis for their feelings and actions when processing their bereavement. Often these rituals consist of spiritual or religious meaning which are meant to help the bereaved process their grief (Testoni et al., 2021). Typically, cross-cultural studies of grief only report experiences on how Western ideas are assimilated into Asian, South American, Middle Eastern or African Cultures, and overlook how other cultures incorporate their cultures into European or North American spaces, (Klass & Chow, 2011). Incorporating CRT and meaning making (Neimeyer & Thompson, 2014) as guiding theories within my theoretical framework, I hope to provide insights on how minority ethnic parents' experiences of stillbirth relate to each other accessing support for their loss. Both theories will help provide context to the analysis of how parents choose to participate or not participate in peer support programmes and what types of support would be better suited for different communities.

4.5 Ethical considerations

Researchers must consider ethical issues when conducting research which involves a vulnerable population (Mertens, 2009). To ensure best practices are employed to protect both the participants and the researcher, I submitted an ethics application to the University's Ethics Committee which gained approval in February 2021 (Appendix A). I undertook sensitive research training prior to beginning my doctoral studies in 2018 and have worked with vulnerable populations in the past. I completed safeguarding training in relation to working with vulnerable populations both in the UK and the USA. In addition, I successfully completed two training courses during the first year of my doctoral studies in February 2018 which focused on working with bereaved individuals. The first course I completed in March 2018 was called: Loss and Bereavement Working with Grief- a Toolkit. The second course completed in April 2018 was entitled: Supporting parents through pregnancy loss and the death of a baby. Both courses were offered through CRUSE Bereavement Care and Child Bereavement UK who are leading charities for bereaved people in the United Kingdom. I understand the significance of respecting participants who might be vulnerable and made every effort to ensure participants' wellbeing was maintained during the research process.

4.6 Informed consent

Participants who participated in the project were adults of at least 18 years of age and were able to give consent to participate in the study. Prior to conducting an interview or a collage, participants were given a participant information sheet and a consent form so that they could be fully informed in terms of the nature of the research project. I also encouraged participants to ask questions about the research process. These conversations were often discussed verbally, however, we did discuss the study through email. The participant information leaflet included background information on the subject area, the purpose of the study, the procedure participants will follow when participating in the research together with information about the right to withdraw from the study at any point. Two consent forms were given to the participant; one of which they were able to keep and one signed copy for my records. I explained that there were two parts to the study and asked each participant if they had a preference about participating in both the semi-structured interviews and the collage activity, or only one of the activities. Due to the Covid-19 Pandemic restrictions, some participants had to contribute remotely via telephone or through an online interface. Verbal and written informed consent to participate in the study were gained from all the parents. (Appendix B, Appendix C)

To ensure participants' private information is kept secure, I followed Canterbury Christ Church University research regulations and conducted research according to the Data Protection Act (2018). No one other than the researcher and the researcher's supervisors has access to participants' information. I created a protocol that outlined the most appropriate manner to de-escalate a situation where the participant becomes visibly upset. There were also measures in place within the protocol to offer participants information on how to seek care after the interview; both in terms of self-care and seeking out a professional. I notified the baby loss charities that participants may seek support from their staff if they were to become emotionally activated. The protocol was approved by the supervisory team and the University Ethics committee.

4.7 Protecting the researcher

In terms of protecting myself, regarding the sensitive nature of the topic and the reflexive autoethnographic component of this project, I sought out support to maintain my emotional wellbeing. I tended to my own care through bi-weekly therapy sessions and reaching out to my supervisors. Over the course of this project, I've had several losses; three of whom were my immediate family members. It was and continues to be essential for me to seek my own bereavement support from my community and to be upfront and honest about my own mental health and grief journey.

4.8 Core component: Interviews

- 4.8.1 Rationale for choosing grounded theory

Qualitative research is used in social research to observe individuals in their natural environment to explore their realities and perspectives (Trumbull, 2005). It demonstrates how individuals' behaviours and attitudes are constructed by the environment and situations they live in (Hennink et al., 2010). Qualitative research is useful for understanding social phenomena as it explores the participants' perspectives, motivations and beliefs on the question being examined (Gill et al., 2008). This methodology will be applied to this study by exploring minority ethnic bereaved parents' perspectives and attitudes towards parent support groups.

Semi-structured interviews were used for the collection of data, as they provide information from the participants' perspective (Hannabuss, 1996). Interviews provide in-depth information on a specific subject that cannot be obtained by quantitative methods (Gill, et al., 2008). I intend to use a semi-structured interview model, because it was the most effective way to guide a highly sensitive and emotionally provoking conversation, and yet offer space for participants to speak candidly on other matters they wanted to share (Carruthers 1990; Morse & Niehaus 2009). Semi-structured interviews have a degree of structure to them which meant that all participants were asked common questions (Carruthers, 1990). Since there was a structure to the interviews, I could compare the participants' responses within the analysis (McIntosh & Morse, 2015). When in-person interviews were allowed, participants chose a place they felt safe in to conduct the conversation. Two couple interviews took place in their homes as it was the most convenient option while their children were home. The other in-person interview took place at a café near where the participant lived.

To analyse the data, I used the Grounded Theory approach which was "a systematic, qualitative procedure used to generate a theory that explains, at a broad conceptual level, a process, an action, or an interaction about a substantive topic", (Creswell, 2014, p.451). Grounded Theory has been a popular method of data analysis in qualitative research in social sciences (Morse, 2010, because it seeks to understand processes and how the parts of these systems are linked (Charmaz &Thornberg, 2021). Rather than being based on a hypothesis, this theory built itself from the bottom up, meaning the process of creating a theory developed over the duration of the study (Morse & Niehaus, 2009). The imaginative nature of grounded theory complements facet methodology; both facet methodology and grounded theory required the researcher to problem solve in creative ways (Charmaz, 2008). Charmaz (2006) argued that researchers needed to view grounded theory as a craft that needs to be practised. Like practising a craft, grounded theory called upon the researcher to consistently review and reshape the data (Charmaz, 2006). This theory was useful when applied to an emerging area of research or when there were no other theories available that address the problem or represent the participants in the study (Bryant & Charmaz, 2007, Creswell, 2014). When applied in a mixed methods study, grounded theory could only be used as the core component, because it was an individual method rather than a strategy (Morse & Niehaus, 2009, p.95). Due to the limited research looking at minority ethnic bereaved parents accessing baby loss support groups, this research study fit the aim of grounded theory to generate a theory about how and why this phenomenon exists (Charmaz, 2014).

After careful consideration of different approaches to grounded theory, the interviews aligned with Charmaz's (2006) constructivist grounded theory approach because I could see how her background in research culture within the social sciences could be useful in this study (Puddephatt, 2006). Charmaz's more recent work has become a more flexible method in terms of working with newer epistemologies compared to Glaser and Strauss' original version of grounded theory (Charmaz, 2014) which is compatible to Merten's (2007,2009, 2010) transformative paradigm which has only existed for the last two decades (Phelps, 2020). Moreover, constructivist grounded theory examines the social contexts of the phenomenon being studied which harmonises facet methodology's (Mason, 2011) objective to examine different facets of the research problem (Charmaz, 2017). Charmaz views the definition of a grounded theory as one which 'emphasizes interpretation and gives abstract understanding greater priority than explanation' (Charmaz & Thornber, 2021). Aligning with my philosophical position, Charmaz believed that 'truth' was relative and situationally based (Puddephatt, 2006). I interpreted this as a way to confirm constructivist grounded theory (Charmaz, 2007) would be an appropriate method to accompany TP (Mertens, 2007) and FM (Mason, 2011).

From a practical perspective, Charmaz's (2006) book, *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, was arranged in a linear form which outlined how to develop a constructivist grounded theory. I appreciated the format of Charmaz's (2006) text and the straightforward language which made a complicated method more accessible to a novice researcher. It guided the reader through the entire grounded theory research process which served as a practical example (Charmaz, 2006).

Because I followed Charmaz's (2006) approach, it is important to note that I cannot be totally impartial in the analysis process. My interpretation is "constructed" by my own experiences and perception (Charmaz, 2007; Davis, 2020). Charmaz's (2017) work encouraged researchers to self-reflect and examine their positions and privileges and how it affects their understanding of the phenomenon being studied. Therefore, I accepted that I brought my own experience of loss, grief, bereavement, and seeking support, when co-constructing the coding categories (Charmaz, 2019). Furthermore, Charmaz (2017) argued for implementing critical inquiry which she said is consistent with Merten's (2007,2009) transformative paradigm which sought to address inequalities and forms of oppression. Conscious of Charmaz's (2017) position on methodological self-consciousness, I recognised the importance of the researcher being reflexive in the process and wanted my position as the researcher to be used as a tool in the process which was why I also participated in the collage elicitation portion of this study. Creating collages facilitated my study of my positionality and social position (Charmaz, 2017).

There was a step-by-step systematic procedure for analysing data when I developed the grounded theory (Creswell, 2014; Charmaz, 2014). I followed Charmaz's (2006,2014) work to develop the initial analysis which grew into the Road to Hope Through Grief theory. Constructivist grounded theory's power lied in the development of midrange theory; meaning this type of theory made it generalizable to other instances and to future instances (Morse et al., 2008). First, data was collected from the interviews and coded (Creswell, 2014). This process of coding data enabled the researcher to interpret the data and applied a code to categorise it (Denzin & Lincoln, 2000). The most frequent codes which emerged from the data was categorised (Charmaz, 2006). In the grounded theory approach, researchers may collect and analyse data simultaneously (Creswell, 2014). The relationship was symbiotic; the data guides the analysis and vice versa (Bryant & Charmaz, 2007). During data analysis, notes were made to document data and the categories that emerge (Creswell, 2014). NViVo was the programme through which the data was stored and coded. NViVo was a software programme that "combined efficient management of non-numerical, unstructured data with powerful processes of indexing, searching and theorizing", (Creswell, p.267, 2014). The programme does not undertake the analysis for the researcher, however; it did help situate the data in a way where I recognised patterns and make conclusions in relation to the data (Creswell, 2014).

4.6.1 Questions from the interview schedule

The following questions were the main interview questions which addressed the research aims of this project. I discussed these questions with each participant during the semi-structured interviews. These questions arose from the gaps within the literature on baby loss peer support (Appendix D).

1. How did parents find out about baby loss bereavement groups? Who recommended the peer support channels to the parents, or was it a sought out by themselves?
2. What are the factors that contribute to their attendance and to their participation in the groups? What are the barriers that keep parents from attending?
4. Do parents prefer to attend groups led by charities or from within their communities? Which do parents prefer and why?
5. Why do more women attend the groups compared to men? What other forms of support do men access peer support groups (for example football clubs)?
6. What is still needed to better support BAME communities' access to baby loss support, and which channels are preferred?

4.9 Sampling

Qualitative research's key feature is to represent the complexity of the world through collecting perspectives of multiple individuals (Creswell, 2014, p.229). Purposive sampling applies to both the individuals participating and accessing the sites through which people attend (Creswell, 2014). It is typically associated with qualitative research, which involves selecting participants in relation to the research question versus collecting participants randomly, so that the information collected is exhaustive regarding answering the questions (Teddlie & Tashakkori, 2009 p.173). This means that researchers select people or sites through which the study information is passed along to those who can best answer the questions to understand the phenomenon being studied. Creswell (2014 p.228) says that this form of sampling is useful because "it gives voice to silenced people". Sample sizes are usually 30 or fewer cases (Teddlie & Tashakkori, 2009, p.228).

I originally planned to collect data in the greater London region. According to the 2011 census, London is the most ethnically diverse region in England, where 40.2% of residents identified themselves as Asian, Black, Mixed or other ethnic group (ONS, 2018). In previous studies of women living in London, minority ethnic women have a higher risk of stillbirth compared to white women (Balchin et al., 2007; Smeeton et al., 2004; Stacey et al., 2021) As this study pertains to only minority ethnic parents' experiences, London seemed to be the most logical choice in terms of data saturation, because of its diverse population and proximity to where I live. The charities who agreed to promote the study were based in the West Midlands and SE England, meaning participants were generally located in the Midlands and SE England.

To meet the inclusion criteria, parents must have at least one year outside of the initial loss to up to ten years from the loss of their child. Sixteen parents across England participated across three interview cycles; this figure was comprised of thirteen mothers and three fathers. No parent self-identified as belonging to the LGBTQIA community; heteronormative language will be used throughout the thesis (e.g. women called themselves mothers, men called themselves fathers). Parents must be in a befriending programme or a peer support group (in-person or online) or have participated in one of these formats within the last five years. Participants were parents who had experienced pregnancy loss from 22+ weeks and onwards who self-identified to be from minority ethnic backgrounds. The term 'minority ethnic' is appropriate in the UK to describe people of non-white descent (Institute of Race Relations, 2019). However, minority ethnic is also used to include people who are white, but of non-British descent; most commonly including populations from Eastern Europe and Traveller communities (Devon County Council, 2019). Oxford University administration defines Black and Minority Ethnic (BME) as: 'Black (including African, Caribbean and other Black background), Asian (including Bangladeshi, Indian, Pakistani, Chinese and other Asian background), Mixed heritage (including white and Asian, white and Black African, white and Black Caribbean and other Mixed background), Arab or any other ethnicity except white' (Oxford University, 2022)

4.9.1 Recruitment Strategy

Six participants comprising of four mothers and two fathers self-identified as being Black. Nine participants self-identified as being of Asian ethnicity. One mother identified as Polish. Only three interviews took place in person due to national guidance on social-distancing during wave one and wave two of the COVID-19 pandemic. The rest of the interviews were conducted online via laptop or by phone.

Firstly, to promote the study, I intentionally met with baby loss charities who supported bereaved parents who had experienced a stillbirth. Despite cultivating a relationship with SANDS over the course of a couple of years (2016-2018), the organisation decided to not support my study by means of promoting it through their channels. I was disappointed as SANDS is the largest and most well-known baby loss charity across the United Kingdom. I contacted over a dozen charities across England by means of email, phone and their social media pages. Over the course of the first year of my studies, I met with several charity executives to explain my project to them in hope of them agreeing to promote the study to their supporters. I found that charities who were not able to boost the study's visibility to their base were constricted to the support the charities provide parents. For example, there are several charities who support recently bereaved parents in hospital by donating different care packages, but don't offer a peer support or befriending programme for parents further along their grief journey. Therefore, the focus of the study didn't fit their interests. There were also many smaller and regionally based charities who didn’t offer peer support bereavement services due to staff constraints; these charities would often refer parents interested in this type of support to access the larger charities like SANDS. Even with these challenges, I was able to form three community partnerships with three baby loss charities (Aching Arms, Lily Mae Foundation, Muslim Bereavement Support Services) in which they agreed to back the study by disseminating the study’s flyer and participant information sheet to the people who access their services. Only one couple came from one of the community partner organisations. Although there was interest from the charities, the majority of interested people did not fit the inclusion criteria. Most did not self-identify from a BAME background; a small portion had lost their babies outside the time span of 10 years.

The second strategy concentrated on developing a connection with healthcare professionals, such as bereavement midwives and chaplains, who could help pass along the recruitment flyer and participant information sheet to parents who they thought might be a good fit for the study. Knowing how significant both roles play out in the lives of bereaved parents made their input invaluable to this study. In a similar way to the experience of contacting baby loss charities, I also sent out preliminary emails to a handful of bereavement midwives across the country to gage the interest in this study. The bereavement midwives responded more often to my emails and phone calls than the charities did. I met with several different bereavement midwives in person and by phone to discuss the study and to ask them to circulate the information to couples they thought would be a good fit. It was through these conversations where I was connected to chaplains across England. From these conversations, there were four participants who were referred to the study directly from bereavement midwives (Appendix E, Appendix F).

Social media was the most successful medium to increase the study’s exposure and to attract potential participants. The study flyer was shared on Twitter by the baby loss charities (community partners and by others not affiliated with the study); bereaved parents who I’ve met during my course; and other grief and bereavement researchers. Nine participants came to the study through Twitter. Participants saw the flyer from an account they followed and contacted me directly to speak about the study and what would be required of them. One participant came from an online support community on Facebook. I had sent the flyer and participant information sheet to the group’s moderators who then posted it on their private page. It is possible that social media was the most accessible way to attract potential participants to the study considering the impact Covid-19 had on the world by severely limiting in-person contact to limit exposure to the virus. People felt the need to connect with people through online mediums, which benefitted this particular study. Additionally, social media platforms expanded the study’s scope to include people outside greater London and the home counties. The Midlands were the most represented geographical area of the study.

Recruitment occurred from March to November 2020. I received several requests from women who self-identified as white British to participate in the study. What I perceived as their enthusiasm to contribute to the study made me feel apprehensive about telling them they were unable to participate. None of the parents disputed the inclusion criteria. To compensate interested parents for their interest in research, I referred them onto other baby loss projects that were recruiting parents. Of the three recruiting tracks, it is interesting to note that bereavement midwives seemed to have more sustainable relationships with bereaved families than chaplains do as I received more referrals from midwives compared to chaplains. Chaplains relayed that they often support bereaved families in hospital settings and quickly lose touch with the families once they are discharged. One chaplain in particular expressed interest in working with bereaved families, but there were too few resources available to help support parents outside of the immediate time from the loss. Throughout the duration of the recruitment process, I responded to email inquiries about the study from parents who have accessed the three different charities, however, these potential participants didn't reply to my messages. (Appendix)

4.9.2 Participants in cycle one

The first cycle of data collection consisted of two interviews which took place at a precarious moment of March 2020. The UK was waiting to hear what the government's strategy would be to combat Covid-19. The country was bracing itself for lockdown that seemed to be looming. Fortunately, I was able to meet with three participants; one couple consisting of a mother and a father, and the third was a mother. Both interviews took place in person within a two-week span before the first national lockdown. The couple self-identified as Black and spoke of their Ghanaian heritage frequently throughout the interview. I interviewed the couple in their home. The mother self-identified as Polish and would classify herself under the 'any other white background' category in a government form such as the Census. She asked to meet in a public space, so we met at a local café where we could find a quiet area to conduct the interview. She was married to a white English man; however, he was not able to participate because he did not match the inclusion criteria based on his self-identified ethnicity. All three participants resided in Kent. A bereavement midwife with whom I had met during the first year of my PhD urged me to contact the mothers to participate in my research study as they had previously expressed interest in participating in research. The Polish mother created a collage once the interview had finished. The couple chose to not create a collage due to time constraints. The table below provides a summary of the participants' experiences which were discussed during the interview, to provide context for their data.

Table 2: Participants in cycle one

Pseudonym	**Ethnicity**	**Region**	**Type of Peer Support Group**	**Current Attendance**
Iris	Polish (white other)	Kent	SANDS; PALS	Not active
Jade & Arthur	Black	Kent	SANDS (mum); church group (dad)	Not active (mum) Active (dad)

4.9.3 Participants in cycle two

The second set of interviews took place between August and September 2020. I had returned from being in the United States for four months. The national government guidance at the time permitted small groups of people to meet indoors. During this time frame, I conducted one group interview in person, one interview with a couple in person, and three online interviews. The group interview was held at a hotel conference room in Leicester city centre. This was the most practical and safest option for everyone to attend. Three mothers participated in the interview. Another mother joined the second portion of the group activity which was to create a collage (she completed an online interview prior to the meeting in Leicester). In total, all four mothers chose to make collages.

Table 3: Experiences of Participants cycle 2, group interview

Pseudonym	**Ethnicity**	**Region**	**Type of Peer Support Group**	**Current Attendance**
Ruby	Asian	Leicestershire	SANDS; new charity	Active (group Leader)
Sophie	Asian	Leicestershire	SANDS; social media	Active in person and online
Alice	Asian	Leicestershire	SANDS	Not Active

The couple interview took place in person at the participants' home. Their home was where they felt most at ease to discuss the loss of their child. Considering the sensitive nature of our discussion, I wanted to reassure participants that they oversaw selecting the space (whether online or in person) where they felt most comfortable to discuss how they sought out bereavement support.

Online participants chose what platform they wanted to meet on. Whilst it was university guidance to use MS Teams as much as possible, I found that most people in autumn 2020 didn’t use Teams. There was a strong pushback from participants against downloading a platform to which they didn’t already have access. Equally, participants didn’t want to download a video conferencing platform they were unfamiliar with for a one-to-two-hour interview and never use it again. Each of the three interviews were held on Zoom as it was the most popular platform. There were several technical issues that impeded the online interviews; every participant tried to fix any technical issues in a timely manner to get back to the topic at hand. Although it was somewhat disruptive, I felt that each parent was keen on completing the interview despite any technical difficulty. Due to the technical issues, the interviews tended to last longer. The table below outlines this cycle of participants’ experiences.

Table 4: Experiences of Participants, cycle 2, remote interviews

Pseudonym	Ethnicity	Region	Type of Peer Support Group	Current Attendance
Nicole	Black	Leicestershire	SANDS; Maternity Voices Partnership	Active
Sandra & Vern	Asian	London	SANDS; Aching Arms	Active (mum) Not active (dad)
Amelia	Asian	Leicestershire	SANDS	Active
Carrie	Black	Sussex	SANDS	Active
Abigail	Asian	Leicestershire	SANDS	Active

4.9.4 Participants in cycle three

The final cycle of participants was held strictly online. All four interviews took place during October and November 2020, just when national restrictions were reintroduced in England. Like participants in cycle two, there was an issue finding an online platform that participants wanted to use versus what the current policy was at university. Two interviews were held via Zoom; two were conducted on Whatsapp; and one was completed on Facebook Messenger. Three mothers self-identified as Asian whereas one mother self-identified as Black British. The sole father self-identified as Black British.

Table 5: Experiences of participants, final cycle

Pseudonym	Ethnicity	Region	Type of Peer Support Group	Current Attendance
Betty	Asian	Leicestershire	SANDS; Leicester Loss Group	Active

Sheila	Asian	Warwickshire	Luca's angels	Active
Daphne	Asian	Leicestershire	SANDS	Active
Dominic	Black	Greater London	SANDS; Dope Black Dads	Active
Maya	Black	Yorkshire	SANDS; social media	Active online

4.10 Secondary component: Collage

4.10.1 Implementing Collage-Making in Research;

Following Butler-Kisber's (2010) approach, I invited participants to create collages where they could reflect on their experiences of seeking bereavement support for their loss. This project was given ethical approval by Faculty of Health and Wellbeing Research Ethics Committee at my university. As I had been collecting newspapers and magazines throughout my studies, I was able to provide participants with all the equipment needed to create a collage. All participants were invited to construct a collage immediately following the completion of the semi-structured interview, or have another session scheduled at a time and venue which was convenient for them. Asking parents to participate after the completion of the interview was an opportunity to invite further dialogue and insight which may have supplemented their interview. Participants could choose to decline to take part in the activity; equally they were also encouraged to return at a later date to make a collage if they changed their mind. The purpose of incorporating the collage-making activity was to enhance the data collection procedure in anticipation of the generation of additional rich data that might not have been produced through semi-structure interviews alone. Collage serves as a rich supplementary secondary data source because it produces qualitative data while working with sensitive topics (Vacchelli, 2018). The collages were not displayed in a public setting but are included within this thesis. Participants were given the choice to keep their collages or donate them voluntarily to me. If a participant chose to keep his/her/their collage, I included a photograph in place of the physical collage with the agreement of the participant. To protect participants' identities, I anonymized the collages, and gave each one a number. Later in this thesis, I interpret the collages through the lens of thematic analysis.

I collected magazines for nearly a year to supply them for this project. I received several large donations of supplies from contacts near me who were also saving their magazines for my project. The range of subjects included: fashion, home and garden, food, regional publications, hiking and outdoors, travel, tabloids, automotive, and weekly publications such as TimeOut and The Evening Standard, which are free to commuters on London transport. I provided the coloured construction paper, scissors, and glue sticks for the collages. This was intentional, because I didn't want participants to feel they were obligated to purchase any of the materials to create a collage. Since all were parents to living children, each interested parent offered to use their children's school supplies. Parents got to choose which colour of paper they used as their background. Participants had the option to choose from the following pastel colours: green, pink, blue, yellow, or cream. Those who couldn't meet in-person received a parcel of collage materials by post. The parcels contained one sheet of paper per colour; an assortment of magazines, instructions on what the task was and how to make a collage; a pair of scissors, and a glue stick.

There were eight participants who participated in creating collages. Four collages were created in person with me present in the space while participants were creating them. The other four collages were created by the participants in their homes who had to participate remotely due to the national restrictions. The participants who participated remotely all received a parcel through the post. No fathers took part in the collage-making activity. The father who participated in the interview by himself said he was interested but he didn't have the space nor time to create a collage. One of the two couples who completed the interview were interested in creating a collage, however, the piece never materialised. The mother of the couple informed me that she alone had tried to create a collage, but she didn't find images or words that pertained to her experience of seeking out baby loss bereavement support. When I offered to send a new parcel of materials, she declined due to the time constraints between finding space for her to create the collage and her work and home duties.

Although participants were nervous to begin the project, all produced lovely and meaningful pieces of art. It is interesting to note that participants who created collages in-person wanted to talk about their creation. The small group session in Leicester had all three participants who were there compare the images they selected. Participants who created the collages remotely did not have the same experience of being able to compare with other parents or to tell me about the images they selected. Though it was not part of the task, a couple of participants wanted to tell me about their collages and the reasons for which they selected the images. Participants were encouraged to keep their collages as a token of remembrance of their child. As part of the task, each participant had to send a photograph of the collage for the research study if they did not want to keep the collage. Each participant understood (from our conversation and through the participant information sheet) that the collages would be included in this thesis for the analysis and for the examination of this thesis.

5 Semi-structured interview results

5.1.1 Introduction to the chapter

The aim of this research project was to explore how minority ethnic bereaved parents accessed baby loss peer support groups. Chapter five discusses the significant findings that were generated from the semi-structured interviews and the collage activity. It examines how bereaved minority ethnic parents of stillborn babies choose to access peer support bereavement services during their grief journeys. This chapter begins by outlining the major themes that were identified within the data collected from the semi-structured interviews and will end by discussing the themes that emerged from the collages which were developed using Thematic Analysis (Braun & Clark, 2006). Chapter examines the influences that determine whether minority ethnic parents participate or do not participate in peer support and befriending programmes across England. Secondly, this chapter describes the sixteen parents' experiences when attending a peer support group to explore why some bereaved parents find community within charity bereavement support programmes outside of their own communities. Thirdly, this chapter illustrates how bereaved parents find meaning in their grief by participating in peer support and befriending programmes. I share findings regarding how civic engagement within the charity sector on behalf of their child has affected these parents' attitudes on baby loss are reviewed. Finally, this section of the chapter concludes by exploring how to better construct culturally appropriate bereavement services for minority ethnic families.

In the second half of the chapter, I will discuss the findings from the collage-making activity. I will compare the findings of the semi-structured interviews with the collage-making activity.

5.1.2 Confidentiality and anonymity of participants' identities

To protect the identity of the participants, they are referred to by the pseudonyms that have previously been used in this thesis. Furthermore, any place names or other information that could be used to identify participants have been removed and replaced. However, it should be noted that references to charity names have been kept identifying which charities' approaches are appropriately supporting research participant parents and which ones are not. I note that this study sample is too small to make generalisations about the data, so the particpants' experiences may not be representative to other minority ethnic bereaved parents' experiences of accessing baby loss bereavement support.

5.1.3 Interview themes

There were sixteen parents (thirteen mothers and three fathers) who participated in the interviews. Excerpts from the interview transcripts illustrate the categories that emerged from the data and serve as the basis of the theory I have developed. The quotes were chosen based on their relevance to the research questions to demonstrate the importance of the participants' experiences and the variation within the data. Each quotation is verbatim and is in the participants' own words. As was mentioned earlier in the thesis, the interview transcripts were anonymised so that all identifiable information was removed. I utilised NVivo to organise and analyse the semi-structured interviews. Although the software does not perform analysis on its own, it provided tools to help me sort and arrange the data in a systematic way to identify relevant themes.

5.1.4 Findings from semi-structured interviews

5.1.4.1 *Factors which facilitated accessing baby loss bereavement support services*

None of the parents reported that they had anticipated having a non-viable pregnancy. The unexpected and devastating news left them shocked to learn that they were not going to have a live baby. Because these losses were unexpected, participants shared that the process of learning that the baby had died was exhausting in terms of processing the information that health care providers were providing. Mothers and fathers shared that they had no previous knowledge about any of the baby loss charities before their own experiences of perinatal loss. Parents only learned about these bereavement support charities once their babies had died. Here, they were faced with the reality that they had to learn about the services that were available to support them. Most participants recalled memories of being given pamphlets of the different organisations after the loss of their child; SANDS was the most mentioned charity throughout the interviews. Some mothers shared that they had learned about SANDS from their midwives and doctors. One mother, Amelia, found her way to SANDS from a simple online search.

*"It was like a process over the months that just got worse and worse and worse and then someone said Sands to me and I think I Googled Sands."- Amelia, Leicestershire, SANDS*Several participants described the hesitancy they experienced when trying to contact the baby loss charities. Accessing support from this charity sector reaffirmed that their baby had died; they felt helpless and yet the anxiety they experienced in contacting a support charity felt taxing. Some participants reported that receiving encouragement from their GP and/or midwives influenced their decisions to contact befrienders and the organisation coordinating the peer support groups. If they had not received support to contact the charities from their healthcare providers, it was likely they would not have made the effort to access peer support. Below is a quote from one participant which represents this:

"Personally, if Rose (the bereavement midwife) or SANDS didn't approach me through the hospital, I probably would have just come home and listened to everybody else and just gotten on."- Iris, Kent, PALS (Pregnancy After Loss Support)

Once participants had contacted the baby loss charities, they shared that having access to a befriender with whom they could connect was critical in persuading them to attend a meeting. Often the befriender tried to sway newly bereaved parents by reassuring them that participating in a group could have been beneficial to their mental health. The reassurance of another bereaved parent who was further along in their grief journey was vital to convincing the newly bereaved parent(s) that accessing bereavement support was a way for them to process their loss. Attending a peer support group was a way for parents to feel a sense of normality; they had space to share their grief with others who were grieving similar losses. They did not have to hide their grief in the way they did in their daily lives, instead, the newly bereaved parent could expose their emotional selves in a safe space. The quotes below address how participants in Leicestershire felt being in a shared space with other grieving parents, and how it affirmed that other parents feel, and grieve in the same way as they did. Being with other parents with shared experiences helped to normalise emotions related to their experiences of perinatal loss.

"Obviously just going there and talking to other parents and stuff, you know, who have actually been through what we've been through, what I've been through just helped me because there was days where I'd be thinking something but be so scared to say it just because I thought, God, if someone hears me say it they're going to think oh, how, like how rude is she or is she going mad? But when I have to sit in a support group and somebody else used to say it, it used to make me think oh, phew, I'm not losing it just yet. I'm not going crazy because it must be a natural way of thinking if other people are thinking what I'm thinking as well. Other mums are thinking what I'm thinking as well."- Abigail, Leicestershire, SANDS

"I think it's because you have mums and dads there that have lost earlier on and, and some that have had babies that have lived days, weeks even, is that, you know, all our stories are different, but we're all united in the grief. So, again, that goes for religious backgrounds, culture, whatever, erm, you know, it, it's the one thing connects all of us is that and I think maybe that's, that's what we've always tried to focus on."- Alice, Leicestershire, SANDS

"We left that session, and we were like we need to go again; it's helping. Straight away we could feel that it's letting something go and you feel like you're part of… not just, you're now in a community of people that get it and that was big. That was really big for us."- Sophie, Leicestershire, SANDS

"At SANDS, if we were having a giggle about the most randomest thing, it doesn't matter, and everyone still gets it and everyone still knows how real your grief is and how real your love is. It just…so in, in that way that support group"- Ruby, Leicestershire, SANDS Group Leader

5.1.4.1.1 Misplaced support from family and community

The most prevalent reason families chose to access support for their grief outside their immediate communities was that they did not feel they were receiving adequate support from their immediate family or friends. All participants recounted examples of hurtful comments or misguided support from their immediate social circles. Participants shared encounters that they had with people who had unintentionally caused emotional pain; every parent could acutely remember how they felt when they did not feel supported by their family of origin or their communities. Bereaved parents largely felt that their friends and family who had not lost a child did not understand or could not support them to process their grief. Repeatedly, parents shared that their communities did not know they were being harmful rather than helpful, and how hard they had tried to let go of the resentment they felt when they were hurt by those they loved. Participants designated aunts, uncles, cousins and friends as the loved ones who didn't support them. There was an obvious disconnect between the type of support newly bereaved parents wanted and the support they received. For example, Sandra, Greater London, Aching Arms suggested:

"Repeatedly by like the closest, the most well-meaning friends and family and with very good intention which we know, I know was very good…and it was making me very angry so I was like, but I shouldn't feel that because these are the people who care about me"

Black and Asian parents shared that their communities' cultural expectations often dictated that baby loss should not be discussed. There was an inherent unspoken suggestion that the death of a baby was less significant than that of a child or an adult; it was replaceable. Some participants shared that the death of their baby was not discussed so that they would not become distressed with the suggestion that not talking about the child made it easier for them to move on with their lives. Other cultural tendencies focused on which topics one 'should' and 'should not' speak of. The death of a child was one topic of conversation that must not be spoken of, particularly with the newly bereaved parent. The oppressive silence of not speaking about their baby with their loved ones was extraordinarily painful for the newly bereaved parent. For example, Abigail, Leicestershire, SANDS stated:

"I belong to this family but obviously over time I've come to know that the only reason my parents didn't talk to me about it is because they were worried of upsetting their little girl and like if they brought the subject up it would upset me and I'm the youngest of four. So, I'm like their baby and I'm very close to my parents as well but it's only as time's gone on and I've explained to them that you actually made it worse for me by not talking about this, they like were in disbelief that no, we thought we would be doing you a favour by not talking about it and I said if anything you made it 100 times worse"

Whilst Daphne, Warwickshire, Luca's Angels commented*: "We lost, we basically lost our chance to talk about our son because people felt that we didn't want to, but obviously we could 't tell anybody that oh, the reason why we're not telling you is because we've told not, we've been told not to. Do you see what I mean?"*

Conversely, most of the bereaved parents in this study were recipients of platitudes that were meant to comfort them. Instead of unbearable silence, these attempts to comfort the bereaved parents centred around them having more children**—**as a way for the parents to move on from the loss of their child. Despite their loss being outwardly acknowledged by these well-meaning loved ones, there was little sensitivity to the significance of the child's death. If the bereaved parents had other children, they were told to be grateful that they were already parents. Here the suggestion was that they were already a mother and father which meant that their grief should not be as severe as it might have been if they were not a parent to another child. Maya, Yorkshire, online support group commented:

"I know they are trying to comfort you, but it ends up being so, such a painful thing to say. Erm, you know 'you'll get another one, erm, you're still young, you've got other children', err, I know they are coming from a good place but that is just so hurtful. Even that was, that was my baby. Still, they don't think it's a human being, it is a human being, it's a baby from the moment that you know."

Whilst Arthur, Kent, Men's group at church noted*: "Like yeah, be grateful statements, which you are, you are thinking yeah you are because, yeah, some people don't (have kids). But then it's like, you think you're devaluing what just happened to us because we already have one (a living child)."*

5.1.4.1.2 Summary of how parents accessed peer support groups

The misplaced support from their loved ones persuaded the newly bereaved parents to access support outside of their immediate contacts and their communities. Participants needed the literal and figurative space to process their loss in a compassionate manner. They required people who could meet them where they were on their grief journey without the burden of carrying cultural expectations that they were expected follow. The excerpts shared in this chapter are a representative sample of the quotes from the data and offer a central reason why parents access bereavement support programmes and befriending services. Although some parents may not have attended many meetings, it is evident that accessing bereavement peer support and befriending programmes allowed newly bereaved parents vocalise their grief in the company of other parents who spoke the same language of grief.

5.1.4.2 *Barriers to accessing support*

Whilst individual responses varied in terms of why participants stopped attending their peer support group, there were prominent themes that developed during the analysis. Four participants shared that they no longer sought bereavement support through the peer support groups they attended earlier in their grief journeys. For example, Nicole, Leicestershire, SANDS, Maternity Voices Partnership suggested:

"I felt like I'd got the answers that I needed for that one that, you know, for that time and then, erm, I kept in contact with another couple, erm, and then that was it."-

This is representative of the four participant mothers who shared that they had received all the support that they could from a peer support group. They felt that the practise of accessing bereavement support groups was finite. As Nicole's grief became less severe, so did her dependency on seeking out support. Three out of these four participants made life-long friendships with other bereaved parents which they took with them once they stopped attending their support groups.

Only one participant of the four who did not develop a lasting bond attended a peer support group that was only for mothers who were 'pregnant after a loss' which was called Pregnancy After Loss (PALS). The format of the PALS groups somewhat prohibited the expectant mothers from seeking help and attending their support programme once the baby was born. Once the rainbow baby (the first child born after a baby loss, said to bring colour back into their parents' lives (Wheeler et al., 2022)) had arrived, mothers were not encouraged to return to the group, to protect the pregnant women who had yet to give birth. Seeing a mother who had a living baby was considered a potential trigger to unwelcome emotions to the attending members.

5.1.4.2.1 Pregnancy after loss

Participants reported that they felt that they should not be attending the peer support groups if they had a subsequent pregnancy during the time that they were actively participating in a support group. Participants reported a sense of responsibility in terms of not causing emotional distress to parents who did not have living children or who were not expecting to have another child following their loss. Sheila, Warwickshire, Luca's Angels stated:

"I did go to one meeting, err, in person, erm, by then I was expecting my rainbow baby as well and, erm, and at the meeting I, I asked how, erm, how does pe-, how do people cope when they're having a rainbow baby. Erm, but it didn't kind of go down well because, erm, there was women there who had just lost their baby and I was talking about having a rainbow baby. So, it wasn't received very well, and I felt like I'd said something that I wasn't supposed to. So, erm, I didn't go back again, erm, because err, it just felt like an awkward atmosphere, err, when I spoke about that and I felt unsupported."

Sheila decided not to attend further meetings to avoid feelings of guilt for conceiving and later being visibly pregnant. Those who did attend group whilst they were pregnant felt shame for expecting a living baby and attending a bereavement support group to process their grief for their deceased child. It was easier for them to stop attending meetings than to participate in the group they were familiar with, despite no longer having access to the friendships they had developed during their time attending peer support meetings.

Two participants mentioned that they were referred to the pregnancy after loss group once they had become pregnant again. The Pregnancy After Loss (PALS) groups are designed to support parents who are expecting another child after perinatal loss. These groups are designed to alleviate the expectant parents' fears related to the new pregnancy and to give parents the space to process the loss of one child while expecting another baby. Alice, Leicestershire, SANDS commented:

"When I found out I was pregnant I thought, ok I can't keep going anymore, erm, coz I know it's a trigger and I did really miss everybody after that, I really missed them. I really missed that. I couldn't tell them why I'm not coming anymore coz I didn't want to trigger any emotions for them but, yeah, stepping away from it was a bit tough and then there was obviously the after pregnancy after loss group."-

Here Alice hid the reason why she stopped attending the original peer group because she did not want to upset the parents who were still actively participating and attended a PALs group instead.

5.1.4.2.2 Logistical complications

The most frequent barrier participants reported related to logistical support when accessing the group. It was difficult for both a mother and father to attend meetings together, and therefore the couple considered which parent would benefit most from attending group whilst the other parent stayed home to care for their children. Often, it was the father who stayed home to care for the children whilst the mother attended the peer support meetings. Some mothers shared that attending the group became too difficult once other commitments conflicted with the support meeting schedule. When there were changes to the home routine, it was likely to impact on both parents' attendance patterns. These changes often led to parents attending the group less frequently, which led to parents not attending meetings at all. The following quotes are representative of this:

"Even now a lot of times, Victor be like -Victor is my husband- he'll be like I'll come along but, like I said, we both can't go together. He often says I'll come, and something always comes up (with the kids)." Amelia, Leicestershire, SANDS

"I don't feel like I don't need them anymore, obviously things changed with Alan's works so sometimes it was clashing." Jade, Kent, SANDS

For Maya, who accessed online support groups, there were not any in-person support groups in her local area that she could easily access.

"Physical support would be good but geographically it's a, and logistic-, logistically is, is, it's impossible. Because I think if people knew you could go to this place and meet these kinds of people, they would turn up but logistically it's impossible." Maya, Yorkshire, online support

During her interview, (Maya who is a single parent) told me that although she would have liked to meet with other bereaved parents in-person compared to meeting parents virtually, it was too difficult to manage attending the group and caring for her children. The logistical complications she faced persuaded her to seek out online bereavement support in a private Facebook group for stillbirth bereaved parents across the country. A benefit of participating in an online forum was that she could access support at any time of the day. She did not have to wait for the next meeting to connect with other bereaved parents~~;~~ instead, she could log onto Facebook. It is important to note that Maya was the only parent to access virtual support before the Covid-19 pandemic. The influence of active isolation from other people during the pandemic forced in-person bereavement support programming to move to virtual platforms. A couple of participants reported not attending online peer support, because they didn't have the time to attend meetings. Other parents said they had to learn how to navigate new online platforms like Zoom to engage with their group members.

5.1.4.2.3 Issues stemming from class

Beyond logistical issues, I learned that there were other significant influences which deterred participants from not attending or stop attending bereavement support programmes. Carrie, a SANDS group leader, revealed that there were parents who had attended the group once and then never returned. She disclosed that she noticed there was a risk of parents from lower socioeconomic status backgrounds not feeling comfortable socialising with other parents from different backgrounds. Here Carrie Group Leader, Sussex, SANDS notes:

"We had people come who, who were, who were younger or from a working-class background or whatever but they, you know, they haven't returned. They haven't returned. They've come, well you know, once or twice or whatever. Erm, and then there's other people who have, who have stayed in, in every single month and stuff like that but, again, I think that the group is a much more social space and if you don't feel like there are people who are like you who, who understand you or you can, you can, err, you know, hang out with or stuff like that then, you know, maybe it doesn't feel, erm, as welcome, er for you."

In her quote, Carrie highlights the importance of belonging to a group, where belonging is considered in terms of shared experience and being from a similar background. As an experienced group leader and a bereaved parent, she recognised the critical importance of resembling others by appearance or socially, and how these factors may impact a newly bereaved parent feeling welcomed into this social space. It is an immense task for a newly bereaved parent to take the first step in accessing bereavement support; it is moreover very challenging to attend a programme where parents feel they do not belong. The structure of a peer support group may be perceived to be exclusive from an outsider's perspective.

The use of language was a noteworthy subtheme within the larger theme on class. For example, Nicole, Leicestershire, SANDS, Maternity Voices Partnership commented:

"If I'm going through this (loss of a baby) as an English speaker, you know? What more a woman that English is their second language? And she can't fully get her feelings out? How is she feeling?"-

Attending a bereavement support group requires people to engage through verbal communication, which can be a challenge for bereaved parents whose first language may not be English. Openly discussing grief is difficult when fluent in a particular language; it is even more challenging when also attempting to access the right vocabulary in a different language. Parents may struggle to access the correct words to describe their feelings related to their experience and build relationships with other peer support group members. Although charities have made advancements to produce information pamphlets in languages other than English, there is limited available information which indicates that there are established peer support groups that are conducted in languages not in English taking place in England. Ruby, the former SANDS group leader, is developing a charity to support Asian parents who experienced baby loss and hopes to create advocacy materials (e.g. brochures and flyers) that are in different languages and to establish peer support groups that are delivered in languages other than English

5.1.4.2.4 Inequalities perceived by minority ethnic bereaved parents

The minority ethnic parents who participated in this study revealed the racism they experienced within the healthcare system and the challenges of seeking baby loss bereavement support. Several participants discussed negative feelings towards the 'institution' of the NHS which stemmed from their adverse experiences receiving care. Parents were concerned that little was being done at national level to tackle the maternal mortality and baby loss crisis in the UK, where rates of baby loss in Black and Asian communities are often double the rate of white babies (Matthews et al., 2022; MBRRACE-UK, 2021). Participants were aware of the disparity between minority ethnic families' rate of perinatal loss compared to white families (Wise, 2021). Whilst anti-racist healthcare practitioners are working in the NHS, the bereaved parents felt that there were systems in place within the NHS that were still largely racist. Healthcare providers in maternity services must acknowledge how racism can flourish in structural and internalised biases (Burnett, 2020).

*"There was even, there were student midwives that were actually on the, the erm Zoom call too, at our recent meeting, and they said that they've experienced it [institutional racism] in class with their lecturers. Their lecturers, you know, being from the white background, whenever they would speak about something to do with BAME women they would say to them: 'So, what, what would, what, give us, you give us an example about this and some of them said: you know we've never had children and then the, the teacher would say: Oh, so, has your mum ever spoken to you about her experiences?' So, they said they felt really picked on, you know? And it's, yeah, it's rea*lly bad!", -Nicole, Leicestershire, SANDS

Distrust of the healthcare system was evident in one father's experience of trying to find bereavement support.

"I'm sure people are not killing babies, you know, on purpose. And the only thing that people haven't been able to debunk is the institution, and how the institution behaves towards a certain group of people to that effect, you know?" -Dominic, Greater London, Group Leader, Dope Black Dads

Dominic is an active bereaved father group leader who is working to change the poor maternal outcomes for Black and Asian women and ultimately the families of Black and Asian women who lose their lives during pregnancy and childbirth. Dominic told me that he had approached SANDS early in his grief journey and had not received a response from the organisation. A befriender did not contact him; he was never informed about how to access the bereavement support groups. A few months later, he contacted SANDS again. He experienced the same outcome—no response and no further guidance received. According to Dominic, it was only when the Dope Black Dads group started to gain online momentum that SANDS responded to his inquiries and proposed that they work collaboratively with the Dope Black Dads group in tackling maternal mortality.

Even with SANDS' national presence and being the largest baby loss charity, some participants suggested that SANDS did not fully address the support that was needed for minority ethnic bereaved families. Although her white English husband is a befriender at SANDS, Iris, a Polish national, divulged that she did not choose to access the SANDS services and observed:

"I did not end up going to SANDS meetings. It was partly of me feeling 'I'm a foreigner'. I didn't, it didn't advertise as is for everyone, no matter nationalities, skin colour, whatever. I felt like I'm going to be outside of there."- Iris, Kent, PALS

Here Iris thought she was going to feel like an outsider due to her otherness of being a Polish mother. Several parents commented that the SANDS pamphlets, other reading materials, and the SANDS website did not feature minority ethnic families. When SANDS did feature Black and Asian families, it made participants feel it was a tokenistic gesture. Participants wanted SANDS to make their groups more inclusive by encouraging ethnic diversity through better-made marketing materials and encouraging minority ethnic families to seek ~~out~~ support.

The 2020 global protests in response to the murder of a Black man, George Floyd, killed by a Minneapolis police officer took place whilst I collected data (Dreyer et al., 2020). I experienced the protests immediately after George Floyds' murder when I was at home in Minneapolis during this period. Like many others in my local community, and around the world, I was concerned by the injustice of what happened to George Floyd and many other Black people's lives. Carrie, a SANDS group leader, is an African American woman who lives in Sussex. She understood the severity of what was happening in the United States and could see how the Black Lives Matter (BLM) movement became a global concern that included the UK. In conjunction with BLM's rising prominence, Covid-19 had also disproportionally impacted minority ethnic families. During her interview, Carrie called upon the baby loss sector to take note of the current events taking place and suggested that it was imperative that support should be provided for minority ethnic families.

"I think that charities really need to, to just think about, you know, things, you know, just we've been talked about like Black Lives Matter movement for the but, you know, the last year and interesting that how it's been overlapping with Covid and, how, you know, Black and Asian people are disproportionately like affected by all of these health things"- Carrie, Sussex, SANDS Group Leader

5.1.4.2.5 Summary of barriers to access support

There were several themes that were generated in the data that demonstrated the barriers participants experienced when accessing baby loss bereavement support. Some participants felt that attending peer support meetings for a short amount of time met their needs to connect with other stillbirth bereaved parents. However, although some participants wanted to continue attending group, the group management arrangements, or the mothers' feelings towards their pregnancies prevented them from taking part as they had before becoming pregnant again. Notable obstacles, including class and racism, are recurring themes within the data set. Participants felt that their child's death mattered less to charities when they did not receive a response to the participants initial contact. Some participants felt excluded from attending a peer support group as they believed they might feel like an outsider within the group, fearing they would be the only person of their ethnicity and culture there. Conversely, some were afraid that they would see someone they knew within their social circles. Considering the global events that took place when the data were collected (March 2020-November 2020), participants felt that charities should have been more perceptive of their responsibility to protect and better serve minority ethnic families. The subthemes that were discussed in this section emphasise the challenge of ethnic diversity, and the importance of providing minority ethnic bereaved parents with support to create a more equitable system where each parent affected by baby loss can receive the support, they need (Burnett, 2020; Lokugamage, 2019).

5.1.4.3 *Leadership opportunities for bereaved parents in charities*

Eight of the sixteen participants took on a role where they participated in a leadership capacity. Two mothers decided to launch charities. Two participants (one mother and one father) led their own small peer-support groups. Three mothers participated as a trustee of their respective charities. A trustee is someone who participates on a trustee board where these trustees review and ensure that the charity's work and goals are in line with its mission (Reach Volunteering UK, 2020). In addition, one participant is now a non-executive board member of an NHS board that focuses on improving experiences in maternity services.

When I began collecting data, I anticipated participants would take on a leadership role in honour of their deceased child. Contrary to what I had hypothesised, the predominant reason for parents becoming more engaged in a leadership role was to mitigate the pain of newly bereaved parents and not in terms of the baby's legacy. It could be suggested that the rationale for this was to make a more active contribution in terms of supporting the pain of the newly bereaved rather than taking a leadership position in honour of their deceased child. Parents further into their grief journey can provide newly bereaved parents hope that there will be life beyond their immense loss. They carry a figurative torch support the newly bereaved parent when coming to terms with the loss of their anticipated baby. For example, Ruby, Leicestershire, Befriender, and former SANDS Group Leader commented:

"For me it is all about just like I said, helping other bereaved families or mums or whoever along their journey and basically sharing my experience with them of what happened to me, but then giving that hope as well that, you know? It doesn't get better; it gets easier as time goes on. Because obviously even with me now at the time it happened, I thought, you know what's gonna happen and how I'm gonna cope and I'm not going to be able to and all sorts of things go through your mind. You think it's just going to be, you know, that whole depressed state for God knows how long, but with the right help and support and people around you, like I said, you can get the help you need."-

This finding validates the earlier findings in this chapter, and the importance of having contact with a skilled befriender to encourage a newly bereaved parent to access bereavement support.

Ruby, a respected SANDS befriender, and peer support group leader decided to leave SANDS to create her own charity which aims to primarily support minority ethnic bereaved parents in Leicestershire.

Ruby left SANDS because she felt the work she and her small group contributed to SANDS, was not appreciated by the organisation. She said she was never thanked for the time and effort she contributed to the charity. When I met Ruby, she was in the process of selecting the new charity's board of trustees and developing the charity's website. Two of the newly elected Trustees who were participants in the current study made the following comments:

"Going to that support group around people who actually understand me without feeling judged and everything else is the reason is why I'm actually, erm, I actually sit on the board of trustees now for this new charity."- Abigail, Leicestershire, former SANDS attendee

"My hope is that anybody going through something like this will have a range of support options open to them. So, yes, it's in its very early stages but, erm, the initial help that I was able to give, erm, was more from a legal perspective because I'm a lawyer and there were things to tie up from her (Ruby) exiting SANDS to setting up the new charity. If we can assist even a small percentage of ethnic minorities, erm, who wouldn't have otherwise had the support then that's, that's a success in my book and I imagine, you know, as experience and knowledge develop year on year, I'm sure that will just get better and better. Erm, it won't, it won't be something that happens overnight I'm sure but it's a long-term, it's a long-term objective these things, isn't it?"- Daphne, Leicestershire, former SANDS Group attendee

Both Abigail and Daphne stated that they wanted bereaved parents to feel welcomed when accessing bereavement support and to have a range of options that cater to the diverse needs of grieving families. Both bereaved mothers are experts by experience (Noorani, 2013) and have knowledge of attending peer support groups and understand which strategies are useful those which are less helpful in supporting bereaved parents.

As a national organisation within the UK, SANDS has organisational rules and procedures in place to ensure their befrienders and peer support group leaders are trained to support the needs of bereaved parents. However, the current system appears to discriminate against parents who may want to become involved but are unable to due to the amount of time it would require for them to attend the group and then train to become a leader. Carrie, a SANDS group leader, asserted that having firm constraints on training befrienders and group leaders did not reinforce the goal of supporting bereaved families. For Carrie, Sussex, SANDS Group Leader the provisions for the training of new leaders are a restrictive policy implemented by the organisations management, rather than providing support at a local level:

"They (SANDS) have like these rules like you must be bereaved for all this time and you have to have been coming to the groups and all that. You're not gonna get anybody in that way. You're not gonna

get anything that way. Part of my responsibility is to start breaking down that barrier and saying that, you know, I can go to these spaces, and I can be there, and I can be that person to help connect you."

Sandra was recruited by the founder of the Aching Arms charity to participate on the board of trustees when she was volunteering for the charity. She was recruited to improve corporate policies on pregnancy loss as a result of her expertise working in the corporate setting. She later assumed the role of Chairperson of the Board of Trustees for the charity and now uses her role to build strategic partnerships on behalf of the Aching Arms charity. Sandra explained that she needed time to process the loss of her child before she could seek out support from the charity sector. Before becoming an active member of the Aching Arms charity, Sandra participated in fitness challenges to fundraise for SANDS. She had not attended any of the SANDS baby loss support groups; the peer support model did not appeal to her. Sandra felt that the Aching Arms charity provided her with more appropriate support SANDS because the founder contacted her directly to ask her to participate in a leadership role. This made Sandra feel a valued member of the volunteering committee:

"You can help with these like small things where they needed a professional like coz, I work in a corporate set-up, so I was able to do some of those bits and pieces, just an extra pair of hands and that's where it started. Leanne (founder of the charity) and the team were at that time looking for a trustee and a volunteer and that's how I got involved with, with Aching Arms, err, err, but it was, err, a good year and a half or so after we lost our baby."- Sandra, Greater London, Aching Arms

5.1.4.3.1 Summary of bereaved parents participating in leadership roles

Parents assumed leadership positions within the baby loss charity sector method of providing support to other bereaved families who have suffered perinatal loss as they had. The participants who spoke of their leadership roles indicated that they hoped that it would improve the experiences of newly bereaved families accessing bereavement support services, instead of participating in honour of the child. It gave them a purpose in terms of their own pain of losing a baby. Participants in this study felt valued when they were approached to take on a more active role within the organisation. In return, volunteers expanded their network through the meaningful friendships they made through their work of contributing to their respective charities. Participants who were mothers were able to use the professional skills they had developed throughout their careers to contribute to their roles as trustees.

Whilst some parents found support through SANDS, a couple of parents reported they faced obstacles when trying to access a leadership position when working with SANDS. One participant spoke of the administrative challenges that deterred prospective befrienders and group leaders from obtaining the training they needed to lead meetings. There were too few training sessions throughout the year which meant prospective trainees had to modify their schedules around the SANDS facilitator training. From her experience, the current barriers related to accessing SANDS facilitator training programme made it difficult for parents to complete the training, which further impedes progress in terms of expanding the support group services to different communities. Interestingly, prior to collecting the data I had not anticipated that half of the participants would have a leadership role. Furthermore, I observed the participants' enthusiasm about the work they undertook and the care they took to support grieving families, which was a positive finding in this study.

5.1.4.4 *Impact of baby loss on fathers*

The data showed that there were differences between how the fathers who were participants and the mothers who were participants grieved. Participants revealed their experiences when attempting to access support and finding that there were more programmes and services for grieving women compared to grieving men. Mothers received more attention and physical care due to the nature of perinatal loss (Koopmans et al., 2013). Participants who were fathers felt their experience of losing a baby was less important than the experience of the mother. The three fathers in this study indicated that healthcare practitioners did little to include fathers in the mothers' postnatal care. Dominic expressed that he felt excluded not only as a result of the loss of his daughter but from his relationship with his wife.

"I felt very isolated in…and he sort of belittled the whole, erm, incident, the whole experience…" – Dominic, Greater London, Dope Black Dads

Dominic perceived his grief to be less valid and less important since he was not the parent having to give birth to the baby. He felt that there was little support from the healthcare community. At one appointment he attended to support his wife, the healthcare visitor asked why he had come with her to the appointment which made him feel that he was not part of the plan of care.

At times, the lack of support for fathers created a barrier between the couples. Participants who were mothers and fathers acknowledged how difficult it was for men to build a bond with the baby that had died. Participants who were fathers felt that they did not feel as close to the child as the mother did because they did not carry the baby. The fathers only knew their child through their wives' experiences of being pregnant. In return, it was the absence of the bond between the father and child that led to emotional difficulties within the participants' marriages. For example, Sheila, Warwickshire, Luca's Angels commented

"As a man, I think they don't really understand until you're so blunt and you snap and, that for me was when my husband really understood what I was going through because he could then picture it himself,

he would have felt that, if the baby had been in his arms and that, that would have happened. Erm, so it was a, it was a change, in… definitive change in our relationship actually and, err, I think me snapping at that point is probably what saved our marriage. Because we were going down different paths at that point".

Sheila's quote highlights the communication challenges she and her husband encountered after the loss of their baby. The loneliness and isolation in her relationship brought on by grief led her to suicidal ideation (Cacciatore, 2013). From Sheila's perspective, it was her mental health crisis that enabled her husband to understand the severe emotional anguish she felt over the loss of their child.

Arthur and Jade were one of the two couples who were interviewed together. For most of the interview, they spoke directly to each other and shared intimate thoughts (that were never previously discussed) about their different experiences of grieving the loss of their daughter. For Arthur, Kent, men's church group*,* grief was focused on not having a future with his daughter; he struggled to grieve the loss of Jade's pregnancy. Like other participant fathers, Arthur did not feel that he had bonded with the child as much as his wife had because he did not experience carrying the baby and observed:

"As I said because I never had them physically in me unlike Jade who had to give birth. It was always a case of you thinking to yourself oh, what it could have been. But maybe because I've just naturally got a closed personality, not closed emotionally, but about letting things get to me. I probably just shut that door quickly. No emotion not really understanding this probably just left it. I don't know whether if that's a bad thing or not, but it was a strange thing. I really- I've never really spoken to anyone about it."

Interestingly, Jade recognised Arthur was grieving although he did not actively identify his emotions as grief and commented:

"I knew he was hurting as well at the same time, but I think he was more worried about me than anything else and like I said initially, I came across as being ok but as that period went on to that year and a half after my loss, by the ninth or tenth month I think I was in a real pickle."- Jade, Kent, SANDS

Arthur believed that his main duty was to support his wife processing her grief and later when she had a mental health crisis. It was after this crisis that Jade felt she needed to find some bereavement support. Arthur did not feel comfortable attending a peer support group centred around baby loss, however, he did share the story of his stillborn daughter with his men's church group. Although not designed specifically for people grieving the loss of a loved one, Arthur's men's group served as a place where he felt encouraged to share his experience of loss. He heard of other men who had lost children and used the group as an outlet to process his feelings.

A similar experience to Jade, Amelia, Leicestershire, SANDS felt she needed more emotional support than her husband and commented:

"The thing is that I was, I need, and erm, my husband kind of dealt with it a slightly different way to how I did with the grief. So, he would just go and work out a lot out at the gym and, you know, kind of talk to friends and, err, his best friends and he was quite happy doing that. I felt like I needed so much more, erm, on a personal level." Amelia, Leicestershire, SANDS

Her husband processed his loss through action-oriented expressions of grief such as exercise and spending time with his friends who had not lost children. Amelia's husband felt he was adequately supported by his immediate community and did not need to connect with people who had also experienced baby loss. Similar to Sheila and Jade, Amelia spoke candidly about how she had experienced a severe depressive episode that included a mental health crisis before she contacted SANDS for support. The data set demonstrated that participants who were women needed to connect with other bereaved mothers to access support for their mental health needs.

Participants who were mothers and fathers offered constructive insights into how baby loss affects each parent differently. From the onset of learning that their child had died, participant fathers felt that their grief was disregarded. Participant fathers shared that they felt disconnected from their child that they never known. They grieved the loss of the future with that child.

"He said, because obviously you look forward to the baby and then it's happened even though he said he wasn't physically attached, but there was, you know, a bond." – Jade, Kent, SANDS

This is in comparison to participant mothers who both grieved the loss of a pregnancy and the loss of a future with their child. Often, participant fathers learned to cope by suppressing their own experiences of grief to support their wives' grief journey. This point echoes the earlier section on the barriers to accessing support in this chapter. Participant fathers supported their wives who were accessing bereavement support by caring for their other children at home. Participant fathers believed that providing tangible support to their spouses was more beneficial than seeking support for themselves. Moreover, participant fathers reported that they did not feel there were as many bereavement support programmes available to fathers as there were for mothers.

5.1.4.4.1 Fathers using baby loss support services

It became clear throughout the data collection process that there was variation between the participant mothers and fathers when accessing baby loss support. In the data, when considering the participant fathers' perspectives on grieving the loss of a baby, most stated that they were unlikely to attend a peer support group compared to participants who were mothers. Whereas participants who were mothers found solace in meeting with other bereaved parents, participant fathers struggled to speak openly about their child. Fathers believed it to be a private matter and one that was not meant to be shared with other people, especially other men. For example, Vern, Greater London, Aching Arms commented:

"I would not be comfortable talking about my child loss with another dad (on attending group) and opening up to him. I would open up only to a very, very close friend of mine and most likely the guy would not know how to handle this"-

I sensed there was frustration felt by both participant mothers and fathers in relation to finding appropriate bereavement support for their loss. Participant mothers wanted to share the experience of attending a peer support group with their husbands, for example.

"One of the meetings there was a man there, which I was surprised, so when I came back, I told Arthur, you know, it's not just for the women and that he could come."- Jade, Kent, SANDS

Two of the participant mothers stated that their husbands had briefly attended meetings with them at their request. However even with this encouragement, participant fathers were less likely to attend consistently over a period of time. Conversely, participant fathers articulated that they wanted bereavement programmes that they could access even though they might not use these support services. They wanted their grief to be considered and respected, although they might not want to share their experiences of loss.

"I suppose from my husband's point of view, hearing other fathers speaking about what they were going through may have been, erm, a huge, a huge support because it naturally then allows you to speak in that kind of forum about the feelings that you're going through. It does encourage you to, to kind of speak up because even if you're not able to speak openly in front of the whole group during the meeting"- Daphne, Leicestershire, SANDS

It emerged from the data that peer support programmes, regardless of the charity they belonged to, were predisposed to be gendered. At the time of the data collection, Dominic had just begun his bereaved father's group, and was not able to offer insight in terms of what makes men want to attend a group designed specifically for fathers. Carrie, a SANDS small group leader, confirmed that daytime pregnancy after loss groups were attended less frequently by men. It is noteworthy that in her experience, men were more likely to attend evening sessions.

"*Well, the evening group will get more men and the group that I'm a member of now, regular fathers engaging, er, the daytime group pregnancy after loss is just seems like it, it…I mean there's little kids running around, there's babies and maybe it just doesn't feel like the place that, you know, newly bereaved dads don't want to be in."* – Carrie, Sussex, SANDS Group Leader

The results from the semi-structured interviews suggest that the participant mothers and fathers appear to require different bereavement support programmes. There was a tendency for the participant fathers in this data set to avoid discussing the loss of their child with other bereaved parents accessing peer support groups. Participant fathers utilised the social support they had within their communities. When the participant fathers in this study attended baby loss bereavement support groups, they preferred to attend groups that were designed to be men-only spaces. Although no two people grieve alike, it is important to acknowledge that having gender-separated spaces to grieve provided a secure environment for the participant fathers to process the pain of losing a child.

5.1.4.5 *Need for faith-based support*

As the data collection progressed, it was observed that there was an obvious body of support that was consistently missing from the participants' experiences of seeking bereavement support. Even though participants spoke openly about their faith beliefs, they did not mention finding a faith-based baby loss support group. The individual participants held beliefs that were from the Sikhism, Hinduism, and Christianity religions. Only one participant father, Arthur, was involved in a faith-based support group where he was able to share his experience of baby loss. However, this group was not constructed to support grieving parents. When attempting to access participants from different communities I tried to build community partnerships with different faiths. Although I contacted Polish priests, and different pastors who led baby loss memorial services; I did not receive a response from any of the religious groups I contacted. I was pleased to partner with Muslim Bereavement Support Services (MBSS) on this study, and yet no participants who were Muslim participated in this study. Recruitment from may have been impacted by the COVID-19 pandemic. The GP leading the bereavement support group wasn't able to promote the study as much had there not been a global public health crisis.

Vern (Greater London, Aching Arms) and his wife Sandra (Greater London, Aching Arms) were distraught on learning from their families that were no Sikh ceremonies or traditions to honour a deceased baby. They informed me that a stillborn baby was not considered to be a living person, and as such there was no formal guidance, they could follow on how to mourn their loss. As a result, to acknowledge the death of their child, they decided to give their baby a Christian burial, which is contrary to the Sikh tradition of cremation. They preferred having the baby buried in a faith different from their own rather than the child's existence not being recognised at all by their tradition. This was a controversial decision, however; they preferred to have their baby buried.

"I don't think it exists, at least not that we know of because we are not, err, we haven't read, err, scriptures for our respective religions, erm, so, I, think there is… it's not even, there isn't even an

acknowledgement of that as a death. It's an acknowledgement of something that never came to be, which is different from death, you know?"- Vern, Greater London, Aching Arms

"You know, while I'm not religious but if there was something that the faith had which were milestones, I would have followed it."- Sandra, Greater London, Aching Arms

Christian participants struggled to grasp how limited bereavement support was outside of funeral ceremonies. Dominic (Greater London, SANDS, Dope Black Dads) suggested that the Catholic Church took an active stance on abortion, and yet did little to support families whose babies die during pregnancy. As a practicing Catholic, he shared that he would have chosen a Catholic peer support group if it had been available to him and commented:

"I have is, it's, you know, what I find this disengaging is the church talk so much, especially the Catholic Church talk so much about NO abortion. Every life is precious. But when you lose a child, there's nothing. There's no support. There's no system. There's no recognition, there's not any acknowledgement."- Dominic, Greater London, SANDS, Dope Black Dads

Here this loss did not appear to matter to the Catholic Church and the lack of acknowledgment he experienced compelled him to detach somewhat from his religion.

Like Dominic (Greater London, SANDS, Dope Black Dads), Maya (Yorkshire, online support group) identified as a practicing Christian. She commented that there was little involvement from her religion or other religions in her local community that supported parents beyond the funeral. Although the grief of losing a baby lasts a lifetime, grief in the Western world is often only validate shortly after the death and at the funeral (Bakker & Paris, 2013). Maya felt that religious groups were missing an important opportunity to offer advice to grieving parents about organisations that could help them with their bereavement and commented:

"My faith is really what pushed me along. So, err, I know, I know for a fact we, we… that is always our fallback, always our go-to. So, church would be place that where we will get that information. Churches would understand bereavement and, erm, I think even, even if it's, err, a church that is maybe indigenous to African people, from a spiritual perspective they understand the support. So, they would be saying: we can only do this much but here is an organisation that can help you a little bit more and if it's coming from church then it's more reputable"- Maya, Yorkshire, online support group

Maya's quote offers insight on the significance of the role that Christianity plays in in the life of person who is a Christian. Religion had a prominent role in African communities and therefore it could be suggested that religious groups could do more to facilitate a connection between bereaved parents and charities that serve those who have experienced perinatal loss.

The death of their child made some parents question their faith in God. For example, Abigail (Leicestershire, SANDS) described the faith crisis she experienced when she searched for spiritual reasons when attempting to understand the meaning of her loss and commented:

"I'm very religious, oh well like I said, I was very religious at the time as well and the biggest thing for me is why did God do this to me? And honestly that is the big question… even after I overcame a lot of things, the one thing that I couldn't overcome even three or four years later is why did this happen to me and why did God do this to me? And initially I lost faith in God. I mean from going to my shrine being my pride to not even being able to step into the temple. And that was my anger on God that, you know, why? Why?"- Abigail, Leicestershire, SANDS

The loss challenged her sense of justice. Abigail did not understand the reason why she had lost her baby. Like other participants in this study who were searching for meaning, she felt unsupported by her local religious group.

Natalie's (Leicestershire, SANDS, Maternity Voices Partnership) developed this further and observed: *"It's sad because even in that case, you probably could have a woman that doesn't, is a non-believer but just because she might just say: you know what? I want to actually speak to somebody and that could actually bring her to the faith, you know? Because it's a time when you're broken. You, you want answers. And, you know, gosh, if it wasn't for prayer, I would have lost my mind to be honest with you. Coz I really felt like I was losing it, at one point.* – Nicole, Leicestershire, SANDS, Maternity Voices Partnership

Here Natalie reiterates the need for parents, regardless of whether they have religious beliefs or not, to have the opportunity to connect with faith-based organisations. Even when bereaved parents are atheists, they may want to engage with faith support practitioners to find meaning in their loss. Within the literature on baby loss and spirituality, Bakker and Paris (2013) found that grief is an exception for people to speak about faith through the shared experience of losing a loved one. Additionally, Cowchock and colleagues (2010) argued parents who lost a child may use religion as a way to find meaning in their loss. Similar to Vern, (Greater London, Aching Arms) and Sandra's (Greater London, Aching Arms) experience of borrowing Christian customs which involved burying the baby rather than the Sikh tradition of cremation, participants in this study, regardless of their faith, utilise rituals that they feel acknowledges their child's life.

Pregnancy loss is a physical, emotional, and spiritual experience. The data in this study appears to demonstrate that there is limited religious baby loss bereavement support services in England. The nature of perinatal loss caused several participant mothers to experience mental health crises, whilst another experienced a crisis of faith. Participants articulated that they wanted their babies' lives to be recognised by their culture and religion, as they felt largely unseen and unsupported by their faiths' institutions. Participants suggested that faith leaders and baby loss bereavement charities need to build better relationships to appropriately support the needs of families who want to access faith-based bereavement support.

5.1.4.6 Improving bereavement support services for minority ethnic families

Grieving the loss of a baby is a significant challenge experienced by some parents. During the semi-structured interviews, bereaved parents observed that baby loss charities could improve bereavement support services for minority ethnic families. As the literature review indicated, there is limited knowledge and research in terms of how to support minority ethnic families who want to access bereavement services (Van & Meleis, 2003). Nicole (Leicestershire, Maternity Voices Partnership) suggested that improvements must be genuinely made to support grieving parents rather than a tick box exercise:

"Not just having them there just for the sake of numbers or quota or just to tick a box but it's to have somebody there that is passionate, you know?"

Amelia (Leicestershire, former SANDS attendee) developed this in her comments:

"Have people feel like it belongs to them. They, they've co-created it, that they, erm, have a say in what happens. That it looks like them, that it feels like them." – Amelia, Leicestershire, former SANDS attendee

For this participant it was important that baby loss charities co-create changes within current services so that access was more equitable for minority ethnic families, or risk having different communities disengage further from their services. Amelia was part of the group that Ruby (Leicestershire, SANDS Group) created which was separate from SANDS which was set up because they did not feel that their work translating pamphlets and appearing in marketing campaigns was appreciated. Participants in this study wanted to participate in support groups that they could identify with.

Recently, SANDS and other charities have established football leagues for bereaved fathers. These football leagues successfully enabled men to engage with bereavement support. Supporting the earlier section of this chapter which considered how participant fathers manage perinatal loss, a football league appears to be a good initiative which facilitates connections between men who have experienced baby loss whilst participating in an activity. Whilst there aren't publications about bereaved father football leagues, it is important to mention that stereotypical cultural beliefs about masculinity may impact bereaved fathers accessing support (Jones et al., 2019). Men may be able to express their feelings through football because it is more ‘manly’ (Jones et al., 2019) compared to attending a support group. Unfortunately, football league bereavement support is only open to fathers at the moment. Carrie disagreed with this specific SANDS policy because it would naturally exclude grieving mothers who do not enjoy attending the typical peer support meeting model and commented:

“I think that, you know, they have like the football groups that they’re starting, er, all around the country and stuff, there’s a way for, you know, men to connect, er, which I think is really interesting that they’re like oh, ok, so women don’t wanna play football so we’re only gonna start a group for men”- Carrie, Sussex, SANDS Group Leader

It was interesting that Dominic (Greater London, Group Leader, Dope Black Dads) said he would not participate in a bereaved father’s football league because he believed it would only perpetuate men from connecting to their feelings of loss.

Sandra (Greater London, Aching Arms) articulated those charities need to build better relationships with Black and Asian communities through meaningful engagement and stated:

“If the service was to be offered, in a way through the, to the BAME community -I dunno what, Black and Asian communities- then they will see a few takers and over a period of time it will become norm, or, and that way, why I think it’s gonna be a norm is because, err, it’s word of mouth in the community and word of mouth is a well-established channel of information in the Asian community, than the white community.” – Sandra,

For Sandra this recommendation should originate from within the bereaved parents own community. Within this quote it was important that baby loss charities understood that spoken communication and sharing personal recommendations of accessing support is better received in Asian communities than receiving pamphlets in hospitals and producing insincere marketing campaigns. This would help to improve baby loss bereavement services if undertaken intentionally with minority ethnic communities.

5.1.5 Summary of the interview findings

Within the data, participants articulated that baby loss charities can improve bereavement service access equity by adjusting peer support programming. This would in turn help to facilitate an increase in satisfaction of minority ethnic bereaved families. Peer support groups must be inclusive of people of all backgrounds and faiths. To enable befriending and peer support programmes to be equitable, charities could co-create programmes with minority ethnic parents which would enable the change that participants wanted in relation to what they perceived as current programming limitations. Action-oriented peer support groups, such as the bereaved fathers' football leagues, could be offered to women. The sixteen parents who participated in this project offered suggestions to improve the experiences of newly bereaved families who might require bereavement support. Many of the participants who took part in this study did so as a means of offering insights about how meaningful and sustainable change could be implemented. The grounded theory that was developed using grounded theory methodology will be discussed in the discussion chapter.

6 The collages: An analysis

6.1 Introduction

This is the second results chapter of this doctoral study. In this chapter, I will discuss the findings from the secondary component which featured collage, an arts-based research method (Vachelli, 2017; Culshay, 2019). Within the introduction, I reference a publication I wrote with my first supervisor, Dr Jacqueline Wier, in 2020. The article was entitled 'Implementing creative methods in baby loss research: Exploring stillbirth bereaved parents' journeys through collage' and was featured in a special issue of the British Psychological Society's Qualitative Methods in Psychology Bulletin (QMiP). This peer reviewed publication featured my plan to implement collage in baby loss research and the reasons why I chose to use this arts-based method. Chapter eight describes the results from the collage-making activity. I hope to publish the results in a subsequent special interest issue.

I chose to implement collage into my doctoral research because it is a recommended arts-based research method (Chilton and Scotti, 2014; McCloskey and Wier, 2020). Collage is a unique method that may offer researchers better insight into emotional thought processes than traditional research methods like semi-structured interviews (Jongeward, 2009) because the items the participants select to include within the collage metaphorically reflect their emotions towards the phenomena being studied (McCloskey and Wier, 2020). Arts-based research methods derived from the humanities are beneficial in health research as these methods can better explain facets of participants' experiences (Here, Washington, and Moxley, 2008) than other qualitative research methods (McCloskey and Wier, 2020). Furthermore, arts-based methods like collage encourage researchers to disseminate their findings in various ways which can increase "research integrity, uptake and applicability", (Dew and Boydell, 2017, p. 143).

After each semi-structured interview I conducted, I invited each participant to create a collage, as the secondary aspect of the data collection. I asked the participants to create a collage detailing their experiences seeking baby loss bereavement peer support opportunities with no further instructions. I followed Butler-Kisber's (2010) approach to implementing collage which follows that collages are created from the participants' emotions related to the research question. The purpose of assigning participants a task which did not have specific direction was to give them the freedom to interpret the task from their own perspective and to give them the opportunity to create a college which was entirely of their own making (McCloskey & Wier, 2020). Additionally, the purpose of the limited direction was to observe whether the images and words that the participants selected would correspond to the themes that emerged from the semi-structured interview data (McCloskey & Wier, 2020). For example, the semi-structured interview data demonstrated that there was a noticeable lack of faith-based support for bereaved parents, I therefore wanted to observe whether faith-based images or words would emerge in the collages. The in-person collage-making sessions took between 30 minutes for the individual participant and an hour and a half for the group participant session.

The relaxed instructions for the collage making activity made three participants slightly anxious; some required further direction on how to create a collage. For those participant mothers who did feel apprehensive, I showed them the collages I had created for the reflexive autoethnographic exercise I completed whilst collecting data. I explained why I had selected the images and texts that I was going to include on my collage and how these items corresponded to my experience of seeking out appropriate bereavement support. Once the participants saw the collages I had created, most parents felt more prepared and willing to create their own collage. Other participants accepted the challenge of completing the collage making task with little guidance. I clarified to participants that there were no expectations in terms of artistry, and that there were no wrong or right image images or words they could choose to incorporate. One of the most prominent benefits of incorporating collage as a research method is the innate flexibility it provides participants to create a piece that corresponds to them in the moment the collage is created (Yuen, 2016). Moreover, collage is concentrated on the participant's account meaning they hold the power to decide what they disclose within their art (Dutton et al., 2019).

To ensure that participants could participate without incurring any expense, I provided magazines, newspapers, paper, scissors, and glue sticks to all the participants. Materials to create the collages were relatively inexpensive and readily available. I collected magazines from my neighbours and had several genres from which participants could select their images. Additional materials such as crayons and markers were made available, however, I was told by participants they already had access to these supplies because they were parents of young children.

In total, there were nine participant mothers who were interested in making in the collage, however, there were only eight participant mothers who completed the task. No fathers took part in the collage-making activity. The data were collected from March to November 2020. One participant mother who did not complete the task stated she did not find any images that corresponded to her experience of seeking baby loss bereavement support from the materials I supplied her nor from any items she had at home. I informed her that she could use materials other than the magazines and newspapers that she had access to. Moreover, I suggested that I could send her additional supplies, but she declined the offer. Four of the collages were created in-person after the mothers and I completed the semi-structured interviews. Administrating the collage after the semi- structured interviews was a conscious decision as I believed that this would build rapport with the research participants so that they felt at ease to create the collages (Malhotra et al., 2021). I sensed that creating a collage before the semi-structured interview would have been more challenging for participants. My decision to conduct the interview prior to the collage activity was influenced by the literature (Sakaguchi & Okamura, 2014; Malhotra et al., 2021); in these studies, researchers interviewed participants prior to facilitating the collage elicitation exercise. Whilst the authors didn't explicitly explain their reasoning as to why, I believe it help build trust between us. Parents were more relaxed after the semi-structured interview. The mothers could learn more about me which helped negotiate my position as a researcher (Dutton et al., 2019). Even when I perceived initial hesitancy to make a collage from some participants, I found that I could inspire them to take part because we had spent time getting to know each other during the semi-structured interviews. I encouraged the mothers that their collages could contribute to building awareness on perinatal loss (Ball et al., 2021), and keep the collage as a token of remembrance.

The remaining four collages were created by participants who took part through online semi-structured interviews. For those who were participating remotely, I sent a parcel of collage-making materials to them. Besides the craft materials, participants received a stamped envelope with my address so that they could return their collage to me if they chose to. I offered remote participants the opportunity to keep their collage, however, I requested them to send a photograph of the collages they made to me by email or text. All four remote participants gave consent to share their collage through a photograph. None of the remotely made collages were returned to me. I was pleased that the participants wanted to keep their collages, because I interpreted this as they enjoyed the activity.

To thank the participant parents who took part in the collage activity, I encouraged them to keep the collages they created as a token of remembrance of their children and their grief journeys. Six out of eight participant mothers chose to keep their collages; four of the six remote participants who created the collages retained their collages. Two physical collages which were completed in-person were returned to me to keep. I have included photographs of all eight collages in this chapter and included larger photographs of the collages within the appendix.

Paralleling the semi-structured interview results chapter, this chapter will explore the major findings from the collage elicitation exercise by noting the images that were selected in the collages. The chapter begins by discussing facilitators and barriers to access baby loss bereavement support programmes. Following this discussion, the chapter will review the images participants selected in conjunction to their experiences seeking support. Next the chapter will examine the collages to determine whether the participants chose images that correspond to baby loss bereavement support being more culturally appropriate. Finally, the chapter will conclude by considering how the participants make meaning of their loss and ascertain whether engaging in baby loss peer support programmes help them to make sense of their grief. As this is the secondary component results chapter, I identify the findings that are related to the research questions and the broader themes that arose from the thematic analysis. I will interpret the findings in relation to the interview results and discuss the implications of the findings to the existing literature in the next chapter.

6.2 Barriers to participating in collage activity

Whilst the benefits of arts-based research methods and the participation in the arts have been noted within this thesis, it is important to note that only nine of sixteen participants expressed interest in taking part in the collage activity. Literature within the arts-based research has demonstrated that socio-economic dynamics impact on people taking part in the arts (Fancourt and Mak, 2020; Renton et al., 2012). Ethnicity is a contributing factor in terms of how people engage with the arts (Arts Council England, 2013). In 2020 Mak, Coulter, and Fancourt investigated patterns of social determinants of arts participation within the UK, found that people who self-identified as Asian or Asian British were less likely to take part in the arts. However, Black and Black British people were more likely to engage within some arts-based activities (Mak, Coulter, and Fancourt, 2020). Though the authors were unable to give a reason for the stark results (this report was one of the first studies to investigate social patterns of arts and cultural engagement across the UK), they did hypothesise that non-white ethnic groups may be disproportionally represented in lower socio-economic groups (Mak, Coulter, and Fancourt, 2020). Although it is impracticable to compare Mak, Coulter and Fancourt’s 2020 study to mine due to the sample size variances and different methods used to analyse data, it is noteworthy that there were more mothers from an Asian ethnicity who participated in the collage-making activity in my study, compared to mothers from other ethnic groups. Altogether, there were six participant mothers of Asian ethnicity who created collages. Two collages were created by Black participant mothers, and one collage was created by the Polish participant mother.

Despite arts-based methods’ inclusive nature (O’Neil, 2016), all of the collage creators in this study were women. It was clear that there was a gender gap between the men versus women’s collage participation rates. The gender gap was confirmed in Mak, Coulter, and Fancourt’s (2020) work, where women were 32 percent more engaged in the arts compared to men. Within the creative methods field, arts-based research methods make space for women who are ‘othered’ in British society (O’Neil, Mansaray, and Haaken, 2017). O’Neil’s arts-based extensive work with women asylum seekers show that creative methods specifically facilitate a space for women’s voices to be heard (O’Neil, 2001, 2008, 2009, 2017). Feminist researchers who work with women dominate the arts-based research field. There is scarce evidence to show that men participate in as much arts-based research as women. It may be that there are limited opportunities to men.

Despite my offer to assist the participant fathers to make a collage, none of the three participant fathers who took part in the semi-structured interviews expressed an interest in the arts-based component. One of the three participant fathers gave time constraints as a reason for not participating in the collage activity. He was working from home due to the pandemic and did not feel he had time to create a collage because of his work and family commitments. The other two participant fathers did not give a reason why they did not want to create a collage.

Currently, there is a paucity of evidence in relation to arts-based research that focuses on men making collages. Where there are both men and women taking part in a collage-based studies, women make up the majority population (King & Gurland, 2007). Malhotra et al. (2021) carried out a collage-based study with veterans with Gulf War Illness which is a chronic multi-symptom condition first diagnosed in veterans deployed in the Gulf War. Along with intense physical symptoms, this illness also impacted participants’ mood (Malhotra et al., 2021). In this study, there were more men (n=9) who participated than women (n=5). Martin and Barnard, (2013) suggest that this was probably due to military veteran populations having a higher proportion of men than women. Nevertheless, the study provides valuable insight in terms of how research can elicit nonverbal data from people of different genders, the majority being men in Martin and Barnard’s (2013) study who have experienced trauma (Malhotra et al, 2021). Similar to this study, participants in Martin and Barnard’s (2013) study were first interviewed and then invited to create a collage to represent their experiences of Gulf War Illness. Verbal data from the interviews and visual data from the collages were coded. The findings from both methods were compared to determine how the collage could enhance traditional research methods (Martin and Barnard, 2013; Malhotra et al., 2021). Current literature excluding Malhotra et al.’s (2021) study would suggest that collage-based research is often carried out with women but not male participant’s (Williams & Taylor, 2004; Lai, 2009; Vacchelli, 2018) which perpetuates the arts-based gender participation gap.

6.3 Confidentiality and anonymity

To protect the eight participant mothers’ identities who took part in the collage-making activity, the collages were assigned a number and different coloured sticky notes when the thematic analysis was being conducted. When I spoke with potential participants, I informed them that if they chose to participate in the collage-making activity, photographs of the collages would be included within the doctoral thesis. Through these conversations, participants who decided to create a collage were also made aware that to protect their identities, their collage would be anonymised as they would be used in presentations and reports as part of the dissemination process. One participant asked me if she could include photographs of her family and friends who had supported her during her grief journey. I accommodated her request to use the photographs since she shared that she wanted to keep the collage as a memento of her baby and did not want it to be displayed publicly. I explained to this mother that I would like to include her collage within my doctoral thesis. She gave informed consent for her collage to be used in this doctoral thesis. To maintain confidentiality, this collage which uses pictures of the participant's family will not be included in any external presentations other than this doctoral report, nor will it be featured in any additional publications that may be written following the completion of this study.

Figure 1: Colours assigned to individual collages

6.4 Collage themes

The eight collages are presented below to demonstrate to the reader the images that correspond to the three predominant themes. The task the participants were asked to complete was to select images and words that best corresponded to the parents' experiences seeking bereavement support. Even though this was the only guidance I gave, the items that the participant mothers selected which corresponded to their experiences of attending baby loss peer support programmes were wide-ranging. Some participants selected images of visual metaphors which are symbolic of their stories, whilst others chose images and words that were a literal representation of their experiences. Each collage is unique and yet there are noticeable similarities between the images the participants selected.

Collages made by bereaved mothers in chronological order

Figure 2: Collage 1, In-person interview, in-person participant, March 2020

Figure 3: Collage 2, Group Interview, In-person participant, September 2020

Figure 4: Collage 3, Group interview, In-person participant, September 2020

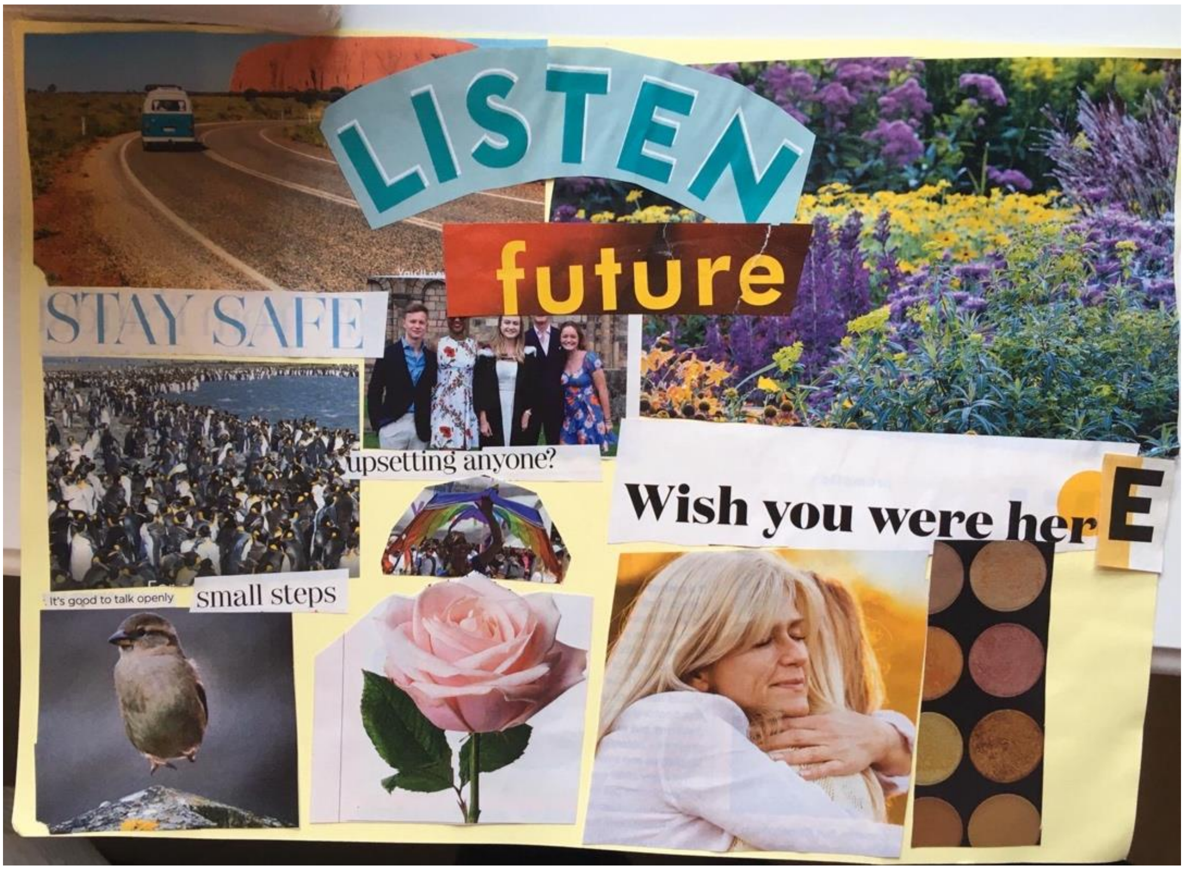


Figure 5: Group Interview, In-person participant, September 2020

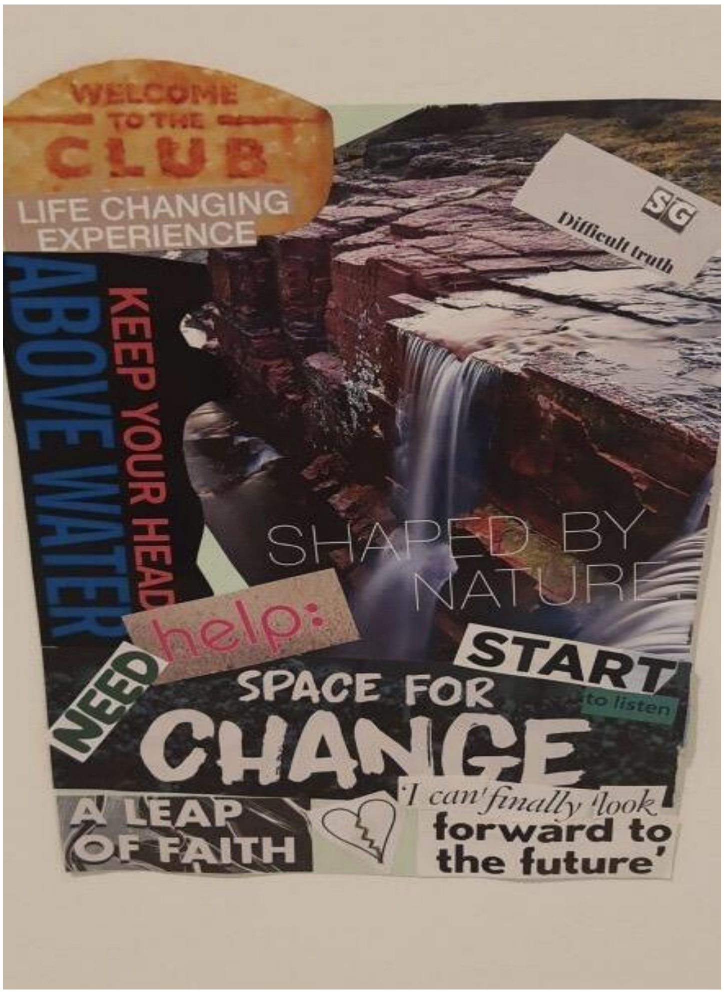


Figure 6: Collage 5, Online interview, Virtual participant, Octover 2020

Figure 7: Collage 6, Online interview, virtual participant, October 2020

Figure 8: Collage 7, Online interview, Virtual participant, November 2020

Figure 9: Collage 8, Online interview, virtual Participant, November 2020

6.5 Stylistic commentary

Collage 5 was the only collage that is vertical; the others were all presented horizontally. The image of the waterfall on the cliff may have influenced the participant's decision to use a vertical position for Collage 5. Collage 6 has two pieces of paper taped together to form a larger collage. One side has images from magazines whilst the other has photos of the participant's friends and family to symbolise their support in her grief journey. There is a physical divide between the two sides of the collage; where the two sides of the collage meet do nevertheless depict where her experience of grief and the support of her loved ones meet.

6.6 Collage results

The following sections will explore the themes which I developed from the data analysis. I will present the findings that address the study's research questions. Then I will present the findings from the thematic analysis.

6.6.1 Facilitators and barriers parents experienced accessing support

The following results in this chapter respond to the first aim of this doctoral study. The first research question explored the reasons why parents choose to participate in peer support groups, and why other parents choose not to participate in this type of bereavement support programmes. I chose to separate the research aim between facilitating factors and factors that act as barriers to deter bereaved parents from accessing peer support programmes. I made this decision based upon the findings of the semi-structured interview data. Within the semi-structured interview data, participants spoke of both facilitators and barriers of them being able to attend peer support meetings. Whilst some participants had a distinct time-period where they attended meetings, other parents' attendance patterns weren't linear. Based off the interview results, I decided to structure the findings from the collage activity and present both facilitators and barriers the parents experienced when choosing to participate in peer support programmes.

6.6.1.1 Facilitators

6.6.1.1.1 Isolation

Participants were asked as part of the creative methods task to create a collage that demonstrated their experience of accessing baby loss bereavement support. Collage 1 highlighted the experience of feeling alone and isolated. The participant who created this collage explained she wanted to accentuate the loneliness bereaved parents feel grieving the loss of their child. This participant mother felt that society did not recognise her as a parent because her baby died before birth. The theme of not being regarded as parents resonated within the semi-structured interview data. Collage 1 features an image of a woman who is isolated in a body of water. A picture of an empty pool borders the image of the floating woman. There is also an image of a woman's profile; she's reading alone. The participant shared that she felt this picture symbolised her experience of reading materials to understand how her baby died. For her, grieving was an isolating experience that she endured alone. When she felt able, she searched for emotional support through peer support groups. Through her involvement of attending bereavement peer support groups, the support of the groups helped ameliorate the intense isolation she felt in early grief.

Figure 10: Detail from collage 1

Collage 2 was created by a participant mother who was further in their grief journey, meaning that there were several years that had passed since the initial distress of losing her child. Similar to Collage 1, Collage 2 features bodies of water implying her experience of isolation. It was her isolation that encouraged her to seek help from SANDS. Over time, she trained as a leader of peer support groups. Her innate understanding of this type of loss and the process parents undergo to seek support made her a knowledgeable resource for newly bereaved parents.

Figure 11: Section of collage 2

Collage 8 captured isolation through images of nature scenes. Only one image has people, and this is an outline of a parent and child walking away from the viewer. Documenting the seasons, this participant mother chose images that corresponded to her experience of feeling that she was left in the wild trying to navigate her grief journey alone. I was particularly struck by the picture of a fountain surrounded by an autumnal scene in the bottom left corner. There is a sense of melancholy in the image. Despite the colourful foliage, the scene is barren. The participant created a collage that captures the essence of the loneliness she felt in the immediate weeks and months of losing her baby.

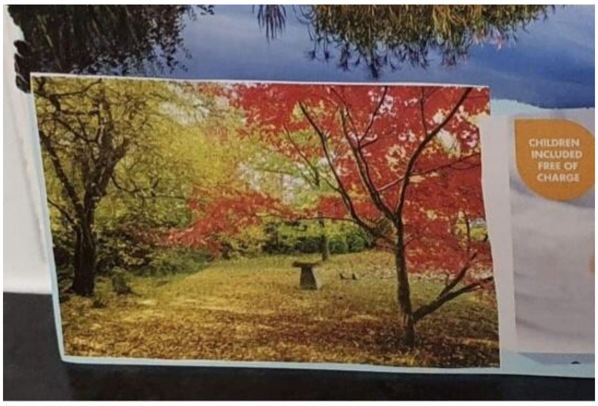


Figure 12: Detail of collage 8

6.6.1.1.2 Anger

Collage 3 has the word 'anger' near the centre of the collage to document her grief journey. Anger was a powerful feeling for the creator of this collage. This participant mother felt that she was unprepared for the possibility of having a stillborn. She had had little warning about what was going to happen during the birth, and what life was going to be like without the baby she had planned to raise. Nothing about her pregnancy had gone according to plan. 'SOS' represents the participant's urgent need for emotional help; the black text on the white background is highlighted against the pink background. Weeks after giving birth to her daughter, she was still unsure of what to do with the emotional pain she had experienced as a result of her loss. After reviewing the materials that she received from the hospital, she chose to seek support through SANDS where she slowly began to process her grief and her anger.

Figure 13: Detail from collage 3

6.6.1.1.3 Encouragement from family and friends

Collage 6 is a collage that is divided between images and phrases that are symbolic of this participant parent's grief journey and the people who supported her through her early grief. This collage has a picture of a person standing alone with a no entry sign and long winding road which represents the inaccessibility of normal life that the participant felt for the first initial seven months after giving birth to her baby.

Figure 14: Detail from Collage 6

An image of a doll with a physical injury to her arm was included, which the participant explained represented the physical injuries she suffered during her pregnancy and the emotional trauma she endured during and after her loss. This participant informed me that she was grief-stricken for the first seven months after she had her baby and felt as if she was incapable of knowing her life as it once was. The loss of her baby made her feel that she had been reduced to nothing which is why she selected an image that says, ‘*ALMOST ZERO*…’. These negative emotions were included on the left of the collage, whilst to the right of Collage 6 are the family and friends who encouraged her to seek out bereavement support and receive the care she needed.

Figure 15: Further detail from collage 6

Collage 7 features an image that is cut out in a shape of a heart and has a couple embracing each other underneath the words ‘love again’. The participant’s husband persuaded her to find support to process her grief because the death of their child was having a negative impact on their marriage. Attending peer support groups reduced the friction that existed between the participant and her husband. She could connect with other parents beyond her husband which alleviated some of the burden that her husband felt when supporting his wife, and their relationship improved. After the initial loss of their child, the mother leaned heavily on her husband rather than reaching out to other people. This mother became a regular participant in her local baby loss support group and sought ways in which she could become more involved in perinatal loss advocacy opportunities, such as contributing to a patient advocacy panel for the hospital in which she gave birth. She also received training to befriend newly bereaved mothers.

Figure 16: Detail from collage 7

6.6.1.1.4 Summary

Although all the participants in this study were recommended to seek personal counselling options by their healthcare professionals to process their grief, not all parents who experience perinatal loss wanted to access support through therapy. Whilst some chose to access both therapy and peer support groups, others preferred to receive peer-to-peer support by befrienders or through attending baby loss support groups. The collages demonstrate that there were a range of factors that encouraged parents to seek peer support programmes. The visual data indicates that the loss of a baby is an isolating experience. Emotions related to grief are intense. These feelings may feel amplified for the bereaved parent who does not receive support to understand why their baby died. Some participants felt their motivation to access baby loss peer support originated from their families advocating on behalf of the participant. Connecting with other parents who had experienced similar loss reassured participants that they were not alone in their grief and that perinatal loss occurs in other families. Regardless of the reasons why these participants accessed support from baby loss organisations, attending these programmes alleviated some of the grief they felt.

6.6.1.2 Barriers

When analysing the data, I concluded there were no obvious words or images within the collages that suggested that participants encountered barriers accessing support. For example, the words “barrier” or “obstacle” were not used. Neither are there any discernible images that I perceived as a literal barrier to access support. During the collage making workshop in Leicester, I asked if the three mothers included any images on their collages that indicated they had difficulty accessing peer support. Despite verbally discussing barriers they encountered, they said they had not included any images or words on their collages that they thought were barriers. However, there are metaphoric references within some of the collages which suggest that seeking baby loss bereavement support is an emotional challenge for bereaved parents. For example, I sensed the act of seeking a programme was a brave thing to endure. Mothers needed to be prepared to meet other bereaved parents and to prepare their hearts to speak openly about their losses. I see it in Collage four where it says ‘upsetting anyone?’ and ‘small steps’.

Figure 17: Detail from Collage 4

6.6.1.3 *Timing of accessing support*

One major barrier for parents in the way of accessing support was knowing how long into their grief journey they should seek support. In the semi-structured interviews, the participants discussed the challenge of receiving baby loss information in the hospital when they had just lost their child. Many of the participants stated that they felt unable to process information on how to access emotional support. The time that had elapsed from when the stillbirth had occurred need to be of sufficient duration that they felt emotionally able to contact organisations to learn more about support options and receive bereavement support. Collage 2 has an image of a duvet which signifies the importance of the participant taking care of herself during her early grief journey. Hiding underneath her duvet was respite from living in a world without her baby. She mentioned that staying in bed was part of the grieving process, which may be interpreted as a barrier to seeking support. This mother chose to isolate herself to privately process her grief; her bed was the safest place to grieve. Avoidance is a strategy some bereaved parents use to avoid reliving their traumatic loss (Fernandez-Basanta, Coronado, and

Movilla-Fernandez, 2019). A bereaved parent needs to feel that they are prepared to meet others who have had similar losses (D'Agostino et al., 2008; McGoldrick and Walsh, 2011). The act of accessing emotional support made some participants feel emotionally vulnerable and which increased the range of emotions the participant felt when grieving. Findings from the semi-structured interview data indicated that researching the organisations online and attending the first group meeting of their preferred organisation was an overwhelming experience for some participants. Participants commented that they felt nervous before attending their first meeting. They lacked clarity about the peer support programme which prevented some parents from accessing it immediately after their loss.

"I just didn't know what to expect and I think that was the bit that I was the most afraid of. Erm, and if I went there and I said something wrong, even though I know that you can't say anything wrong, because everybody in that room felt what you felt. I guess to a certain extent I felt a bit alone as well, initially."

Within the collages 'Keep your head above water' is featured on Collage 5 and represents the struggle the participant felt when attempting to adjust to their new reality. This phrase can be interpreted as demonstrating the difficulty that this participant experienced when accessing support particularly when the parent is physically and emotionally adjusting to the unanticipated event.

Figure 18: Detail from collage 5

Collage 7 is the only collage to feature emojis to signify the range of emotions bereaved parents' experience when grieving. Surrounding the emojis are words which describe the feelings the participant felt on the loss of her baby. There is a range of emotions depicted on the collage from feeling 'initial shock' and feelings of 'despondency' to thinking 'feel-good thoughts and 'hope'. The participant created the phrase 'wars of the mind' above the listed emotions to encompass the range of emotions she had experienced. From this multifaceted display of emotions, it is evident shed experienced a range of feelings in her early grief journey. Similar to the participants who created Collages 2 and 5, this participant required time to come to terms with her loss. Participants needed an initial grieving period for themselves before they could connect with other parents.

Figure 19: Detail from collage 7

6.6.1.3.1 Hesitancy

Collage 4 includes an image of a van driving along a winding road. The participant mother who created this collage told me it signified her path of grief. She attended the baby loss support group without knowing where it would lead her and did not know whether she was going to gain anything from attending the group. Below the van are the words '*STAY SAFE*' which is what the participant felt that she had to do. Seeking bereavement support is a vulnerable process, and this participant felt apprehensive about attending a peer support group. Additionally, Collage 4 has the short phrase 'upsetting anyone?' which is symbolic of how the participant felt as she considered that she had to be careful to not distress others when she spoke about her baby. She did not want to distress other group members by speaking about her baby or about the emotional pain she was experiencing. This parallels the semi-structured interview data where participants tended to keep their grief to themselves to not disturb others with whom they came into contact outside the peer support groups.

Figure 20: Further detail from collage 4

6.6.1.3.2 Summarising barriers to access

Participants did not plan to need or access baby loss bereavement support services when they became pregnant. The participant mothers who took part in the collage-making activity shared that they needed to process their losses with their loved ones before they could access external support. They wanted to feel safe during this uncertain period of time which often meant they chose to delay seeking emotional support from organisations. Not all bereaved parents are not ready to seek help immediately after they experience their loss (Raitio, Kaunonen, and Aho, 2015). Verbal and visual data from this study appears to indicate that bereaved parents who need to access appropriate support following the loss want to do so after a period of at least three months. Collage data demonstrates that some of the participants hesitated when accessing peer support because they felt anxious about upsetting other people at the peer support meetings.

6.6.2 Experiences of accessing peer support

All eight collages referred to being with other bereaved parents who had lost babies. The range of words and metaphoric images emphasise how each participant saw the emotional benefits they received from attending the support group. The images that corresponded to this theme were the following*: friendship bracelet* (Collage 1), *flocks of birds* (Collages 3,4,6),*a pair of elephants* (Collage 2), *a pair of penguins interacting with one another* (Collage 3), *two women hugging* (Collage 4*), hands in solidarity* (Collage 6), *two women smiling and laughing* (Collage 7), and *a picture of planet earth being held by a pair of hands* (Collage 8) which I was told represented connecting to people around the world through social media and private online support groups. Forming friendships with other parents who have had similar experiences was an impetus for participants to attend baby loss bereavement support programmes.

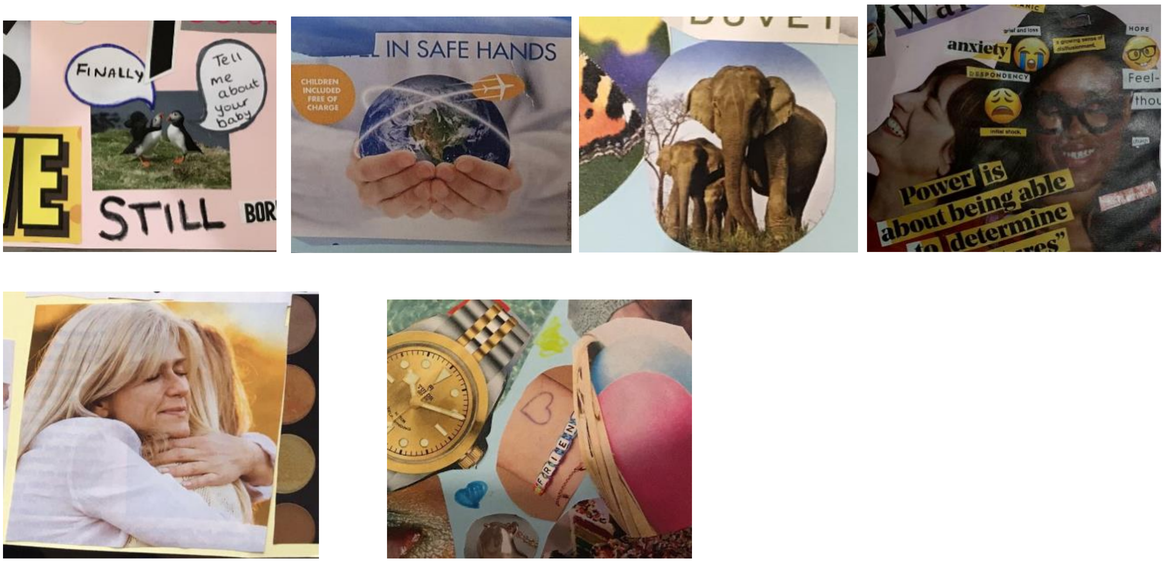


Figure 21: Images from the collages expressing emotional benefit

It is evident from the collage data that bereaved mothers felt there was a need to be with other parents who had experienced similar experience of loss. The following subthemes were found within the visual data.

6.6.2.1 Finding community

Finding community was a significant theme within the collages and within the semi-structured interviews. Parents often felt isolated from their own communities after the loss of a baby. Attending a baby loss peer support programme provided newly bereaved parents a designated space where they felt accepted. The phrases parents chose to include centred around connecting with other bereaved parents and feeling welcomed by others who intimately understood what appropriate and practical support was for someone grieving the recent loss of a child. For example, mothers chose to include phrases such as: '*it's time to speak out*' (Collage 2); '*welcome to the club*' and '*start to listen*' (both of which are from Collage 5); '*freeing to know everyone here is like me*', '*choose caring community*', and '*sometimes it's hard to believe that it only takes one or two people to start a movement*' (Collage 6).

Figure 22: Images expressing connection

Words and phrases were also featured across the collages which demonstrated how they personally felt about attending the group. Participant mothers captured the words '*sensitive relief*' (Collage 1), '*encouraging*' (Collage 2), '*growth*' (Collage 3), and '*safe hands*' (Collage 8). '*Forces for good'* (Collage 6) was selected by the participant who said she met people who understood her experience regardless of their background. It did not matter what community people were from or the type of perinatal loss they had experienced, bereaved parents were still parents. Participants felt that they were nurtured and cared for by the group leaders who were parents further along in their grief journeys. The two identical puffins (Collage 6) are representative of this participant and the befriender who encouraged her to attend her first SANDS meeting. On Collage 6 the befriender who was represented on the collage became a close friend of the participant and through her support the participant was able to manage her grief through developing relationships with the other parents she met at the SANDS meetings. Accessing peer support reassured participants that although they felt isolated from their own immediate social circles that they were not alone in their grief. Each parent's experience of loss was treated as being equally as important as the others within the group and the peer support groups provided a means for peers to support each other.

Figure 23: Detail from collage 6

The phrase "*a leap of faith*" is placed at the bottom left had corner on Collage 5 and is a commonly used phrase that means believing or accepting something which is intangible of being proven (Klass, 2014). This idiom is a reference to the participant attending her first bereavement support group at SANDS. She shared that she did not know whether it would assuage any part of the grief she felt, but she was willing to trust that SANDS was an appropriate organisation to consult when seeking baby loss bereavement support. The participant mother who created Collage 5 also included '*Space for change*' which implied that there was a specific physical space that could facilitate group members' transformation.

Figure 24: Further detail from collage 6

6.6.2.2 Diversity

Diversity was a notable subtheme in the collages. The actual word 'diversity' (Collage 2) appears in a garden of what appears to be a garden of assorted wildflowers. Here the combination of the words and picture may be perceived as a figurative portrayal of people who are different and yet can flourish together.

Figure 25: Expressions of diversity

Collage 1 featured a woman wearing a veil who faces the onlooker. The participant who created Collage 1 included this picture because it reminded the participant of someone who had come to group who wore a similar veil. Through attending peer support groups, parents met other parents from different ethnic backgrounds and cultures.

Figure 26: Section of Collage 1

Collage 4 includes an image of an eye shadow palette which the participant mother told me represented the different shades of skin colour within the support group. Each colour is a different shade, and yet each individual eye shadow is situated in the palette together. She further explained that like an eye shadow palette, when all the individual colours came together, they seem whole.

Figure 27: Detail from collage 4

In addition, Collage 4 featured a group of people of different ethnicities; they are standing together and appear to be figuratively supporting each other.

Figure 28: Another section of collage 4

Similar to this image, Collage 7 featured two women of different ethnic backgrounds smiling and laughing together. Similar to the image in Collage 4, the women are physically close and are seen leaning on each other. They are both smiling, and possibly laughing. This image appears indicative of 'sistering a joist' a phrase used in construction to mean attaching an equivalently sized piece of material to an existing framing structure (Lee, Knapp, and Dalrymple, 2018). By ‘sistering a joist’, the structures are more secure and prevent the framing member from collapsing.

Figure 29: Sistering a joist

When applied to the context of bereavement support, ‘sistering’ can be considered as one woman supporting another woman. Just as the within the construction industry material needs to be reinforced, grieving mothers also need to be emotionally sustained. Newly bereaved parents can gain strength from the support of parents who are further along in the grief journey.

6.6.2.3 Summary

Within the data, it was found that when participants were further along in their grief journey, they were able to find a programme that was appropriate to meet their individual needs. Participants described their experiences positively. Shared experiences, respect, and diversity were essential to providing adequate peer support. Within the data, participants indicated that group leaders need to acknowledge the heritage of parents from diverse backgrounds. For a peer support programme to be effective, understanding cultural competency is essential to building culturally competent bereavement support. Participant mothers in this study felt that they were able to make lasting friendships. In return, these friendships have continued to develop away from the peer support groups where they were originally formed.

6.6.3 Culturally appropriate bereavement support

Within the visual data, one item was identified within the collages that corresponds to the research aim of minority ethnic bereaved parents accessing culturally appropriate bereavement support. The use of creative methods did not answer this research question. It may be that this is a topic that is better expressed through verbal data instead of visual data. Collage 7 features the word *‘church’*. Although the participant attended a secular baby loss support group, attending church and gaining support from her faith was an important part of this participants early grieving process. There were no other items within the visual data which suggested that parents wanted additional forms of bereavement support which were culturally appropriate.

6.6.4 Making meaning from engaging with baby loss bereavement support programmes

Losing a loved one may change the trajectory of one's life, especially when it is unforeseen. Coming to terms with the death of a child is an extreme challenge (Neimeyer & Sands, 2011). Within the grief and bereavement field, making meaning is an important process of accepting a death and rebuilding a world that has been shaken by that loss (Neimeyer, 2001; Neimeyer & Sands, 2011). Evidence shows that bereaved people who are able to find meaning from their loss experience more positive bereavement outcomes (Neimeyer & Thompson, 2014). Neimeyer and Sands (2011) give context to the term 'meaning making' by explaining that it has two narrative processes. First, the bereaved person must process the story of the death by understanding why the loss happened and the impact this loss has within the life narrative (Neimeyer & Sands 2011; Neimeyer & Thompson, 2014). The second strand of meaning making from loss is for the bereaved to provide context of the relationship to the deceased and to continue their bond with their loved one (Neimeyer & Sands, 2011). Finding a meaning within loss has helped participants to process their grief (Hooge & Neimeyer, 2012). A study by Holland, Currier, and Neimeyer (2006) found the bereaved who were able to make meaning of their loss in the initial months following the death of their loved one experienced fewer symptoms of complicated grief. The evidence shows the importance meaning making has in the grieving process. Meaning making is an interactive process that requires community (Neimeyer, Klass, & Dennis, 2014). Some of the mothers who created collages had references to how they found meaning of their grief through accessing baby loss bereavement support.

6.6.4.1 Transformation

Collage 2 had a picture of a butterfly which denotes the transformation this bereaved parent underwent whilst attending peer support groups. Similar to Collage 2, the participant who created Collage 3 selected a picture of a butterfly in the left-hand corner to represent her transformation of attending SANDS peer support group. Like the butterflies they chose to incorporate in their collage, these participants appear to have undergone a metamorphosis which encompassed their change of identity from being an expectant parent to being a bereaved parent to a deceased child.

Figure 30: Images of transformation

When their babies died, their lives underwent significant and unexpected changes. The mother who created Collage 3 (blue butterfly) shared that she used the butterflies as a symbol of hope. Unsure of how they would overcome their losses, the participant mothers who created these collages chose images of butterflies as these demonstrated that they could emerge from their experience of losing their baby as a different version of themselves. The creator of Collage 3 included '*finding a way*' to demonstrate the uncertainty she felt attending the support group meeting, but eventually came to believe that joining the support group would alleviate the emotional pain she felt. Both participant mothers who created Collages 2 and 3 found meaning in their loss through their peer support participation.

Figure 31: From collage 3, finding a way.

6.6.4.2 Engagement and advocacy

There were four collages that included phrases that described the impact that the support had on their lives. Collage 5 contained the phrase "*I can finally look forward to the future*". After attending peer support groups, this participant mother applied to train as a befriender and peer support group leader.

Although her new bereavement supporter role did not justify her loss, she was able to direct her grief in a positive and supportive manner for newly bereaved parents. This participant mother wanted to use her experience of loss to be an advocate for parents who needed emotional support.

Figure 32: Finding a future

On Collage 7 *'Power is about being able to determine our futures'* is positioned across the two women who are pasted on the background of the collage. Through participating in her peer support group, this participant felt empowered to make changes on behalf of her child. The participant mother who made Collage 7 disclosed that other opportunities that led her to becoming involved improving maternity service provision arose from her participation in the peer support group.

Figure 33: Collage 7, power

Similarly Collage 6 includes the phrase '*sometimes it's hard to believe it only takes one or two people to start a movement*', which appears to suggest that for this participant meaningful change can occur from a small number of people. This participant commented that attending a baby loss support group was the first part of the process of healing for her. She credited the befriender she spoke to and the group leader as the drivers of her emotional recovery. From their influence and mentorship, this mother wanted to contribute by becoming further involved in the baby loss organisation.

Figure 34: Collage 6, community

Although death and loss are part of the human experience, each participant's experience of loss was individual. Findings from the visual data demonstrate that baby loss peer support groups provide a safe space where parents discuss their grief and find respite from their communities where participants did not always feel supported. Here the peer support programmes acknowledged the newly bereaved parents' pain of losing a child and yet still recognised their important role of being parents. The act of grieving is a social process which requires bereaved people's pain to be acknowledged (Neimeyer, Klass, & Dennis, 2014). This is what peer support programming provided to the participants in this study. The meeting space provided the participants with the space to process their grief, which in turn helped them to understand who they were as bereaved parents. Positive relationships with befrienders and peer support leaders motivated bereaved parents to be more engaged and take on roles such as volunteering or training to become befrienders and group facilitators. Parents who were further along in their grief journeys acted as mentors for the more newly bereaved mothers. These people were important as they helped to facilitate the newly bereaved parent to make meaning from their loss through compassionate conversations and guidance. In addition, group leaders and befrienders served as a role model where newly bereaved parents could understand that there was life after experiencing baby loss.

6.6.5 Thematic analysis

To analyse the data, I conducted a thematic analysis following Braun & Clarke's (2006, 2021) guidance. I followed the six-step process to conduct a thematic analysis which was discussed in the methodology section of this document. As part of the analysis process, I identified reoccurring images and words across the eight collages which were chosen by participants to include in their individual collages. Pictures, words, and phrases that were consistently repeated throughout the data eventually developed into themes and subthemes which now form this results chapter. Below is a photograph I took during the time period where I was conducting the preliminary analysis. I folded the large pieces of paper so there were eight distinct sections. With each collage, I spent time generating codes for each of the items that were featured on the collages. I created a code per image and word, because each detail that was included was symbolic of the participants' experiences seeking baby loss bereavement support. I interpreted each item they included on their collage as meaningful and worthy of becoming a code. Each collage had numerous codes on post-it notes. When the first stage of coding was complete, I had identified over twenty preliminary themes. Each divided section served as an area I could categorise similar items together. The sections with more diversely coloured post-it notes represent topics that became dominant themes.

Figure 35: Encoding the collages

Following step two, I began to search for themes where I organised similar codes into relevant categories that served as initial themes. I reflected on the relationship between the codes and which preliminary themes could be combined into larger themes. Where some early themes were refined, others were discarded. I concluded that there were two dominant themes that were persistent throughout the collages: nature of grief and grieving is a journey. The two overarching themes capture the mothers' experiences seeking bereavement support. Within these larger themes are subthemes that I identified and included in this analysis. Throughout the analysis, I maintained a constructivist perspective to generate the development of the theme narratives. This means that my understanding of the data was co-constructed with the participants through our interaction. Through my dialogue with the research participants surrounding their collages, I was better able to understand the data and generate the following themes.

Whilst I conducted the analysis, I noticed the differences between how the collages were orientated and presented. Each parent used their creativity to produce collages that were distinctly unique. Some collages incorporated many images and little background space to separate the items, whereas other collages had fewer items and more background space. Although analysing the orientation was not part of the thematic analysis and outside the scope of this doctoral project, it is still worth noting the meticulous planning participants did in order to create their collages.

Almost all the collages incorporated images of nature, however, Collage 7 did not include a nature image. The participant did not identify a reason why she didn't choose images of nature. As a result of conducting a thematic analysis of the collages, it emerged that bereaved parents presented a complex existence of thriving and surviving. Participants commented on the significance of some of the images they had created, whilst there were others that were not explained and yet focused on the contrast of happier and more onerous times throughout the year.

Figure 36: Images of complexity

These hallmark dates included birthdays, holidays and sadiversaries, a phrase I developed which signifies the anniversary of the day someone dies, which combines the words sad and anniversary. These dates mark the time without the person who has died.

6.6.5.1 Nature of grief

Grievers know which seasons hold additional meaning in terms of their loss. In contrast, there are seasons when grief is somewhat easier for those who grieve. Bereaved people emerge once again from the season of grief, and this may be perceived as mirroring the changes of the seasons. Some participant mothers represented their grieving journey as being paralleled with the changing seasons in their collages. Imagery of changing seasons have been symbolic of pregnancy loss since the nineteenth century (Layne, 2020) which means other bereaved parents have noticed the symbolism in annual changes. Spring is often seen as a rebirth of the nature world and serves as a reminder that nature revives itself from the dead of winter (Layne, 2020).

Figure 37: Images of the seasons in grieving

Stemming from the general concept of nature was the recurrence of feeling grief or as I termed it the "seasonality of grief". There were several images across the collages that featured different times of the year by using distinctive images that were representative of the seasons of the year. Collage 1 included several images that were specific to all four seasons. This collage represents spring through images such as Easter eggs and daffodils both of which represented renewal and rebirth for the participant. The participant mother selected photographs of citrus fruit, melons, leafy green plants, and lightly coloured flowers that were in bloom. Autumn was represented by a lone red leaf, and a bouquet of darker flowers and maize.

Figure 38: Collage 1, Seasons imagery

Collage 3 included a blue tinted image of pine trees with the words '*enjoy nature*' and '*time*' superimposed on the image.

Figure 39: Collage 3, nature

Collage 2 included the change of seasons through two images. The first image was a garden of wildflowers to represent a season of growth. This participant also included an image of the aurora borealis taken in a remote forest. The Northern Lights take place on a clear dark night, which often happens from autumn, winter into early spring. This mother stated this image represented that there was light in dark times.

Figure 40: Collage 2, light in dark times

Collage 8 featured pictures of nature which are large and take up the entire page. Similarly, it shows flowers in bloom and healthy green plants that are in season. However, it also features an autumn scene with changing leaves in a park-like setting with an adult walking with a child together on a path that is in a golden field that looks ready for harvest. From the participants' feedback and my judgment, I concluded that these collages may be considered to represent the range of emotions a bereaved parent feels throughout the year.

Figure 41: Collage 8, seasons as representations of emotions

6.6.5.1.1 Seasons of grief

6.6.5.1.2 Symbolic growth

Within the collages emotional growth was depicted using trees and plants. Collage 2 has a small picture of a healthy plant with vibrant green leaves. Similarly, Collage 3 has a prominent picture of a tree that is full of green leaves. The participant chose to paste the word *‘growth’* on top of the image of the tree to signify that emotional growth from grief is a process. Collage 4 had a vibrant image of a garden with yellow and purple flowers. It also had a pink rose that bloomed in honour of the bereaved mother’s baby. Collage 6 contained an item at the top of the collage of a lush forest with sunlight shining through the photograph.

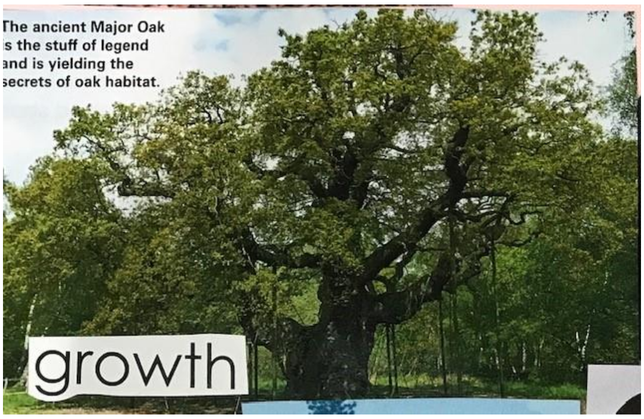


Figure 42: Images of growth

6.6.5.1.3 Arduous journey of grief

More extreme nature images of mountains and mesas are incorporated in Collages 2, 4 and 8. Collage 8 includes an image of a mountain chain and one mesa, both of which are in the distance. Here the inclusion of mountains within the collages reveal that the grief journey is arduous and demanding. Life is uncertain and its vicissitudes create the literal sensation of going up and down. Collage 5 had an intense image of a waterfall flowing off of the edge of a cliff. Predominantly full of words and phrases, this image is the only nature image on the collage. Across the waterfall are the words '*SHAPED BY NATURE'*, meaning there were natural causes that pushed that waterfall to flow the way it did. The participant shared that she felt learning she had lost her baby was a complete shock. She selected the waterfall because it felt as if she had fallen off of a cliff receiving such tragic news.

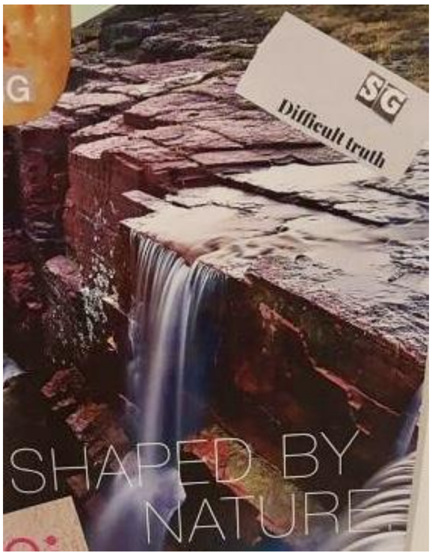


Figure 43: Waterfal detail from collage 8

6.6.5.1.3.1 Symbolism of birds

In four of the collages images of birds were used. Collage 1 had a gold necklace charm of a bird which the participant explained signified her deceased child. She did not further explain the symbolism of the baby bird beyond that the image was meaningful to her in that it reminded her of her experience. Whilst there is limited literature about perinatal loss symbolism in visual data, Layne (2020) writes that when a mother loses a pregnancy, she also loses her innocence. The image of the little bird may suggest that this mother felt like she lost her innocence; it left her when she lost the pregnancy.

Figure 44: Collage 1, baby bird necklace

Collage 3 included three bird items. One picture was a pair of penguins walking side by side; it appears as if their wings are touching each other. This participant mother included that image to represent her and her husband's mutual experience of grief. They walked through the journey together, side by side. They navigated their grief by themselves. She also included an image of two puffins interacting. One bird is asking the other bird about the baby. The bird flapping its wings says 'FINALLY'. The mother said this image indicates the freedom she felt when someone asked her about her child. She felt she needed to receive an invitation to speak about er baby. Conversely, the image of the lone bird demonstrates how she felt how isolated she felt from others.

Figure 45: Collage 3, bird imagery

Collage 4 has two images of birds; one is a little bird, and the other is a colony of penguins. The colony of penguins represented bereaved parents coming together to support and protect each other, similar to penguin colonies in the wild.

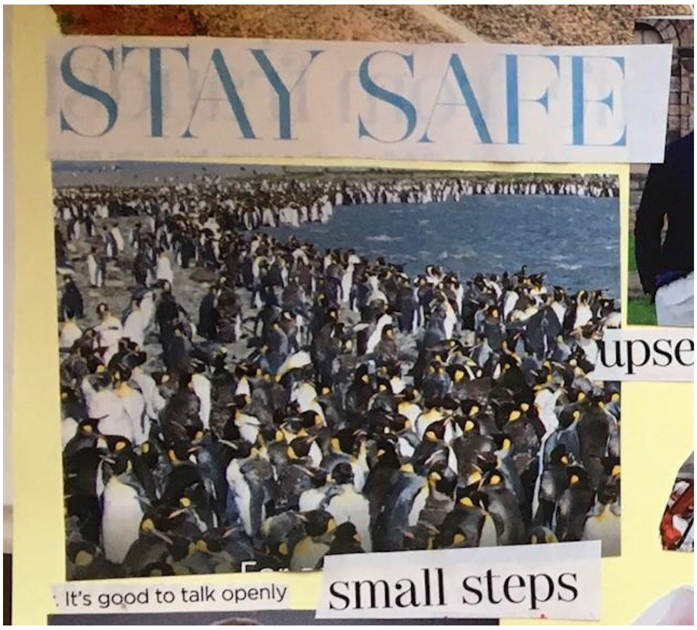


Figure 46: collage 4, penguin images

Collage 6 also had two bird images. Similar to Collage 3, there is an image of a pair of birds who are touching. The participant stated that this cut out heart shaped image was symbolic of her relationship with her husband. The second image is also of two birds; this time the birds are flying near each other. The participant explained that she had selected these images because the act of grieving together brought them closer as a couple.

Figure 47: Collage 6, birds representing grieving couples

6.6.5.1.4 Summary

Despite providing participants a range of materials to create their collages, participants felt connected to images of nature. They felt natural photographs appropriately told their stories of seeking out bereavement support. Three participants created collages to document how accessing baby loss bereavement support shaped their grief in a similar way to the changing seasons. Four participants selected nature specific images to symbolise the growth they experienced through their grieving journeys. Nature themed visual data generated a distinct narrative about baby loss which was not captured in the semi-structured interviews. These data added another dimension to this project that would have not been captured solely through verbal data collection methods.

6.6.5.2 Grieving: Connections with the baby

Participants were asked to create collages that detailed their experiences of seeking baby loss peer support bereavement opportunities. The most prominent theme throughout the collages centred around the participants including aspects of their personal experience grieving the loss of their babies. Poignant images and phrases decorated the collages that provided information about how the participants felt when grieving. It was apparent that the participants had loved their babies and had respect for the connection they held with them. They had maintained a continuing bond (Neimeyer, Baldwin, & Gillies, 2006) with their baby. For example, Collage 1 featured the word "*mama*" twice. One of the two images on Collage 1 contained the word '*mum*' is a smart watch with an incoming call. Similar to a phone ringing, the smart watch has an option for the receiver to answer or ignore the call. This participant told me she chose this image, because although she might not look like a mother to people who did not know her story of baby loss, she remained a mother to the child who had died. Her desire to be recognised as a mother was critical in terms of processing her grief and understanding her loss.

Figure 48: Collage 1, Mum

6.6.5.3 Identifying as a mother

In Collage 1 there are two images of babies; one is a black and white image to represent the experience of not having a living child, and one is a colour photograph to represent her rainbow baby. A symbol for many bereaved families, rainbow babies are babies who are born after a perinatal loss or neonatal death (Tommy's, 2021). A rainbow symbolises hope and promise after a dark time (Smith, Davidson and Roberson, 2018). The baby in the black and white image has its eyes closed and is forever asleep whereas the baby in the colour image has its eyes open looking at the viewer.

Figure 49: Collage 1, baby loss and rainbow babies

This participant now has two children following her loss. The two images of the babies she selected may be considered a representation of how she can equally love her children who are living and the baby who died. The memory of the baby who died is still present and is interwoven into her identity as a mother. This mother also included an image of a birthday cake to acknowledge time passing without her child, and yet finding joy in commemorating all of her children's birthdays.

Collage 3 shares similarities to Collage 1 in that it addresses the mother talking about her baby. The word *'love'* was included twice on Collage 3. The images that were selected represented the baby that had died. In the bottom right corner of Collage 3 is an image of two puffin birds. The participant who created this collage inserted two speech bubbles above the birds. One bird says, '*tell me about your baby*', and the other responds '*FINALLY'*. She references a distinct silence that bereaved parents' encounter. Below the puffin image is a handwritten *'STILL'* and an image of the word "*born*" which provides a deliberate space between the word.

Figure 50: Collage 3, Still born

Stillborn babies are still born; they came into this world and were loved. Comparable to some of the stories within data from the semi-structured interviews, this participant wanted to document in her collage that her child's existence mattered in a communal sense. Like any proud parent, she enjoyed speaking about her child. She went on to further acknowledge her baby on the collage by including the baby's date of birth.

6.6.5.4 Including the child in their journey

Other collages featured tokens of remembrance of the baby who had died. Collage 6 contains the letter 'V' which was the first letter of the baby's name. The creator of Collage 6 also includes the phrase '*you should be proud*' on a shield like background which the participant chose to include as a message to her child. The phrase is surrounded by several photographs of the participant and her family members who had encouraged her to seek support. This participant wanted to document the progress she had made on her grief journey. Most importantly, she wanted to include her support network because they had played a critical role in her physical and emotional recovery.

The mother who created Collage 8 selected an image of a parent holding the hand of a child walking hand-in-hand on a path in nature away from the viewer. This image represents the participants grief journey. The image was used as a means of commemorating her bond with her baby. The memory of the baby was present with her on her grief journey.

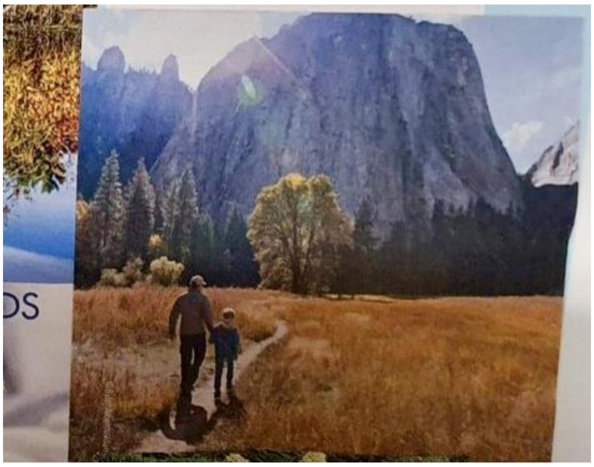


Figure 51: Collage 8, parent and child

6.6.5.5 *Time*

The concept of time is represented by several symbols throughout the collages. Most notably, this is through the use of images of watches. Collage 1 includes two watches placed near the centre of the collage. There are two watches, one for the mother and one for the father. Collage 7 features a watch in the bottom right corner. In Collage 2 '*It's time to speak out'* is included across the top of the collage. Although this phrase was synonymous with describing the process of seeking peer support programmes, it also corresponded to the timing of finding a peer support programme. Here, time is needed following the perinatal loss before a parent is ready to seek support. Collage 3 has the word '*time*' listed in the bottom left corner. The inclusion of time within the collages suggested that over time, the immediate intensity of grief wanes, and positive emotions such as love remain.

6.6.5.6 *Summary*

The eight participant mothers who created collages produced collages that were rich in detail. Parents included words and pictures that were symbolic of their grief journey. Grieving a child in pregnancy or after birth is a type of loss many people do not understand. Societal attitudes towards perinatal loss deeply impacted the participants. They desired to be recognised as parents of both living and deceased children by their communities. Participants included personal mementos such as the birthdate and the first letter of the baby's name on their collages as references to their children. They continued to have a bond with their children through their participation in peer support programmes. The visual data demonstrates that participants required time to manage their loss before they found support connecting with other bereaved parents. Whilst the verbal data captures the parents' grief journeys, the collage data enhances the relevant understanding gained from the semi-structured interviews.

6.6.6 Feedback from the activity

I received positive feedback about the college making activity. One of the collage participants was trained as an art therapist. She was keen to participate in the study, because she appreciated the task and the importance of processing emotions through art. She enjoyed participating in a collage activity, saying,

"Thank you for inviting me to take part. I don't usually get the chance to create something, because I'm often leading art exercises with my clients."

The four women participants who made up the focus group creative session stated that they enjoyed taking time away from their busy schedules to create art in honour of their children. They enjoyed the experience of creating art in a relaxed environment. Moreover, they appreciated that they could take their collage home as a token of remembrance. The participants from the focus group thanked me for including them in both parts of my research. This was the first time any of them were asked to take part in research. Below is a quote from an email I received from the creator of Collage 6 :

"I just want to take a moment and thank you so much for letting me be part of this project. You have truly been amazing and the work you are doing is FAB. If I can be of assistance in any other future ventures that you may have, I would gladly participate".

This comment, and other comments I received from participants made me feel honoured to carry out perinatal loss research with parents who had not had the opportunity to contribute to research and demonstrated the importance of this study to these participants.

6.6.7 Conclusion of the chapter

Collage is an affordable and accessible arts-based research method that elicits participants to create a self-reflective piece of art (Dutton et al., 2019). It has been applied in several qualitative studies that have used the medium of collage as a way to build relationships with communities who are often isolated from participating in research (Kay, 2013; Chilton & Leavy, 2014; Vacchelli, 2018; Dutton et al., 2019). Arts-based research methods build rapport between the researcher and participants and alleviate some of the power imbalances by creating more equity between the researcher and the communities being researched (Van der Vaart, van Hoven, & Huigen, 2018). The collage activity was particularly informative in this study as it highlighted the complex dynamics of the participants' lived experiences as they sought appropriate bereavement support whilst adjusting to their new life without the baby they had been expecting. Furthermore, the collage making provided participants with the space to reflect on the emotions they experienced whilst finding bereavement support. This enables the generation of rich data which, when combined with the semi-structured interview data, contributes to a nuanced understanding of the participants experiences of their grief journey and accessing support. New associations from their experiences as bereaved parents emerged in the images they chose to incorporate in the individual collages.

Each collage was handmade with care, attention, and love. This exercise enabled participant parents to purposefully set aside time from their daily lives and commitments and reconnect with their emotions through a safe and structured task that had limited risk to the participants (Tripp, Potash, and Brancheau, 2019). The eight collages enrich this qualitative study by adding visual depth to the participants' voices thereby drawing attention to the emotional essence of their experiences.

7 Generating a constructivist grounded theory

7.1 Rationale for applying grounded theory to this study

Qualitative research is used in social research to observe individuals in their natural environment to explore their realities and perspectives (Trumbull, 2005). It demonstrates how individuals' behaviours and attitudes are constructed by the environment and situations they live in (Hennink et al., 2010). Qualitative research is useful for understanding social phenomena as it explores the participants' perspectives, motivations and beliefs on the question being examined (Gill et al., 2008). Grounded theory methodology is applied to this study by exploring BAME bereaved parents' perspectives and attitudes towards parent support groups.

Semi-structured interviews were utilised for the collection of the primary data and were selected because this type of interview can provide information from the participants' perspective (Hannabuss, 1996). As a whole, interviews can provide in-depth information on a specific subject that cannot be obtained by quantitative methods (Gill, et al., 2008). I created and followed a semi-structured interview model, because it would be the most effective way to guide a highly sensitive and emotionally provoking conversation, and yet offer space for participants to speak candidly on other matters they might want to share (Carruthers 1990; Morse & Niehaus 2009). Semi-structured interviews have a degree of structure to them will means that all participants are asked common questions (Carruthers, 1990). When in-person interviews were allowed, participants chose a place they felt safe in to conduct the conversation. Two couple interviews took place in their homes as it was the most convenient option while they children were home. The other in-person interview took within a closed section of a café near where the participant lived. This area of the café provided a confidential space for me to conduct the interview.

To analyse the data, I used Grounded Theory approach: "a systematic, qualitative procedure used to generate a theory that explains, at a board conceptual level, a process, an action, or an interaction about a substantive topic", (Creswell, 2014, p.451). Grounded Theory is a popular method of data analysis in qualitative research in social sciences (Morse, 2010). Rather than being based on a hypothesis, the theory builds itself from the bottom up, meaning the process of creating a theory develops over the duration of the study (Morse & Niehaus, 2009). This theory is useful when applied to an emerging area of research or when there are no other theories available that address the problem or represent the participants in the study (Bryant & Charmaz, 2007, Creswell, 2014). When applied in a mixed methods study, grounded theory can only be used as the core component, because it is an individual method rather than a strategy (Morse & Niehaus, 2009, p.95). Due to the limited research that examines BAME bereaved parents accessing baby loss support groups, this project fits the aim of grounded theory to generate a theory about how and why this phenomenon exists.

There is a step-by-step systematic procedure for analysing data under grounded theory (Creswell, 2014). Grounded theory obtains directions from the initial analysis to the subsequent set of data (Charmaz, 2000, as quoted by Creswell, p. 451, 2014). The strength of this theory is that it is generalisable so that it can apply to other areas of research (Morse et al., 2008 as cited by Morse & Niehaus, 2009). First, data is collected from the interviews and coded (Creswell, 2014). This process of coding data enables the researcher to interpret the data and apply a code to the to categorise it (Denzin & Lincoln, 2000). The most frequent codes which emerge from the data will be categorised. In the grounded theory approach, researchers collect and analyse data simultaneously (Creswell, 2014). The relationship is symbiotic; the data guides the analysis and vice versa (Bryant & Charmaz, 2007). After careful consideration of different approaches to grounded theory, I found that I aligned with Charmaz's constructivist grounded theory approach (2006). I recognised the importance of the researcher being reflexive in the process and wanted my position as the researcher to be used as a tool in the process. Furthermore, I acknowledge that I co-created knowledge with participants and accept my subjectivity in terms of developing a theory. Due to the importance of the role reflexivity plays within constructivist grounded theory, researchers working with this method recognise they are a part of the research process (Charmaz, 2020).

During data analysis, memos were made to document data and the categories that emerge (Creswell, 2014). NViVo was the programme through which the data was stored and coded. NViVo is a software programme that "combines efficient management of non-numerical, unstructured data with powerful processes of indexing, searching and theorizing", (Creswell, 2014, p.267). The programme does not undertake the analysis for the researcher but supports the researcher to find patterns and make conclusions in relation to the data (Creswell, 2014).

7.2 Introduction to developing a grounded theory to address baby loss bereavement support

The aim of the principal portion of this doctoral study was to develop a theoretical understanding of how BAME bereaved parents choose to access bereavement peer support to assist them during their grief journeys. This chapter provides the data analysis process to demonstrate how the road to hope through grief grounded theory was developed by following Charmaz's 2006 guide on constructivist grounded theory. Theory generation was realised through three cycles of data collection and analysis. In total, eleven interviews (including nine individual participants and two participants were interviewed as couples), and one group interview (three participants) were collected and analysed. I will present each stage of initial coding, focused coding, and theory development to show the process by which codes were developed. In chapter 6, Il discussed the categories that emerged from the analysis. I will present the developed theory in the discussion section. There, I compared the theory to the collage findings and how it relates to current understandings and practises in the baby loss bereavement field. The analysis was performed by hand and using NVIvo. I used NVivo to organise and analyse the semi-structured interviews. Although the software does not do any analysis on its own (Hutchison, Johnston & Breckon, 2010), it provided tools to help me sort and arrange the data in a systematic way to identify relevant themes with which to explore the research questions. I chose to work with NVivo because it records the evolution of how the grounded theory developed which can promote transparency in a doctoral thesis (Bringer, Johnston & Brackenridge, 2004).

I followed Charmaz's constructivist grounded theory (2000; 2006; 2008; 2011; 2014; 2015) to analyse interviews with 16 participants. As a reflexive researcher, it is an obligation to state explicitly how I worked with and later interpreted the data (Charmaz, 2006). I was inspired by feminist grounded theory (Wuest, 1995) which encourages the researcher and participant to build an authentic connection. The relationships I built with the participants when collecting the data were emphasised in the analysis as Charmaz (2014) considers both researcher and participants as co-creators. In constructivist grounded theory, the analysis begins with transcribing the interviews (Charmaz, 2006). The researcher then begins the analysis by coding the transcripts, and labelling portions of the data (Charmaz, 2006).

7.3 Developing the interview guides

Grounded theorists are interested in social processes of a phenomenon (Sbaraini et al., 2011). Following Charmaz's (2006) approach to grounded theory, a simple interview guide was created to facilitate the conversation during the semi-structured one-to-one interviews and the group interview. The purpose of constructing an interview guide is to prepare the research novice (such as myself) to focus on the data by having set questions to ask without overloading the participants (Charmaz, 2014) and to expand on shared key components that are found through the participants' experiences (Charmaz, 2006; Foley and Timonen, 2015). My guide consisted of ten open ended questions (Foley and Timonen, 2015) which enabled me to lead interviews that flowed well despite technical difficulties during the virtual interviews. The most frequent issue was having a consistent and reliable wi-fi connection. It wasn't uncommon for the online interviews to be stalled due to the application shutting down or the participant receiving a phone call in the middle of the interview which often forced the application to disconnect from the interview. I used the semi-structured interview guides for all of the interviews in this study. I concluded each interview by providing the participants space to reflect on our conversation and encouraging them to ask questions about me and the research project. Each interviewee was urged to seek out support from their preferred channels if they felt distressed by the content of our conversation. Although the semi-structured interviews weren't typically distressing at the time of the interview, I tried to encourage participants to seek support if the interviews stirred negative emotions. I gave participants contact information to mental health charities that could support them if they felt extremely distressed. Sensitive research can pose risks to participants' wellbeing (Baarnhielm & Ekblad, 2002; Melville & Hincks, 2016). I tried to safeguard participants to seek out their preferred support and signposting them to mental health charities as an attempt to protect them from re-experiencing the trauma of losing a child.

7.4 Reflexivity through the creation of grounded theory

Charmaz (2006) writes that reflexivity goes beyond dissecting a researcher's personal experience and knowledge of the topic; the researcher must broaden one's reflexive position to include how the researcher carries out research, connects with the participants, and speaks for them in the results. Within constructivist grounded theory, the creation of data and analysis is a shared experience between the enquirer and the enquired (Charmaz, 2006, 2019). The theory that develops is influenced by the researcher's perspective and experiences (Charmaz, 2006). As a result, an intentional effort was made during data collection and analysis to be reflexive about my own experience of grief and bereavement, and the influence my personal understanding has on the data. The aim of highlighting reflexive excerpts is to improve the reliability of the findings and openly address that the assertions made in this body of work does have autoethnographic components weaved into the findings. Cotterill and Letherby (1993) maintain that feminist research interlaces both the researcher and the participants' stories due to the nature of feminist research examining through participants' stories (Graham, 1984), and by "telling ourselves a story about ourselves" (Steier, 1991, p. 3 as cited by Cotterill and Letherby, 1993).

Memo-writing is a critical exercise where researchers capture their own thoughts between collecting data and analysing the data (Charmaz, 2006, 2014). This step helps researchers to find links and compare data to improve initial codes (Charmaz, 2014). I wrote memos throughout data collection and analysis; often the memos were written effusively. Additionally, I created quarterly collages detailing my research experience during the first wave of the Covid-19 pandemic, world events that happened in 2020 and 2021, and my developing understanding on how to grieve my losses and conduct research with those who have also experienced immense loss. I found both methods of drafting memos (written and visually) enabled me to process the new information which arose from conducting this study and to further explore my ideas related to grief and bereavement. Written memos helped me to recall what was being reported to me which ultimately improved my preliminary codes; the memos facilitated an inner dialogue where I could examine my assumptions about the data. From a constructivist lens, memo writing enriches the study by highlighting the relationship between the researcher and the research process (Charmaz, 2014).

Jones and Murphy (2019) stress the importance in recognising how a researcher's emotions can impact a study's findings. Researching death, bereavement, and grief may provoke painful memories that can feel acutely distressing (Lee, 1993). Considering my intimate relationship with death and grief, I felt it was necessary to address my emotions before meeting with participants. I began writing memos in February 2020 shortly before my first semi-structured interview to reflect on my position as someone who was raised in a family where perinatal loss was well known. As a sibling of two stillborn children, I knew that they were missing from our family. My mother spoke about her pregnancies; their lives and legacies were significant in my upbringing. I had first-hand knowledge of knowing that I was missing two siblings.

Moreover, I wanted to observe what uncertainties I had about working in death and bereavement while I was grieving and my response to working in the field would evolve over the course of the research process. Some examples of the reflexive memos are included in the chapter to demonstrate how reflexive memo writing was a vital process to move the data analysis forward to construct a theory (Charmaz, 2014). Below is an extract from the first memo I wrote.

I know my family's history with pregnancy loss, and although I feel like an advocate on opening conversations about baby loss, I feel nervous discussing it with people I've never met. I wonder if they share the same hesitation. I'm curious to see what other topics come up in the interviews that I didn't anticipate. I hope that I am as best prepared as I can to support parents if they become distressed. My goal is to best capture their voices to honour their children's legacies. I would like to think that some parents might enjoy participating in research, especially if they have not before.

I need to remain conscious about the power and privilege I have as the researcher and being a white woman conducting research with parents who self-identify as being from a minority ethnic population. Some parents will have experienced discrimination and racism within the healthcare settings, and perhaps losing their child was associated with racism. I must take care to prevent re-victimising the parents who participate in this study. I don't want I want to as much of a balance between the positions (researcher versus participants) as possible. How do I best do that?

Figure 52: Memo one, February 2020

7.5 Recruiting study participants

The key feature of qualitative research is to represent the complexity of the world through collecting perspectives of multiple individuals (Creswell, 2014). Purposive sampling applies to both the individuals participating and accessing the sites through which people attend (Creswell, 2014). It is typically associated with qualitative research, which involves selecting participants in relation to the research question versus having random participants, so that the information collected is exhaustive regarding answering the questions (Teddlie & Tashakkori, 2009). This means that researchers select people or sites through which the study information is passed along to those who can best answer the questions to understanding the phenomenon being studied. Creswell (2014 p.228) says that this form of sampling is useful because “it gives voice to silenced people”. Sample sizes are usually 30 or fewer cases (Teddlie & Tashakkori, 2009).

7.6 Addressing the study’s sample size

Parents needed to have at least one year after the initial loss up to ten years after the loss of their child to take part in this study. In total, there were 16 parents who took part in the study. Within this population, there was a total of thirteen mothers and three fathers who participated. Although it would have been preferable to have more fathers participate in the study, there were enough data captured through purposive sampling to reach theoretical saturation (Charmaz, 2006; Guest, Bunce, & Johnson, 2006). Charmaz defines saturation as the moment “your categories are robust because you have found no new properties of these categories and your established properties account for patterns in your data” (Charmaz 2014, p.213). In the field of health sciences, reaching saturation has become a standard measure to justify a qualitative study’s sample size and validity (Guest, Bunce & Johnson, 2006). Earlier in her career, Morse argues that “saturation is the key to excellent qualitative work” (Morse, 1995, p.147). Later in her work, Morse readdressed the topic of saturation; she writes that the amount of data does not automatically equate to the number of participants (Morse, 2015). Instead, saturation is an important marker of academic rigor (Morse, 2015). Researchers who achieve saturation can construct an in-depth analysis that can best represent participants’ quotations and attest to the study’s validity (Morse, 2010).

Furthermore, Bertaux (1981) reasoned that fifteen is the smallest sample size in qualitative research that is acceptable. He preferred using the term “saturation of knowledge” (Bertaux 1981, p.37), which refers to the researcher’s experiencing of learning a great deal of new information within the first few interviews. By the fifteenth interview, he reasoned a researcher would be able to identify emerging patterns with the number of interviews collected (Bertaux 1981). Further interviews would merely confirm what the researcher had detected. Crouch and Mckenzie (2006) argue that a smaller number of interviews (under 20) enable the researcher to build a connection with participants and “enhance the validity of fine-grained, in-depth inquiry in naturalistic settings” (p.483).

Meanwhile, grounded theorists such as Glaser (1998) and Stern (1994) maintain that smaller sized samples and therefore limited data do not negatively impact the study because grounded theory intends to generate “conceptual categories and thus data collection is directed to illuminate properties of a category and relations between categories" (Charmaz, 2006, p. 18). Grounded theorist Dey (1999) argues that researchers need to reach "theoretical sufficiency" (Dey, 1999 p.257 as quoted by Charmaz, 2006).

Charmaz (2006; p.114) states that by implementing sufficiency rather than theoretical saturation, researchers can assemble a suitable number of categories "suggested by data" rather than using the notion of saturation which depends on the researcher's speculation that there has been enough information gathered to generate saturated categories. Nelson (2016) defines theoretical sufficiency as the moment when the researcher has gained an in-depth understanding of the matter to construct a theory from the collected data (Nelson 2016). Charmaz (2006) and Dey share concerns about obtaining too much data to construct an analysis that has many participants and yet the theory developed lacks meaning. Following Charmaz's (2006) lead in acknowledging what events contributed to my study's sample size and "being willing to grapple with it" (Charmaz, 2006, p. 115), I am confident that I garnered an appropriate number of participants during a global pandemic to generate a meaningful theory in terms of why minority ethnic parents access baby loss bereavement support.

7.7 Participants in cycle one

The first cycle of data collection consisted of two semi-structured interviews which took place at a precarious moment of history when the COVID-19 began to sweep across the world in early 2020. Fortunately, I was able to meet with three participants; one couple consisting of a mother and a father, and one was a mother. Both semi-structured interviews took place in person within a two-week span before the first COVID-19 national lockdown in late March 2020. Boris Johnson, the Prime Minister, ordered people to stay at home and only leave for essential reasons which included purchasing food and exercising once per day, to stop the disease from spreading. The couple self-identified as Black and spoke of their Ghanaian heritage frequently throughout the interview. I interviewed the couple in their home because it was the most convenient location for them. The couple chose to not create a collage due to time constraints.

The mother self-identified as Polish and classified herself as being 'any other white background' category in a government form such as the Census (ONS 2021). This participant asked to meet in a public space, so we met at a local café where we could find a quiet area to conduct the interview. We reserved a table in secluded area that served as a confidential space that could maintain the participant's privacy. The mother was married to a white English man; however, he was not able to participate because he did not match the inclusion criteria based on his self-identified ethnicity. The Polish mother created a collage once the semi-structured interview had finished.

All three participants resided in Kent. A bereavement midwife with whom I had met during the first year of my doctoral study urged me to contact the mothers to participate in my research study as they had previously expressed interest in participating in research. Participants were asked to describe how they came to find baby loss bereavement support. I encouraged participants to begin their story where they felt most comfortable; I informed them that they did not have to disclose their birth experience in hospital. Both participants who took part in this first cycle shared their birth stories. The table below provides a summary of the participants' experiences which was discussed during the semi-structured interview, to provide context for their data.

Table 6: Demographic information of participants in cycle one

Pseudonym	Ethnicity	Region where participant resides	Type of Peer Support Group	Participation in Peer Support group
Iris	Polish (white other)	Kent	SANDS; PALS	Not active
Jade & Arthur	Black	Kent	SANDS (mum); church group (dad)	Not active (mum) Active (dad)

7.7.1 Written memos during cycle one

Memos were made after each semi-structured interview throughout the three cycles. I enforced a capacity rule of two semi-structured interviews a day to protect my well-being as the semi-structured interviews were addressing a sensitive topic. I felt I provided an intense amount of emotional labour (Evans et al., 2017) throughout the course of the semi-structured interview cycles which continued throughout the data collection and analysis. The semi-structured interviews required intense concentration and regular emotional safeguarding to maintain professional boundaries, and yet find the balance to facilitate poignant conversations with bereaved parents. Knowing I had set a firm limit on how many semi-structured interviews I would conduct each day gave me time to think critically about each conversation and enabled me to spend time reflecting about my time with the participant(s).

The extract below is from one of the "early memos" (Charmaz, 2014, p.169) and originates from the semi-structured interview with Jade and Arthur. This memo begins by detailing the scene and how the experience of interviewing two parents at a time compared to interviewing one parent. The memo goes on to discuss how it felt witnessing a couple discussing their daughter. Writing memos after each meeting helped to support me to process the experience of conducting an interview and to debrief the material with myself through an internal conversation (Charmaz, 2014).

It was a different dynamic interviewing a couple than interviewing a parent who was alone. I felt like I was observing a conversation rather than leading an interview. It was a comfortable setting; we were facing each other directly in the sitting room. The children were taking naps, so there was minimal noise and no distractions. I did not have to give them prompts from the interview schedule for them to carry out the conversation. It was a thorough interview, with what felt like no topic left undiscussed. The duration of the interview was nearly an hour and a half long. They addressed each of the questions on the interview schedule and they went beyond the topics I wanted to address within the hour-long conversation. There was even a discussion about celebrities openly discussing their own pregnancy loss and infertility issues and how their accounts could enhance the general public's awareness on baby loss.

Jade and Arthur disagreed on some topics which was thought-provoking as a researcher to witness. It did not feel like an argument. Their discussion served as a reminder that within a couple, partners can experience the same event differently and feel contrary to their partner about how the phenomena happened. Their experience of losing the baby and the aftermath of getting bereavement support was very different. One thing remained the same: they did not feel completely supported by their family. I am making an internal note to see if this will carry through.

I was struck by how honest Jade was about her mental health struggles after the loss of their baby. I wonder if she felt more comfortable disclosing this information because Arthur was with her. Losing a baby is incredibly isolating, particularly when you are the parent who is at home recovering.

Figure 53: Memo two, March 2020

7.7.2 Initial coding

Coding the newly collected data is the next step to generating an emerging theory to explain the phenomenon (Charmaz, 2006). Charmaz (2006, 2014) writes that there are at least two phases to code data through a grounded theory lens. Initial coding is the first phase whereby the researcher compares data with data (Charmaz, 2014). I chose to conduct line-by-line coding (Glaser, 1978; Charmaz, 2006) where I gave each line or every other line of the semi-structured interviews a code designating its importance. Charmaz (2006) advises researchers that although initially coding each line might seem like a tedious exercise, this method of coding expects the researcher to think and analyse critically about the data to see what information is missing and direct further investigation in subsequent data collection cycles. As such, line-by-line coding provides the researcher with clues on what to look for next.

7.7.3 Initial codes using Gerunds

In addition to conducting line-by-line coding, I followed Glaser's (1978) and Charmaz's (2006) procedure of using Gerunds whilst coding data. Gerunds places the emphasis on action (Charmaz, 2006). Charmaz (2006, p. 136) prefers highlighting the actions of what is being said rather than placing the emphasis on the individual because focusing on action is a "strategy in constructing theory and moving beyond categorising types of individuals". Implementing the use of gerunds kept the data active and drew attention to the connections between bereaved parents' experiences. Examples of gerund initial codes can be seen below.

Table 7: Gerund coding of interviews in cycle one

Interview One	Shared Gerunds Between Interviews	Interview Two
Attending peer support groups alone	Mourning the loss of baby	Attending hospital led support group
Building awareness around baby loss		Feeling abandoned and not supported by healthcare workers
Remembering Baby		Not grieving the way, she would have wanted to according to her culture

7.7.4 Focused coding

Once I completed noting initial codes, I conducted focused coding which is the second main phase of Charmaz' (2006) coding guidance. Focused codes are more discerning than line-by-line coding (Glaser, 1978). Charmaz (2006; p. 57) writes that focused codes are formed by "using the most significant and/or frequent earlier codes to sift through large amounts of data". This stage of coding requires the researcher to make decisions about which initial codes are significant and make the most sense to advance to thoroughly sort the data (Charmaz, 2006). It requires that the researcher returns to the original aim of the research and the research questions. The process of sifting through codes takes place throughout the different cycles of semi-structured interviews and advances the direction of the developing theory (Charmaz, 2006, 2014). Focused coding is a critical exercise to generate a theory as this step requires the researcher to examine their own presumptions about the topic (Charmaz, 2006).

In the first cycle of data collection, I scrutinized the line-by-line coding of each semi-structured interview and compared the most frequently used codes in the data to determine which codes emerged as the most important. I also had to examine the data and decide which data were useful in developing a theory and which data supplemented the semi-structured interview but did not answer the research questions. In the previous discussion on initial coding, it can be observed that there is a shared Gerund between semi-structured interview one and semi-structured interview two. Whilst both semi-structured interviews had a section where the process of mourning the loss of the baby was discussed, this shared code does not address the research questions. The practise of filtering the data is useful as it separates codes into which are meaningful in terms of developing a theory and which are meaningful data and yet are not applicable to the research questions.

7.7.5 Developing the analysis in cycle one

A key asset of grounded theory coding is that it requires the researcher to take an active role in processing the data (Charmaz, 2006). Charmaz's (2006, 2014) methodical processes provide novice researchers structure in developing a theory. In this study there was rich data to sift through from the first two semi-structured interviews. However, at this early stage it was not possible to determine where those codes would lead. I was able to see that throughout the codes that the loss of a child had a significant impact on a parent's sense of belonging in their communities. Seeking bereavement support appeared essential for the parents and provided a method of maintaining their wellbeing during the part wave of their grief journey.

7.8 Cycle two

7.8.1 Participants in cycle two

The second set of semi-structured interviews took place between August and September 2020. I had returned from being in the United States for four months. Between caring for my grandmother and the time difference, there were barriers recruiting participants for the study. In September 2020, the national government guidance permitted small groups of people to meet indoors which meant that I could carry out the group interview in Leicester with three women from the same peer support group. During this time frame, I conducted one group semi-structured interview in person, one semi-structured interview with a couple in person, and three online semi-structured interviews. The group semi-structured interview was held in a confidential hotel conference room in Leicester city centre. This was the most practical and safest option for everyone to attend. Only groups of six people or less from could meet in person from different households; this applied to both indoors and outdoors. This hotel, like many businesses during this time, joined the NHS Test and Trace programme to manage the spread of COVID-19. The conference room offered enough space for the four of us to keep two metres apart to observe social distancing guidance. Three mothers participated in a focus group interview. Another mother joined the second portion of the group activity which was to create a collage as she had completed an online semi-structured interview prior to the meeting in Leicester. In total, all four mothers chose to participate in the collage part of the data collection.

Table 8: Demographics of participants in cycle two

Pseudonym	Ethnicity	Region	Type of Peer Support Group	Current Attendance
Ruby	Asian	Leicestershire	SANDS; new charity	Active (group Leader)
Sophie	Asian	Leicestershire	SANDS; social media	Active in person and online
Alice	Asian	Leicestershire	SANDS	Not Active

The couple semi-structured interview took place in person at the participants' home. Their home was where they felt most at ease to discuss the loss of their child. As this was a sensitive discussion, I wanted to reassure participants that they could select the space (whether online or a location in-person) where they felt most comfortable to discuss how they sought out bereavement support.

Online participants chose the platform where they wanted to meet. Whilst it was university guidance to use MS Teams whenever possible, I found that most people in autumn 2020 were unfamiliar and did not use this platform. Participants did not want to use a platform that they were unfamiliar with and did not have previous access to. Participants did not want to download a video conferencing platform that they were unfamiliar with for a one-to-two-hour semi-structured interview and never use again. Each of the three semi-structured interviews were held on Zoom as it was the most popular platform for public users to access at the time. Even though Canterbury Christ Church University selected Microsoft Teams as its preferred online platform to use during the Covid-19 pandemic, I chose to adapt the participants' wishes to meet on their preferred online platform rather than participants downloading MS Teams to accommodate my needs. Most participants didn't have an outlook email account and didn't know it they would qualify for an account. This led to them feeling uncertain about accessing a MS Teams online meeting. I perceived this as a barrier that could be resolved by accommodating the participant's preferences. Zoom includes end-to-end encryption which guarantees the meeting between participants is secure (Zoom, 2021), which confirms the interviews were completed in a confidential space.

There were several technical issues that impeded the online semi-structured interviews. The most common problems related to the participants' internet connections. During a couple of interviews, some participants lost their wi-fi signal. This meant the interview was interrupted until the participant was able to enter the online platform. Conversely, my internet connection was slower than its normal capacity because I shared my wi-fi connection with my flatmate. The outcome of this issue meant I had connectivity issues which made it difficult for me to hear what the participants said. When my connection was delayed, I asked the participants for clarification of the statements they said. At times it felt as if we were interrupting each other, because of the delay. In addition to these intricate technological barriers, there were times when the participants' laptop or smart phones would lose power to the point of disconnecting from the interview which paused the interview until they could charge their devices. Likewise, interviews stopped when participants received a phone call; the incoming call disrupted the course of the conversation and at times disconnected the participant from the online platform.

There Participants attempted to resolve these technical issues in a timely manner so that the collection of data could continue unimpeded. Although it was somewhat disruptive, I felt that each participant was keen to completing the semi-structured interview despite the technical difficulties. Due to the technical issues, the semi-structured interviews often lasted between an hour and an hour and a half. Below, table 4 outlines this cycle of participants' experiences.

Table 9: Demographics of participants in cycle 2

Pseudonym	Ethnicity	Region	Type of Peer Support Group	Current Attendance
Nicole	Black	Leicestershire	SANDS; Maternity Voices Partnership	Active
Sandra & Vern	Asian	London	SANDS; Aching Arms	Active (mother)

				Not active (father)
Amelia	Asian	Leicestershire	SANDS	Active
Carrie	Black	Sussex	SANDS	Active
Abigail	Asian	Leicestershire	SANDS	Active

Written memos during cycle two

Researcher memos are key when developing grounded theory (Charmaz, 2006). The act of writing memos provides a living record of the research process (Charmaz, 2014). Although arduous at times, I found that creating memos served as a useful technique to give the data a 'time stamp'. This helped me to reflect on how I perceived and understood the data that were generated through each semi-structured interview cycle. Below is a memo I wrote after conducting the group semi-structured interview in Leicester.

> Yesterday, I led a group semi-structured interview with three bereaved mothers. All three met whilst attending a SANDS group and are now leaving SANDS to establish a new charity that will host a bereaved parent support group specifically for BAME parents in the Leicestershire area. Ruby, the leader of the group, and I met through Twitter. She is a trained SANDS befriender and has been leading the small group for several years now. She works at the local hospital as a baby loss befriender supporting newly bereaved parents. Ruby is a strong leader and as a result the Leicestershire group have been in several promotional marketing efforts for SANDS. She is in the process of establishing a local charity for bereaved parents in the immediate Leicestershire area.
>
> The semi-structured interview lasted an hour and a half. Everyone seemed to feel at ease; it was nice for us to laugh together while discussing a sensitive topic. I could tell each of the women knew each other well. They were familiar with each other's families and had spent many meetings together. All three mothers shared that they had felt some discomfort and misplaced support from their families and the larger Asian communities. They felt their grief was overlooked and their pain is forgotten. Loved ones shower them with platitudes and well wishes, but they don't recognise how hurtful that might sound to the grieving parents. The mothers shared that there is a tendency within the wider Asian culture to quickly grieve the loss of a baby; to be optimistic that there will be another baby soon. 'Keep trying', 'you'll get there', 'it's God's will' were common platitudes they had all heard from their family and friends. Attending meetings at SANDS helped to affirm that their grief and feelings related to their losses were normal. Peer support is different than group therapy or seeking help

from a counsellor or doctor; the power imbalance is levelled. Everyone attending the meeting is equal.

Sophie had shared that she was initially hesitant to contact SANDS because she did not know whether there would be anyone attending who ‘would look like her’. Sophie was referred from the SANDS main office in central London to the local support group that Ruby was running in Leicestershire. Ruby encouraged Sophie to come to the meetings and assured her she would be supported. Sophie shared that if it had not been for Ruby’s warmth and encouragement, she might not have chosen to attend groups. Sophie’s story makes me reflect on how vital it is to have a group leader who leads well and empathetically. I can imagine the impact of a poor leader might have on newly bereaved parents—perhaps negatively impacting their will to want to come to the support group. A peer support leader figuratively opens the door for newly bereaved parents to access help. As a group facilitator, they need to have the leadership skills to make the meeting space inclusive, and the communication skills to encourage new members to participate in the meeting. The role of a strong peer support leader is critical in facilitating a peer support group. People seek out peer support groups because there is a mutual sharing experiences, giving advice, and receiving support from others who have a perceptive understanding of a similar loss

Figure 54: Memo written during cycle 2

The most noticeable feature of this memo is how vital it is for newly bereaved parents to have a group leader that they can connect with as it facilitates the parent to seek peer support. I felt that from the semi-structured interview and the way the participants interacted with each other that there was a strong sense of community and trust between these three bereaved mothers. They appeared to share a mutual understanding of what it felt to suffer a private loss. Ruby had succeeded at creating a SANDS community that was inclusive of their shared Asian culture. She saw the need to form a new bereaved parent support charity which encompasses a peer support group that serves as a space for bereaved parents to acknowledge both the loss of a child whilst acknowledging that their culture which has a different approach to the dominant white British culture in terms of baby loss. Ruby is the nexus of this newly developed group, and I perceived her strong bond with the other mothers as an asset for the growth of their new charity.

7.8.2 Initial codes

The table below signifies noteworthy data that surfaced during the line-by-line coding for cycle two. There were many overlapping codes in the data which signals that there is a consensus of what research participants regard as facilitating factors and challenging barriers to how bereaved parents access baby loss peer support. Noticing the overlapping initial codes prepared the focused coding. Similar to cycle one, I tried to produce as many Gerund codes as I could as this enables the researcher to identify action and sequence (Glaser, 1978; Charmaz, 2006) which over time generates the developing grounded theory.

Table 10: Prominent initial codes in cycle two

Interview Participant	Prominent Initial Codes
Group Interview	Attending group; Finding reasons not to attend; Dads participating in groups; Participating in parent leadership; Representing BAME parents; Seeking out support; Interacting online with other bereaved parents
Nicole	Supporting Mothers; Participating in leadership position; Wanting to find faith-based support; Seeing health inequalities
Sandra & Vern	Volunteering; Attending bereavement counselling; community misplacing support for family versus culture; Mourning; Breaking silence around baby loss
Abigail	Returning to work after loss; Experiencing traumatic birth; Breaking silence around baby loss; Supporting other people through loss; Seeking out help through work; Searching for charity support
Carrie	Dads participating; Leading group; Finding SANDS; Improving charity support for bereaved parents, noticing health inequalities; Building awareness of baby loss
Amelia	Seeking help at work; Supporting other parents through loss; Mourning; Seeing baby after it died; Community misplacing support; Participating in leadership position; Seeking out charity; Noticing language barriers

7.8.3 Focused coding

Once initial coding had been completed, I moved to focused coding as I had in cycle one. During this phase, it became easier to search the data to identify the codes I could apply directly to answer the research questions. With the three participants in the group semi-structured interview, there was a total of nine participants in cycle two. The larger number of responses made focus coding a straightforward process. I could compare the participants' experiences against each other and to responses from cycle one.

7.8.4 Comparing data from cycles one and two

Initially, I found it difficult to determine how a theory was going to develop from the first cycle of semi-structured interviews as there were only three participants who made up that cycle. The additional participants' experiences in cycle two enabled me to compare the similarities and differences of each parent's bereavement support journey. Participants from cycle one were from Kent whereas the majority of participants in cycle two (eight out of nine) were from Leicestershire. One mother was from Sussex. Despite the geographic distance, most of the bereaved parents' experiences in seeking support shared more similarities than dissimilarities.

In the data analysis a general narrative developed; parents felt the need for empathetic bereavement support from others who understood their loss, and more often than not the recently bereaved parents did not receive this support from their immediate family and friends. There was a hesitancy to contact a charity for support, but some participants chose to attend with the encouragement of the group leader. Only one participant (Iris) from cycle one attended a group that was facilitated in a hospital setting. All the other parents that participated in cycle one and cycle two had attended charity led groups or had volunteered for baby loss charities.

There was one father per cycle who participated in an interview with his wife. Despite being from different ethnic and cultural communities, the role of the father was similar and included supporting the mother in her loss before addressing their own grief. Each father shared that they did not feel that their experience of baby loss was as detrimental to their wellbeing as it was to their wives. Interestingly, no father felt that their experience of grief and bereavement was acknowledged by their communities. It was evident that these men shared a similar experience of hiding the personal impact of losing their baby so that they could focus on supporting their wives, which meant that they did not feel they could admit that they too had suffered a great loss.

7.9 Cycle three

7.9.1 Participants in cycle three

The final cycle of participants was held strictly online. All four semi-structured interviews took place during October through November 2020, just when national restrictions were reintroduced in England. The national restrictions made carrying out in-person interviews more difficult than it was prior to the reintroduction of the restrictions. Each participant in cycle three lived far away from me. I didn't want to travel and risk catching the virus. This meant that all participants in cycle three participated in online interviews. Like participants in cycle two, there was an issue finding an online platform that participants wanted to use versus what the current policy was at university. Two semi-structured interviews were held via Zoom; two were conducted on Whatsapp video call; and one was completed on Facebook Messenger video call. Comparable to Zoom, Whatsapp has built in end-to-end encryption making it a secure platform. Facebook Messenger has the option to set the preferences for end-to-end encryption. The participant who chose to use Facebook Messenger for the online interview platform selected it because it was the main platform she used to communicate with her friends, family, and the other parents in her private Facebook support group for stillbirth bereaved parents. She felt it was a secure option over using other platforms. Three mothers self-identified as Asian whereas one mother self-identified as Black British. The father participating in this cycle self-identified as Black British.

Table 11: Demographic of participants in cycle three

Pseudonym	Ethnicity	Region	Type of Peer Support Group	Current Attendance
Sheila	Asian	Warwickshire	Luca's angels	Active
Daphne	Asian	Leicestershire	SANDS	Active
Dominic	Black	Greater London	SANDS; Dope Black Dads	Active
Maya	Black	Yorkshire	SANDS; social media	Active online

Written memos during cycle three

Below is a memo I wrote whilst conducting the third cycle of research.

Upon finishing the last interview, I am struck by how many parents in cycle three develop an active role (other than attending a group; actively contributing to a cause) after the loss of their child. Daphne is contributing to the new Leicestershire charity ran by Ruby. She is using her background in law to contribute to her work as a new trustee. Dominic is leading a bereaved father's group. Sheila has started a charity and has also published a book about her experience.

I keep asking: what is the drive to do more? I have noticed that throughout the experience there has been a tendency for most of the parents to mention how they want to help other bereaved parents, rather than being involved in the charity as a way of remembering their children. I might have misunderstood the concept of meaning-making. What if 'meaning making' is to prevent the same kind of pain (isolation, loneliness, guilt, depression, anger) of a newly bereaved parent, so their grief journey is gentler and better supported than their own journey of loss?

The resources that are made accessible from the participants' efforts will be well received. I am impressed by each parent's wish to nurture others who are grieving. It takes someone who is familiar with baby loss to provide the right type of bereavement support. Conducting these semi-structured interviews has increased my awareness of the meaningful care that can provided to support newly bereaved parents. This has made me reflect on the word 'transformation' and how I am using the transformational paradigm and witnessing the word in action. Despite the deep pain each parent has experienced, there is a constant flow of hope that their efforts will support others.

Figure 55: Memo written during cycle three

7.9.2 Initial coding

The same process of initial coding was applied to the semi-structured interviews in cycle three. In this cycle there were two parents (Sheila and Dominic) who had created or co-created a charity to support newly bereaved parents who had also experienced baby loss. This cycle of semi-structured interviews was held during wave two of the Covid-19 pandemic where all forms of peer support moved to online channels. Interestingly, Maya was the only parent in the data set to access baby loss peer support from an online support group prior to the pandemic. She had prior knowledge on virtual peer support compared to the parents who had never accessed online baby loss support. The other fifteen participants accessed in-person peer support groups which meant they had to learn how to access online support groups. Maya did not experience the same discomfort as the other parents in navigating the move from in-person to digital support. The table below depicts a sample of codes that from each participant's semi-structured interview.

Table 12: Prominent initial codes in cycle three

Interview Participant	Prominent Initial Codes
Sheila	Creating new charity to honour child; Mourning; Fundraising for charity; Remembering baby; Experiencing mental health issues after loss; Leading new charity
Daphne	Attending group; Bereavement midwife supporting parents; Hiding and not speaking out about loss; Dads connecting with dads about baby loss; Comparing counselling to attending group; Dads attending group; Feeling supported by family
Dominic	Dads connecting with other dads; Grieving like the British; Needing more faith-based support; Recognising health inequalities; Taking part in research to change policies; Comparing other causes to baby loss; Making tangible changes to improve accessibility
Maya	Using social media to connect to parents; Facebook support groups; Supporting other people; Returning to work after loss; Feeling loss on marriage and family unit; Experiencing traumatic birth; Recognising stillbirth is a different type of loss

7.9.3 Focused coding

Over the course of collecting the data, I had become more comfortable applying Charmaz's 2006 approach to constructivist grounded theory. Comparable to cycle one and cycle two, there was plenty of rich data I had to analyse to determine which data I could apply to generate a theory (Charmaz, 2006). There was a consistent trend for parents to want to share more of their experience of losing the baby and their personal journey learning to live with grief. I began each semi-structured interview by telling each participant they did not have to share the birth story of their child, and yet each parent discussed how they came to learn the baby had died and what the birthing experience was like. In addition, there was a need to for me to separate what was considered grief, bereavement, and mourning. Because this is a research study on bereavement support, I had to filter out what I considered to be the act of grieving from the act of mourning which will be discussed later in the discussion chapter.

7.10 Theoretical sampling and saturation

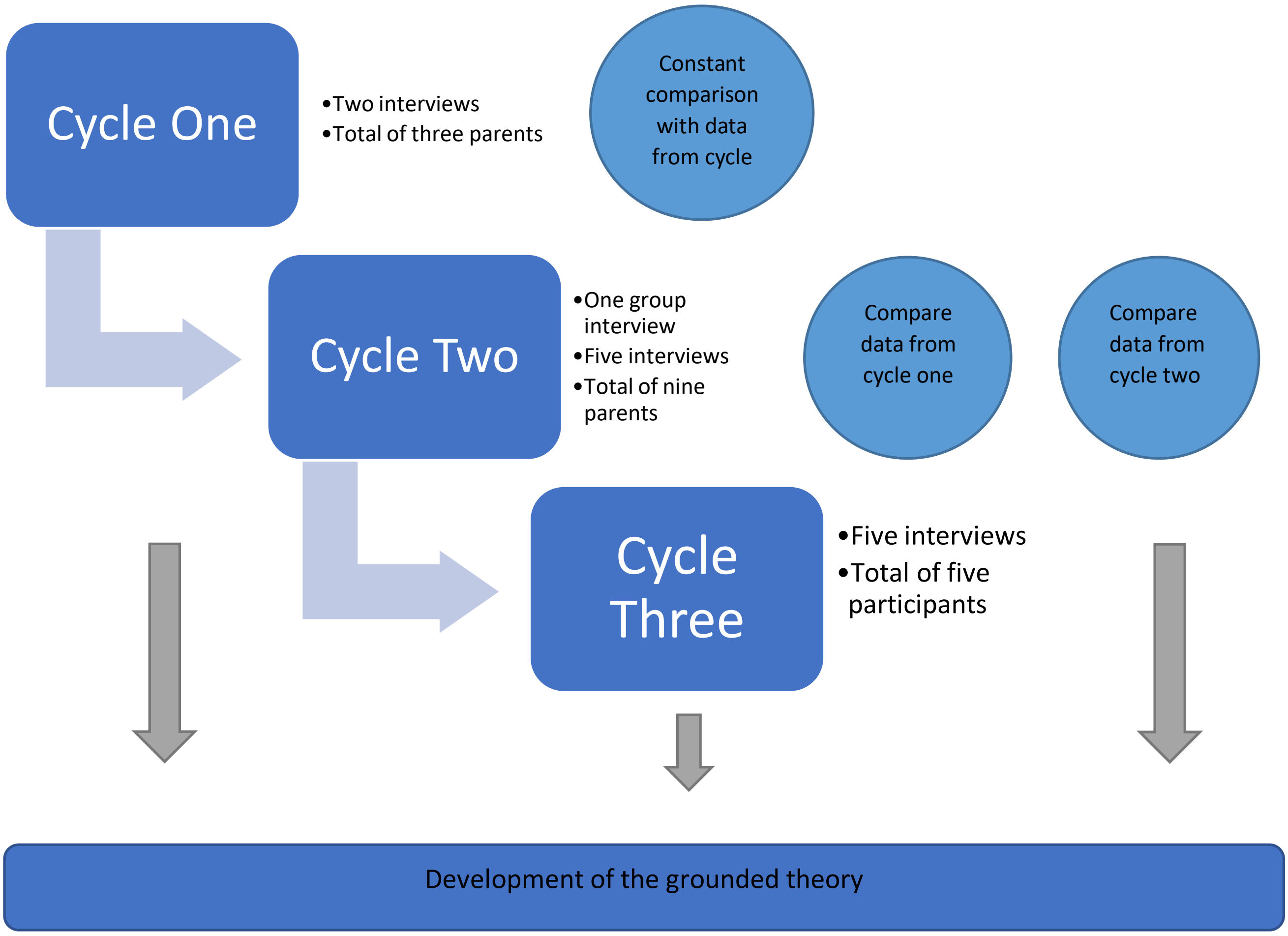
Different from initial sampling, theoretical sampling is the process of seeking relevant data to refine the categories that have developed in order to advance the emerging theory (Charmaz, 2006). Researchers gather and continue to organise the data until no new categories emerge (Charmaz, 2006). This means that the categories are saturated; there is no new data that are being collected (Charmaz, 2006). Unlike other sampling techniques, theoretical sampling relates strictly to developing a theory about the immediate population; it is not meant to be representative of a population (Charmaz, 2006).

I found it challenging to know when I should stop gathering data. I could see the categories that were consistent throughout the data collection, and yet I felt that I wanted to interview more participants to determine whether there was any variation. I stopped collecting data at the end of November 2020. Wave two of the pandemic severely impacted my recruitment strategies by limiting the contact I had with my community partners; wave two also prevented me from building new partnerships with different organisations from which I could recruit. I had organisations say that although they were interested in supporting my research, staff were too stretched to help me recruit participants.

I conducted initial and focused coding throughout the duration of my data collection which took place over three cycles of the semi-structured interviews. Through the coding exercises, I was able to see categories that were developing from the data. I took time to reflect and asked questions such as 'What does this category mean in terms of answering my research questions?' and 'How does this category compare to the other categories?'. Implementing theoretical sampling in this study meant that I was consciously delineating how the data fit into the emerging categories. Charmaz (2014) writes that researchers often misinterpret when they have reached theoretical saturation. Theoretical saturation is different than observing the same pattern being repeated within the data (Charmaz, 2014). Instead, it is recognising the generated categories are robust enough to explain the patterns within the data and there are no new properties found within the categories (Glaser, 1978; Holton, 2007; Charmaz, 2014).

7.11 Conclusion

This chapter explored my rationale for using Charmaz's (2006; 2014) constructivist grounded theory approach to examine how bereaved parents access baby loss bereavement support. In this chapter I outlined how I recruited and gathered my data through eleven semi-structured interviews and one group semi-structured interview. The methods used to analyse the data have also been described. Chapter 5 is the second methodology chapter and aims to improve the quality of this study by demonstrating the process of how I came to my findings. In addition, it demonstrates that I have understood the practise of generating a grounded theory to explain this phenomenon. I created the figure below to explain the process of creating a grounded theory, following Charmaz's (2006, 2014) guidance in a visual format to further explain my work. The theory I developed will be discussed in chapter 7.



8 Discussion: Road to hope through grief theory

8.1 Introduction to the chapter

The aim of this doctoral research project was to explore stillbirth bereaved minority ethnic parents' experiences of finding and accessing baby loss bereavement support through peer support programmes and befriending services in England. The research in this thesis aimed to fill the existing knowledge gap within the perinatal mental health subject area, baby loss support services, and grief and bereavement field by exploring the experiences of stillbirth bereaved minority ethnic parents accessing baby loss support. I applied collage-making to explore how visual data can be implemented within these fields of study (Letherby & Davidson, 2015; Grant et al., 2020) and how the combination of visual and verbal data produces enriched findings (Pauwels, 2011; Spencer, 2011; Letherby & Davison, 2015) with the intention of making an impact within maternity services and baby loss charities. To my knowledge this is the first study that has exclusively investigated the experiences of minority ethnic bereaved parents' accessing baby loss peer support programmes.

In this chapter, I first present the 'Road to hope through grief' (RTHTG) theory I developed from the semi-structured interview data using Charmaz's constructivist grounded theory (2014). Secondly, I summarise and discuss merging the theory with the findings from the collage activity. I then situate the findings of this study in the wider context of current literature.

8.2 Description of my philosophical framework

For over a decade, there have been discussions about the role of theoretical frameworks in mixed methods research (Molina-Azorin & Fetters, 2020). Whilst TP (Transformative Paradigm) is the theoretical framework that I have applied to this research project, I consider my identity as a researcher to be rooted in pragmatist feminism (Whipps & Lake, 2004) which I have mentioned throughout this thesis. I interpret this philosophical viewpoint as means to bring together both pragmatism and feminism's central concepts (Whipps & Lake, 2004). Emerging in the 1990s, this field of philosophy brings together pragmatism's hallmarks of lived experience and pluralism and feminist theory which calls for social change (Whipps & Lake, 2004). Pragmatism's flexibility enables researchers to decide which methods will yield the best results instead of dictating what methods should be used based off of philosophical framework's ontology. (Biddle & Schafft, 2015.) Emphasis is placed on how the chosen research methods generate new interpretation of the phenomenon being studied based on the researcher's interactions with the world (Johnson & Onwuegbuzie, 2004). Combine with feminism, pragmatist feminism is an action-orientated research philosophy (Whipps & Lake, 2004).

I'm drawn to how both TP and pragmatist feminism advocate for action orientated social change (Whipps & Lake, 2004; Morgan, 2014) and the similar emphasis TP and pragmatist feminism place on axiology. TP and pragmatist feminism are both concerned with the axiology of the researcher (Mertens, 2010; Biddle & Schafft, 2015). Mertens' (2007) work argues TP is mainly concerned about the axiology instead of placing emphasis on ontology and epistemology (the axiological position of TP was discussed in chapter two). Mertens continues later on in her work to advocate for research to produce research findings which are used to advance social justice issues (Mertens, 2010). The axiological ethics of TP centre around respecting the lives of the research participants and their experiences, promoting social justice within research, and being mindful about power and privilege disparities (Mertens, 2007,2009, 2010; Biddle & Schafft, 2015) and sees how it aligns with pragmatist feminism. For example, I'm drawn to the work of pragmatist feminist, Nancy McHugh (2015, p. 7), who writes: 'the methodologies of sciences frequently fail those who can least afford to be failed: women in all situations, poor of all colours, people of the two-thirds world, the socially, politically and geographically marginalised and disenfranchise'. It's clear to see from this one quote how easily research can fail to respect those who participate in studies. McHugh's (2015) work calls for pragmatist feminist researchers to engage with communities who are impacted by the results to seek out underrepresented knowledge and marginalised views which reflects Mertens' (2007. 2009) construction of transformative paradigm. With the increased coverage of maternal health disparities in the UK (Esegbona-Adeigbe, 2021), there is a pressing need for research to be change-oriented.

Being a pragmatic feminist means that I used an interpretive approach as a theoretical starting point because this theoretical perspective emphasises 'practices and actions' (Charmaz, 2014, p.231). Furthermore, pragmatism is a central theoretical feature of constructivist grounded theory (Plummer & Young, 2010). Interpretive theories complement my theoretical paradigm as a pragmatist feminist researcher working within the transformative paradigm and implementing facet methodology. Both feminist research and facet methodology (Mason, 2011) call for research to be multi-dimensional (Harding, 2020). Feminist researchers may work in a variety of theoretical frameworks and work across the boundaries of disciplines to advance social justice issues (Hesse-Biber, 2010). To do this, feminist researchers use traditional methods and create new methods to include more voices of underrepresented communities (Hesse-Biber & Leavy, 2006). Facet methodology (Mason, 2011) permits researchers to use their own insight which is a central to feminist theory. Furthermore, facet methodology advocates for new forms of knowledge production which can be produced from a feminist research paradigm (Hahna, 2013). Researchers using facet methodology build a more complete picture of the phenomenon because there is an emphasis to explore layered context of the phenomenon (Muir, 2022). Through the implementation of facet methodology, I combined pragmatist feminist principles with traditional and creative methods to create the road to hope through grief theory.

Although facet methodology is in its infancy, it's promising to see publications on the methodology growing. Mason's facet methodology (2011) has been applied to feminist philosophical studies (Muir, 2022; Lewis et al., 2015). Parikh's (2020) study on reflexive feminist methodology uses drawing as a creative method to explore her position of an insider-outsider in the research process. Whilst she doesn't prescribe her views as a facet methodologist, Parikh's (2020) work meets the criteria set out by Mason (2011). Additionally, creative methods can be a powerful tool within feminist research (Harding, 2020) and can be seen in the work of Harding (2020) who explores a participatory action research project using creative methods exploring the lives of criminalised women. Although none of these studies are related to grief and bereavement, it's essential to highlight the work by feminist researchers who are carrying out work which is equally complex as this thesis.

8.3 Diagramming the research process

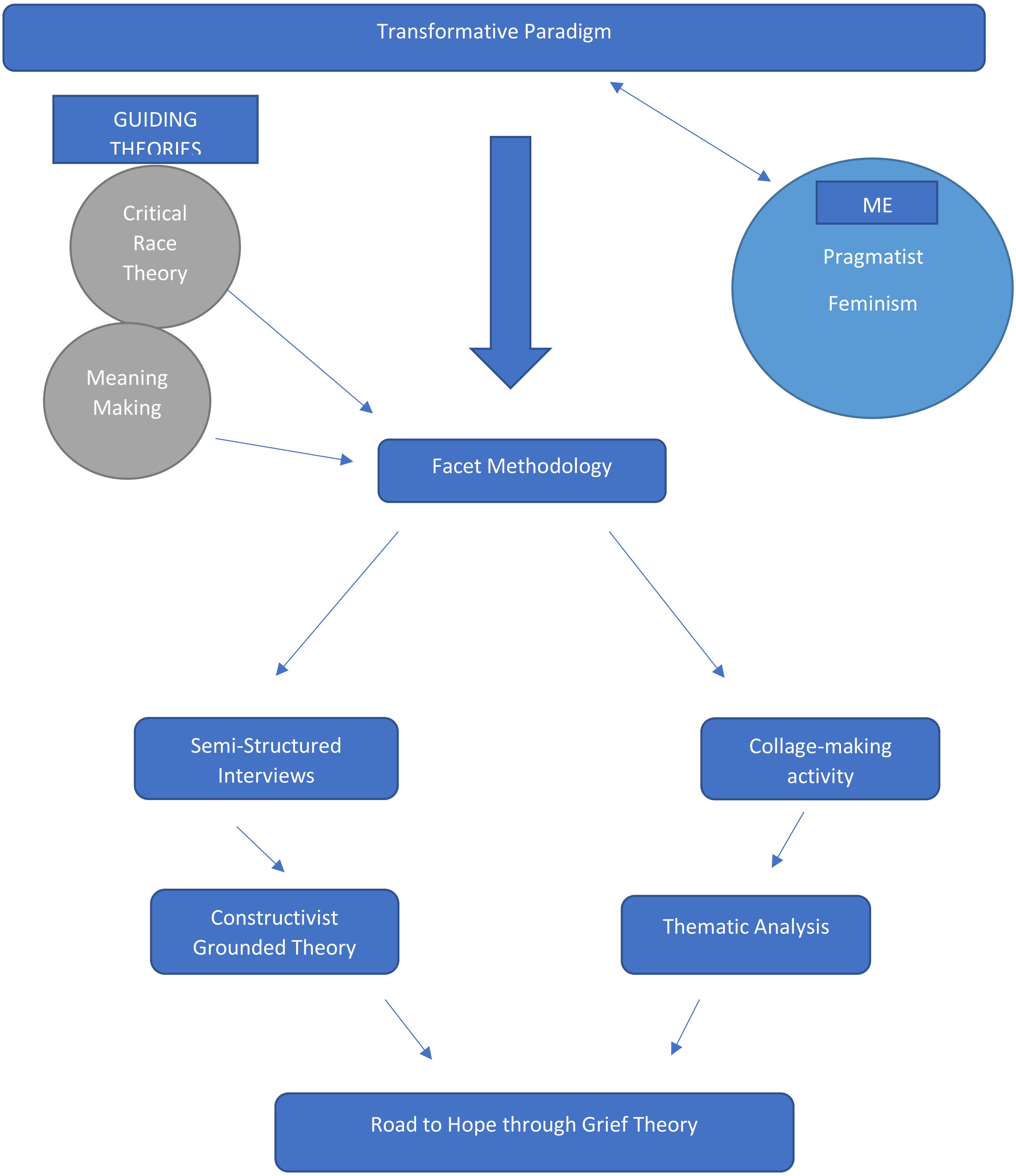
The use of diagrams in grounded theory is a central component in grounded theory (Buckley & Waring,2013). Charmaz (2006) reasons that diagrams are useful for grounded theorists to explain their strategy to explain the how the theory is developed from their analysis of the data. Furthermore, diagrams help explain the narrative of the theory (Buckley & Waring, 2013). Below is a conceptual diagram which outlines my philosophical perspective and the process through which the research is conducted and analysed to develop the road to hope through grief theory.

At the top of the diagram is a box with titled 'transformative paradigm' which represents this study's ontological and epistemological framework. I have included a lighter blue circle which represents 'pragmatist feminism', my personal understanding of knowledge and therefore my identity as a researcher. Between 'transformative paradigm' and 'pragmatist feminism' is a double-headed arrow to symbolise the collaborative relationship between the two positions; it is not one directional.

To the viewer's left are two smaller grey circles which represent the guiding theories of this study. Whilst 'critical race theory' (Ford & Airhihenbuwa, 2010) and 'meaning making' (Neimeyer, 2009) are not the main underpinnings of this project, I see these theories as being facets within facet methodology that must be considered to better understand the complexity of minority ethnic bereaved parents seeking out baby loss bereavement support. Although critical race theory and meaning making are supplemental theories, it is important to include them within the figure because they influenced the way I viewed the facets being studied and how I designed the semi-structured interview schedule and carried out the collage elicitation exercise.

A thick blue arrow leads to a box called 'facet methodology'. From facet methodology, there are two tracks which represent the two methods I implemented in this study. The first (left) is titled 'semi-structured interviews' under the guidance of Charmaz's (2006) constructivist grounded theory. The second method track (right) is the blue box titled ‘collage-making activity’ which was the supplemental component of this mixed method research project. A box titled ‘Thematic analysis’ denotes how the data is analysed under Braun and Clarke’s (2006) work. The results from both methods have influenced the Road to Hope through Grief theory.

Figure 56: Diagram of the research process



8.4 **Developing a grounded theory**

Thornberg and Charmaz (2012, p.41) define a social research theory as 'a theory states relationships between abstract concepts and may aim for either explanation or understanding' (cited in Charmaz, 2014, pp 228). In chapter two, I discussed my theoretical framework and explored the transformative paradigm. In chapter four, I explained how I interpreted TP (Mertens, 2007), how it supports Morse's (2009) work on qualitative mixed methods research, and how TP is an appropriate framework to apply to this study in relation to how it aligns with Charmaz's (2006) constructivist grounded theory. Additionally, I have included critical race theory (Ford & Airhihenbuwa, 2010) in public health and meaning making (Neimeyer, 2009) from constructivist psychotherapy as guiding theories for my research. I argue that including these supplemental theories are necessary to include within this study considering how relevant they are to the research topic.

Grounded theorists create theories to answer how, what, and why a phenomenon happens (Charmaz, 2014). Charmaz (2014) says that the 'why?' sets grounded theorists apart from other researchers who only look for the 'what?' and 'how?'. Charmaz (2014) states that interpretive grounded theories require the researcher to use her imagination to understand the phenomenon that is studied. It seeks to understand the phenomenon in the abstract rather than in concrete terms because the 'truth' is a combination of facts and values (Charmaz, 2014). The interpretive framework uses multiple realities to experience the phenomenon (Charmaz, 2014). I appreciate Charmaz's (2014) constructivist approach to grounded theory because it complements facet methodology (Mason, 2011) in that there are multiple perspectives of a phenomenon. Both Mason's work (2011) and Charmaz's constructivist view of grounded theory calls on the researcher to be consciously creative, meaning researchers must be aware of how they are developing their theory (Charmaz, 2014; Gibbs, 2013), which aligns with the use of implementing creative methods (Brooks, Lainio & Lažetić, 2019). Furthermore, Mason's facet methodology and Charmaz's constructivist grounded theory aim to "to understand and theorise how the lived world connects and relationally implicates the things we think constitute it" (Mason, 2011, pp. 79).

Charmaz (2014, p.216) writes that although all researchers who use qualitative methods organise and process their data to make sense of their findings, grounded theory researchers use the same strategies to develop 'the *theoretical* development of their analysis'. Charmaz states that there are three steps that should be undertaken when finding a theory: sort, compare, and integrate memos that were written during data collection (Charmaz 2014). I began to develop the theory from the written memos I kept when collecting data between February 2020 and November 2020. I theoretically sorted the data

(Charmaz, 2014), compared, and combined the categories I generated to establish theoretical links within the data. As part of the process of developing a grounded theory, I continually compared the transcripts from the semi-structured interviews against each other, and against the written memos I had written during the data collection process (Charmaz, 2014).

Taking a constructivist grounded theory approach, I tried to remain mindful of how reflexivity was incorporated within the development of the RTHTG theory. As a result, I tried to be aware of how my experience of grief and bereavement could lead to me make assumptions about the data (Charmaz, 2014). As a person who has lost several family members within a relatively short time span, I view my grief as a journey and is a common metaphor for grief within the literature (Wolfelt, 2003; Terry, 2012; Doka, 2017). Despite my own experience of grief and loss, the RTHTG narrative was distinct from my story in that they did not have the opportunity to live out a future with the child they anticipated whereas I had known my deceased loved ones since I was born. Losing a baby goes against the natural order of the world where a parent should not have to bury their child (Kofod & Brinkmann, 2017).

A theory grew from the integration of the principal findings that were discussed in the interview results chapter to determine the larger story that emerged from the data (Gibbs, 2013). Additionally, I used the generated themes from the visual data to affirm the different stages of the RTHTG theory. It was critical to take time to reflect upon the relationships between the findings so that the theory could develop (Gibbs, 2013). The generated theory is only one interpretation of the phenomenon (Bryant & Charmaz, 2007), and because an interpretive outlook recognises that there are multiple realities, there may be other theories available which also explain how minority ethnic parents access baby loss bereavement support (Field, Hockey & Small, 1997; Whitaker, Kavanaugh & Klima, 2010). Moreover, only eight out of sixteen participants created collages, which limits the extent to which visual data can confirm the stages of the theory. However, compared to other qualitative methods, Gibbs argues that Charmaz's (2014) constructivist grounded theory is not overly concerned with the theoretical accuracy as it is concerned with theoretical plausibility (Gibbs, 2013). She says often what people consider to be a theory stems from positivism, which argues that a grounded theory is a predictive explanation of why a phenomenon occurs (Gibbs, 2013). For Charmaz (2015), a theory may be a theoretical understanding of abstract concepts combined which see the connections between the variables to offer a multi-faceted understanding of the world rather than a concrete explanation of how a system function.

8.5 Introduction to the road to hope through grief theory

In the previous sections, I introduced my philosophical framework and diagrammed the conceptual process through which the RTHTG theory was created. This section explains the six stages of the theory which seeks to illustrate how minority ethnic bereaved parents access baby loss peer support groups. Within the introduction, I include a diagram to display the theory's trajectory.

I have entitled this theory "*road to hope through grief"* because there has long been a connotation that grieving is a journey (Terry, 2012; Doka, 2016; Wolfelt, 2016). I used the title of the theory as an analogy of a *road* for participants to travel on to reach hope. Even in the visual data, there were images of roads and paths which participants selected to represent grieving as a journey. The RTHTG theory explores the experiences of sixteen bereaved parents in England who sought out baby loss peer support programmes. It connects the most frequent and profound findings together to suggest how minority ethnic bereaved parents access perinatal loss bereavement support. The complex nature of this research project has produced rich data, however; only data from the semi-structured interviews and the collages which directly address the research question are included in generation of the grounded theory. I included quotes from the interviews to demonstrate the participants' experiences of seeking bereavement support. it is important to acknowledge that within this study's population, there were diverse answers corresponding to each family's process of coping with their losses and how they grieved the loss of their children.

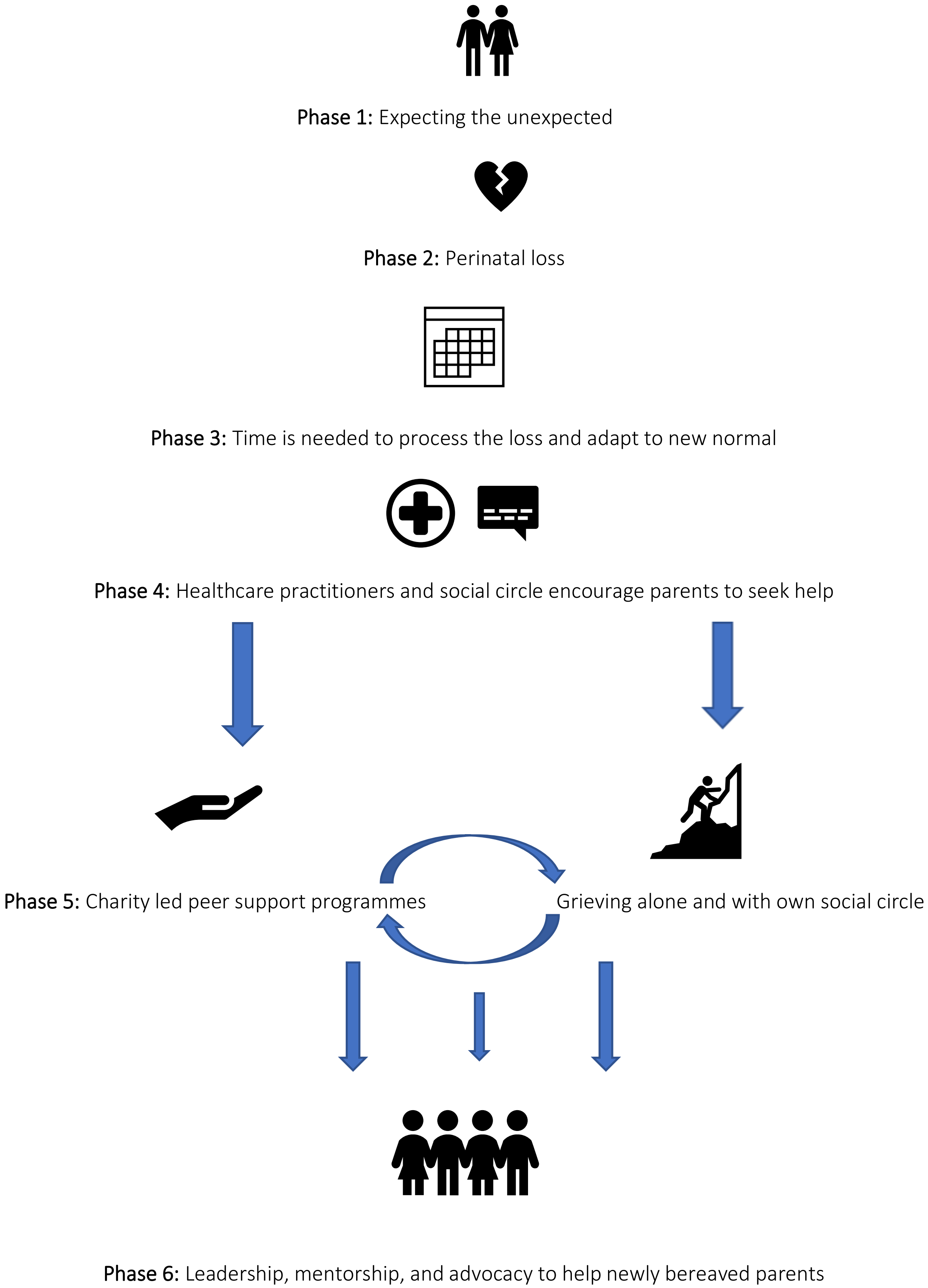
This thesis' primary research question asked, how do minority ethnic parents access baby loss bereavement peer support programmes? Beyond this specific question, the research aims were to explore minority ethnic parents' experiences accessing support and what other ceremonies and rituals charities could offer to make it more culturally appropriate for minority ethnic parents. Additionally, this thesis sought to examine how participating in a leadership position within peer support groups has affected their perspective on baby loss. The RTHTG theory is grounded in the data and helps explain the process through which minority ethnic bereaved parents access baby loss peer support programmes (Chun, Birks, & Francis, 2019).

The eight collages were visual portrayals of some of the bereaved mothers' experiences attending peer support groups and how these support programmes impacted their grief journeys. The collages improved this doctoral study by fostering non-linguistic representations (Gerstenblatt, 2013) to communicate a depth of lived experience that may not have been captured through verbal data collection. Through the constant comparison of both the semi-structured interviews and the collage elicitation exercise (Chun, Birks, & Francis, 2019). I noticed how patterns developed from both research methods. Some of the visual data directly corresponded to what was discussed in the interviews; other visual data were not applicable to the RTHTG theory, so I excluded them from the theory generation.

Both verbal and visual data reiterated that grieving the loss of a child was like a journey that they had to get *through* rather than get *over*. Whilst their loss never fully left them, parents described how they began to adjust to their ‘new normal’ lives through the help of peer support programmes. Parents found *hope* from their interactions with other bereaved parents. As time passed, participants found they needed less support from peer support groups and were prepared to ‘re-enter’ their social circles as bereaved parents. Participants stated that they maintained the connections they had built with the programme facilitators in case they needed to return for further support from their peers when their grief intensified. Whilst the grief journey never concludes, participants found that they wanted to use their experiences of baby loss to help other newly bereaved parents. Parents reported engaging in leadership roles with baby loss charities, creating their own charities and participating in research and advocacy opportunities.

Considering the complex nature of this project, it is understandable there would be a variety of data outside the scope of the research question and the aims of the research project. I intend to publish articles on the supplemental data that I could not include in this thesis.

Figure 57: Diagram of the road to hope through grief theory



Phase 1: Expecting the unexpected

Phase 2: Perinatal loss

Phase 3: Time is needed to process the loss and adapt to new normal

Phase 4: Healthcare practitioners and social circle encourage parents to seek help

Phase 5: Charity led peer support programmes

Grieving alone and with own social circle

Phase 6: Leadership, mentorship, and advocacy to help newly bereaved parents

Phases of the theory

8.5.1 Phase one: Expecting the unexpected

The first phase sets the context of the theory. As stated in the semi-structured interview results chapter (chapter seven), none of the bereaved parents anticipated losing a baby during pregnancy. The key finding in this category emphasizes that the participants did not anticipate that they would lose the pregnancy. Additionally, they were ill-informed that miscarriage and stillbirth existed. Some participant mothers shared that they were unaware that stillbirth could happen in the twenty-first century. This may occur due to the stigma that is associated with pregnancy loss (Bellhouse, Temple-Smith & Bilardi, 2018). Advancements in reproductive assistance and medical technology mean that there is a wider public perception that babies are no longer at risk of dying in utero (Robinson, Baker and Nackerud, 2010; Pollock et al., 2021). Participants reported that they had looked forward to welcoming their child and to building new lives as parents. Parents had formed attachments with the babies during pregnancy (Robinson, Baker, and Nackerud, 2010).

"I was planning for the baby. I said, after Arthur's dad's funeral now I can start focusing on the baby and start doing baby shopping and so felt like 'okay, I knew baby was coming in July' […]" – Jade, Kent, SANDS

In Jade and Arthur's interview, they revealed that Arthur's father died whilst Jade was pregnant. The pregnancy gave the couple something to look forward to whilst they were grieving the loss of Arthur's father. It was shortly after the death of the father that they lost the baby. Two profound losses in a short span of time made their experience of grief particularly difficult to process.

"I, erm, went to work, just went for my scan and then from there suddenly, I didn't go back to work, I just stopped doing everything normally that I would do in a matter of a moment." - Abigail

Some parents reported feeling like time had stopped for them when they learned the baby was in a critical state. Abigail went to a routine appointment to learn the baby was not healthy and learned that the baby was unlikely to survive. There was no time for her to prepare herself or her family. In one appointment, she had to adjust to an unexpected outcome.

8.5.2 Phase two: Perinatal loss

The death of a baby was an unexpected loss for all the participants, which redirected the plans they had made and the future for which they had hoped (McGoldrick and Walsh, 2013). There were no more positive signs of pregnancy such as the growth of the baby and the enlarging uterus. The need for a nursery and the purchase of baby items had gone. All sixteen participants endured profound grief and suffering from their pregnancy loss. Losing a pregnancy at any gestation is devastating (Helps et al., 2020). Perinatal losses should be recognised as being as significant as the death of children who have been with parents for a longer period (Robinson, Baker and Nackerud, 2010). Learning that the baby had died distressed all the bereaved parents. Within the literature, parents often feel that time is distorted when they learn that the pregnancy is no longer viable (Lang et al., 2011). Like Abigail's experience of learning her baby was not healthy, several other participant mothers reported going to their scheduled appointments to find that their babies had already died. The bereaved parents' experiences of learning their baby had died is where the road to hope through grief (RTHTG) theory continues.

"I was in the hospital by myself, just getting a regular check-up and I was told that the baby had died." – Sandra, Greater London, Aching Arms

"All I did see was like a still skeleton on the screen. No heartbeat. Absolutely shocking for me, and he said, so his description was 'oh, this one is not doing so well'. That was it. Nobody told me your baby died you will have to give a birth." – Iris, Kent, SANDS and PALS

"I was in hospital for a good two weeks last after that happened and you know like when I would be going down for, for different appointments, you know, they had to wheel you down and you're, you're passing and you're seeing other, you're seeing balloons in rooms, oh baby boy! Baby girl! Babies crying and it was just like oh my god, this is like a nightmare."- Nicole, Leicestershire, SANDS

Perinatal loss can elicit negative psychological effects on families (Bakhabkhi et al., 2017). The manner through which parents learn their baby has died can negatively impact parents (Flenady et al., 2014). Within the literature, it has been documented that bereaved families want compassionate and empathetic care from healthcare practitioners (O'Connell et al., 2016; Downe et al., 2013; Helps et al, 2020). Maternity services staff must be trained to deliver sensitive bereavement care to bereaved families (Help et al., 2020). Quotes in this section highlight that it is critical for parents to be treated with dignity and respect when hospital staff share the news of the death of the baby (Anderson, 2019). Staff must be appropriately trained and possess sympathetic communication skills to work with bereaved families (Brann, Bute, and Scott, 2020). This phase of the RHTG theory aligns with research in the field that recommends pregnant women and families should be fully informed and included in any decision-making processes related to their care (Sheather, 2011; Helps et al., 2020). Moreover, families suffering from perinatal loss should be given the opportunity to provide feedback on the clinical care provided to them (Bakhbakhi et al., 2017). Whilst many maternity services within NHS trusts encourage debriefing and feedback from families following perinatal loss (Logan, 2021), it is important to acknowledge that interest in bereavement support training is low due to staff scheduling issues and insufficient funding for healthcare practitioners to attend training (Abrhamson, 2019). When there are competing demands on the NHS, bereavement support training is less of a priority (Abrhamson, 2019).

Some of the experiences described by the participants were disturbing and appeared to demonstrate sub-standard care. This may be related to different NHS Trusts practices of care across the country with some NHS Trusts providing care which is more compassionate and caring than others (NHS, 2020). National reports such as the Ockenden report (2020) (a report on Shrewsbury and Telford maternity hospital) insinuate that there are still major failings within maternity services. One key finding of the Ockeneden (2020) report is that parents' input and complaints go unheard. Within the report, Ockenden (2020) recommends the creation of a senior advocate role within maternity services which works independently with families and reports to the Trust at a board level.

Contrary to the quotes reported here, not all participants in this study reported having negative interactions with healthcare staff.

"I think the hospital got it, processes right at least the bereavement part of it, for sure, starting with the physical location. So, she wheeled me away from other mothers given babies to a separate area where I couldn't hear the babies of other mothers." -Sandra, Greater London, Aching Arms

Since 2016, there has been a Maternity Transformation Programme put into place to deliver "safer and more personalised care across England and deliver the national ambition to halve the rates of stillbirths, neonatal mortality, maternal mortality and brain injury by 2025", (NHS, 2020, p. 4). In the *Better Births Four Years On* publication (2020), a survey of 17,000 women found that over 80% of women felt they received appropriate support during labour from their healthcare providers. There has yet to be an update from the *Better Births* (2020) project on how COVID-19 has impacted how families perceived the care they received in maternity units. The *Better Births* (2016, 2020) project is an important piece of research as it strives to build partnerships with organisations across the UK to improve maternity services outcomes. One of the organisations working on the Better Births (2020) project is SANDS which highlights their role in advocacy for families who experience baby loss. Improvements made by evidence-based research may help protect families from experiencing baby loss like the participants of this study. As evidenced in the semi-structured interview chapter, bereaved parents wanted to prevent other families from experiencing baby loss by participating in research.

8.5.3 Phase three: Adjusting to a new normal

When parents returned home from the birth, they felt as if their lives had been disarranged. They didn't anticipate not bringing home a baby; instead, they came home with empty arms. Parents had to take time to adjust to the physical, mental, and social changes that occurred immediately after perinatal loss (Cacciatore, Schnelby and Froen, 2009; McGuinness, Coughlan, and Power, 2014). They have not only lost their baby, but they have also lost a future for which they had been planning (Bennet et al., 2005; Westby et al., 2021). Like the theme of isolation that emerged in the visual data, participants verbally discussed how they chose to isolate themselves away from their communities. Feelings of isolation increased for participant mothers (n=3) who experienced a traumatic birth. Whilst exploring the participants' mental health was outside the scope of this project, it is worth noting that stillbirth is associated with PTSD in parents (Westby et al., 2021). It took time for bereaved participant mothers to heal physically which impacted their well-being. The topic of traumatic birth will be explored later in this chapter.

"In 2015 I did lose my little boy and, erm, following the horrific birth and everything else you have to go through, my problem was that I didn't really talk about what had happened."- Amelia, Leicestershire, SANDS

Several research participants in this study reported that their social circles often did not recognise them as parents because their loss had changed their identifiable traits as parents, as they did not have a baby which corresponds to findings to other studies looking at parental identity after baby loss (Doka, 2002; Pollock et al., 2021). Equally, newly bereaved parents struggled to call themselves 'parents' in their social circles. The experience of perinatal loss dismantled their own identities (McGoldrick and Walsh, 2013). Interestingly, the participant mothers in this study openly addressed their tendency to isolate whereas the participant fathers did not. Cacciatore, Schnelby, and Froen (2009) state that stillbirth may negatively affect the social support system for bereaved mothers. Within their study it was commonly reported by mothers that they preferred to navigate the grief alone to avoid sharing their birth stories with multiple people. Mirroring the literature, bereaved participant mothers felt they would be censured for having a stillborn baby (Pollock et al., 2021).

"I didn't wanna face the world. I didn't wanna face old aunts and uncles. I didn't want to keep repeating myself of what happened to every person who walked through the door. You know? I just couldn't, couldn't cope with that."- Alice, Leicestershire, SANDS

During the interviews, bereaved participant fathers described how they felt obligated to get back to "normal". They perceived that they needed to return to work to financially support the family unit. This is consistent with Jones et al. (2019) where fathers return to work because they feel fiscally responsible for the family's wellbeing. One participant father within the current study discussed what it was like to return to work after the loss of his baby. Dominic did not discuss details about how soon he went back to work, but he did share that he felt people were inconsiderate in the use of their language about his stillborn child.

"Whilst you're at work, you will find that people are insensitive to how you felt. How do you best handle that? You will feel withdrawn from society, you will feel like you just want to go into your bubble. Your partner might feel like she just wants to spend more time more time alone, you might feel that you just want to your own space and more time, but that's okay. It's okay to feel like that. – Dominic, Greater London, Dope Black Dads

After experiencing perinatal loss, grieving participant fathers often ignored their own emotional needs to take care of their partners (Cacciatore, Erlandsson, and Radestad, 2013). Ambiguous loss is a type of loss that remains unclear and usually invisible, making families feel that their loss is invisible (Boss, 2007). Stillbirth is a type of ambiguous loss (Lang et al., 2011), which may have impacted how the participant father felt when describing how he was 'withdrawn from society'. Dominic's quote is also profound in that it addresses how his marital relationship was affected after their child died. The other two male participants also shared how the death of their baby impacted their marriages. It was difficult for all three male participants to connect with their wives after the loss of their babies. They described how they wanted to support their wives by being "strong" which corresponds to previous literature (Jones et al., 2019). Men may not feel like they can openly discuss their grief when they feel obligated to care for their partner who is suffering from the physical pain of child loss (Fernandez-Basanta et al., 2022). Not only does perinatal loss impact gender roles between partners, Lang et al., (2011) reported that spouses often have different grieving expectations; women needed to discuss the loss for a longer period compared to men.

Consequently, fathers may feel their experiences of grief are ignored because they do not openly express their emotions compared to bereaved mothers (Jones et al., 2019). Because of the difficulty of sharing their emotions, men may feel they need to mask their emotions. In a 2022 study by Fernandez-Basanta et al., developed a constructivist grounded theory to explain how men cope with pregnancy loss. In their findings, men hid their feelings from their partners and communities so the couple could carry on with their lives (Fernandez-Basanta et al., 2022). Often these bereaved fathers returned to work shortly after their loss, went out in public to run errands, and tended to childcare duties whilst their partner recovered to avoid their feelings on grief and loss (Fernandez-Basanta et al., 2022). Because men repressed their feelings, many reported they had emotional outbursts later in their grief journeys (Fernandez-Basanta et al., 2022). Fernandez-Basanta et al.'s (2022) findings resonate with the results from this study on bereaved fathers. Adjusting to the new normal means men try to reconnect with who they were prior to the loss by returning to work and carrying out household duties. Men in Fernandez-Basanta et al.'s (2022) study and my study show men build a routine that they can observe to protect their partner experiencing physical pain and avoid processing their own pain.

The results of Phase three: Adjusting to the new normal within the RTHTG theory suggests it takes time for a bereaved family to privately process the loss of a child before they can mentally, and in some cases, physically prepare themselves to seek baby loss bereavement support. It has been documented that stillbirth can make bereaved parents feel stigmatised by their communities (Murphy, 2012). A recent study by Pollock et al., (2021) administered the Stillbirth Stigma Scale through an international survey and found that 54% (n= 480) of 889 bereaved participants felt stigmatised for having stillborn babies. 39% (n=346) of participants who completed the survey also shared that they felt discriminated against by other members of their families (Pollock et al., 2021). Men typically ignore their emotional distress and try to return to their daily responsibilities as a way to distract themselves from processing their grief (Fernandez-Basanta et al., 2022; Due, Chiarolli, & Rigs, 2017). This may contribute to marital distress as it may seem like the father's grief is less severe than the mother's grief. Mothers may perceive their partner has moved on from the pain (Due, Chiarolli, & Riggs, 2017). Given the results of the current research compared to the literature, this phase of the RTHTG theory demonstrates there is a need for further research to be conducted on stillbirth bereaved parents' experiences of stigma from family members.

8.5.4 Second phase of the road to hope through grief theory

Whereas phases one to three of the RTHTG theory focuses on the immediate time period after perinatal loss, phases four to six reflect the time period approximately six months (this is based off the participants' responses when they reported thinking about accessing support) after the bereaved parents' losses. This second phase of the theory includes input from the collages. Together with the data from the semi-structured interviews, phases four to six offer a comprehensive portrayal of how sixteen minority ethnic parents chose to access baby loss bereavement peer support programmes.

Phase four: Encouragement to seek support from social circle

8.5.5 Communication

Professional help and familial support are important to deter negative psychological distress in bereaved mothers (Westby et al., 2021) This category outlines communication as a key finding to encourage bereaved parents to seek baby loss support. The ways in which bereavement support information was relayed to parents were significant in how parents contacted the charities who ran the peer support programmes. Verbal communication was largely provided by the parents' social circle or healthcare practitioners. Both methods and sources of communication are discussed in this phase.

The need for social support was evident in the visual data; however, as phase three showed, parents needed time to process their initial loss. Time was represented on three collages by the word (collages 1,4,7) and by images of watches. Once they had adjusted to their new normal, parents expressed they were ready to seek out bereavement support. Phrases such as 'sensitive relief' (collage 1); 'it's time to speak out' (collage 2); 'SOS' and 'finding a way' (collage 3); 'Need help' (collage 5) refer to the time at which the bereaved mothers wanted to seek help to process their grief. Collage 6 included photographs of the bereaved mother's family to show how vital they were in her initial recovery to seek out support. As the following sections prove, social support from family and friends was critical for bereaved parents to find baby loss support groups.

8.5.5.1 Verbal communication

Relationship to Healthcare Practitioners

Data showed most participant mothers had a strong relationship with their healthcare team even when they had traumatic birth stories. Midwives and General Practitioners (GPs) were the healthcare professionals mentioned in many of the semi-structured interviews. Midwives were often the first support for bereaved mothers. Midwives played a significant role in parents' lives because they shared memories of the baby's birth and death (McGuinness, Coughlan, and Power, 2014). Bereavement midwives were essential to support grieving families immediately after their losses (Abramson, 2019). Within the literature, SANDS National Bereavement Care Pathway (2019) calls for at least one maternity specialist role with knowledge in bereavement care to support grieving families, yet the bereavement midwife role is varied across the country (Abramson, 2019). Through support from healthcare practitioners, bereaved participant mothers felt that they and the lives of their babies mattered. In 2012, the NHS introduced the Compassion in Practice Strategy which centres around six focus areas healthcare practitioners can implement in patient care: Communication, Courage, Competence, Care, Commitment, and Compassion (NHS, 2016). Quotes in this section emphasise the bonds midwives built with bereaved mothers. Building compassionate relationships with bereaved families supported their grieving journeys (McGuinnes, Coughlan, and Power, 2014).

"I had an amazing community midwife who continued coming round to see me. Although she didn't need to be, she was amazing, you know, she'd just come and have a little natter and again. She came to the baby's funeral, and she just kept hanging around, but we built an amazing relationship during those, those moments anyway." – Ruby, Leicestershire, SANDS

"I'm still in contact with the bereavement nurse. She was very supportive, I have to say, throughout the whole thing. Even now, if I was to ever call her, she's still, you know, willing to help."- Jade, Kent, SANDS

"Well, what was good with PALS (Pregnancy After Loss) is that Rose [bereavement midwife] was there as well during the meetings. Because she was there. I was encouraged to go because I felt connection with her. So that was helpful." – Iris, Kent, SANDS and PALS

The data demonstrated midwives and other healthcare practitioners were instrumental in directing bereaved families in terms of seeking bereavement support. For Iris, her relationship with Rose encouraged her to attend a PALS peer support group at the local hospital. Similar to other bereaved participant mothers, Iris trusted the guidance her bereavement midwife gave her because she had worked with her during her labour. Midwives are often the connector between families and other healthcare providers (Fernandez-Bastana, 2021). The findings in this section stress the importance of bereavement training for maternity services workers (Davidson, Roberson, and Smith, 2018) so that they can provide appropriate support to grieving families.

8.5.5.2 Support from social circle

All the participants shared that they had received physical and emotional support from their social circles (McGuinnes, Coughlan and Power, 2014). This occurred even when some of the bereaved parents needed to initially isolate themselves so they could privately grieve before they felt able to seek out support from their social circles. Having strong social support can help safeguard against stress and trauma (Cacciatore, Schnelby, and Froen, 2009). I define the term 'social circles' as people such as family and friends who have established interpersonal ties with the participants (Curseu and de Jong, 2017). In the context of this study, the familiar relationships included the participants' own parents, siblings, and families as well as their partners' parents, siblings, and families. 'Aunts' and 'uncles' were mentioned frequently by Asian participants. All eight Asian participant mothers in this study's sample identified that support from their families was important to them. Whilst not all of them felt wholly supported by their families and culture to fully express their grief, five participant mothers shared that they felt encouraged to seek bereavement support by their immediate family members. Below are three quotes which demonstrate how their social circles provided support to the participants.

"I think had my parents not encouraged me to go and do that, I don't think I'd be brave enough to do it on my own and I think there was a lot of that stigma attached." – Amelia, Leicestershire, SANDS

As Amelia shares, some bereaved parents felt shame and stigma when seeking baby loss support, although it was Amelia's parents who urged her to seek bereavement support.

This quote is interesting when compared to Sophie's quote because Asian mother participants frequently expressed that there was a generational divide within families in terms of whether it was acceptable to speak about a stillborn baby. Generally, participants expressed it was more appropriate and easier for them to connect with women within their generation or younger on the topic of pregnancy loss than it was to discuss it with older generations. Mothers shared they felt less judged and stigmatised by people their age compared to older people within their communities. In a 2020 study by Pollock et al., researchers found stillbirth bereaved mothers felt they had less social power within their communities to change the way baby loss was perceived. Parents within Pollock et al.'s (2020) study felt older generations perpetuated shame and blame of the loss which made it difficult for grieving parents to connect with the greater community. Respondents to Pollock et al.'s survey (2020) noted they felt separated from their communities due to stigma. Several of my study's participants felt supported by their immediate family members, however there was stigma felt by older generations.

"Although they had their view, my in-laws were like, no, you need to talk, you need to go out and we're so glad that you guys are getting help from SANDS. They got it, they understood and my aunts, they all really knew that I needed that. I think it makes a difference. It makes a difference of what generation you are as well."- Sophie, Leicestershire, SANDS

"I think for me, my sister really pushed me as well. So, I remember reading the Leicester SANDS number when I was at her house. My sister's a psychologist so she's very aware of my mental health, erm, so she was like encouraging really and like I remember leaving several messages. Ring again!"- Alice, Leicestershire, SANDS

For Alice's, it was her sister's experience of working in mental health services that was key in terms of Alice contacting SANDS. It is possible that her sister noticed how distressed she was. Participant mothers in this study shared that they appreciated positive affirmations from their loved ones to seek bereavement support. Parents wanted their social circles to authentically engage with them rather than avoiding the topic of the baby's death. This finding supports Gear's (2014) findings on informal social support for bereaved parents which indicated that parents wanted their social contacts to speak openly about death and encourage them to seek additional support.

8.5.5.3 Written communication

Written communication in the form of pamphlets and informational documents were often how the bereaved parents were introduced to baby loss charities. It was surprising to see how influential the role of social media was in bereaved participant mother's grief journeys. This may have been influenced by the COVID-19 pandemic because people were instructed to stay home. Engaging with people online the only way people could stay connected during different stages of the pandemic.

8.5.5.3.1 Pamphlets and information packs

Participants usually received informational documents at the hospital after the birth of their baby. Bereaved participant mothers reported that pamphlets were not immediately well received, due to their perception that the timing was insensitive to the grieving parents. Participant mothers reported that they did not understand and could not process information on bereavement support following their loss. However, one participant mother expressed that it was through this written form of communication that she was able to find an organisation which she could contact. The SANDS information leaflets were frequently mentioned during the semi-structured interviews.

"I realized I needed help and to talk to somebody so actually, erm, the first point of help that I went to was SANDS, erm, their online support really. That was coz it was all in the information pack that we were given at the hospital. So, I didn't know of anything else to reach out to anyway." - Sheila, Warwickshire, SANDS, Luca's Angels

8.5.5.3.2 Social media

Social media platforms have grown exponentially and have changed how people communicate in recent years (Serafinelli, 2017). Baby loss charities have built up their social media presence across a variety of platforms to engage with their patrons (NHS, 2014). Facebook is an American for-profit corporation and online social media platform (Nations, 2021). Facebook was a popular option for bereaved parents to access closed peer support groups where they could meet other bereaved parents who had experienced perinatal loss. The SANDS closed Facebook group is linked to their website which is where Carrie first learned about the closed group.

"I think we went on the SANDS website and looked at what they had, what information they had and then also looked on Facebook SANDS group as well. So, yeah, I mean I think that's a lot of the ways that people find this sort of groups is through Facebook."- Carrie, Sussex, SANDS

Maya was invited to join a private Facebook group for bereaved parents through the Facebook algorithm. Social media algorithms are influenced by a user's engagement on the site and change the way users view new content (Krutrok, 2021). For example, if a bereaved parent entered 'baby loss' in the search bar of Facebook, algorithms would promote posts with which the user identifies; this user would start receiving suggestions about how to access more information 'baby loss' and to join Facebook groups on baby loss (Bucher, 2017). After the birth of her baby, Maya contacted SANDS to learn more about how she could become involved with the charity's activities. The pop-up advertisement for the private group may have been related to her online searches or from her seeking SANDS support. However, the Facebook group Maya participated in was not connected to SANDS. Instead, it was a private international baby loss support group created and monitored by bereaved mothers. This is important to note because the Facebook algorithm recognised Maya as a bereaved parent and suggest a private community group that corresponded to the posts, she 'liked' or commented on (Bucher, 2017).

"I think I bumped into a post or, you know, they come up as pop-ups and I thought: oh, ok, this is something I would like to look at so I opened it and saw that and thought: ok, I'm joining this because that, that's one place I can really identify with and express myself. I think if you have never been through that experience, you don't really understand but once you've been through…you change how you treat people who've lost babies." -Maya, Yorkshire, Online group

Sophie was the youngest participant mother (late twenties) within this study's sample and used Facebook and Instagram daily. She used both platforms for different purposes. Instagram is a social network that mainly presents visual communication (pictures, videos) compared to Facebook which relies more on verbal-centric information (Serafinelli, 2017). Instagram users can insert hashtags (#) followed by a quote to aggregate similar posts (Mercier et al., 2020). Instagram offered Sophie the opportunity to share her grief more openly in comparison to Facebook which was where she felt more connected to her social circle. Through Instagram, Sophie found a 'community' unlike Facebook where she had to present herself differently. Sophie's Facebook and Instagram presences were different. She felt she had to monitor what she posted on Facebook because she was connected to an extended network. On Instagram, she was able to connect with other bereaved parents who didn't know her personally like her Facebook contacts did.

"I think, erm, recently I've been more sort of in tune with like an online community. There's lots of pages on Instagram. I don't know if they're charity funded. With the whole COVID-19 situation, erm, so through Instagram but it's just like almost like a little community that you don't really see but it's just you get to know people's babies which is interesting but it's not, not so much a charity. I'm really divided and so I go to Instagram and that's got a lot of baby O [deceased child] and me being a mum to both children. Whereas if you go to my Facebook, you will just see lots of baby M [living child]. It's interesting. I think it's because with Instagram I've got my community of loss whereas with Facebook I've got my family and friends."- Sophie, Leicestershire, SANDS

Social media bereavement support groups offer grieving people a relatively new method to access peer support (Segerstad and Kasperowski, 2014). Engaging through social media platforms may be less threatening than attending in-person programmes (Gold et al., 2012). A study by Mercier et al., (2020) explored Instagram user's experiences of miscarriage and how they engaged with others using the social media application. Mercier et al., (2020) found that Instagram offers a virtual space for women to disclose their experience of miscarriage and honour their pregnancy. Mothers grieving the loss of a baby through miscarriage can thematically search for posts which can influence what they see on their Instagram account (Mercier et al., 2020). Given the results of Mercier et al. (2020) study, it is clear that Sophie's experience of engaging through Instagram to find bereavement corresponds to the wider literature.

8.5.5.3.3 Internet searches

Three bereaved participant mothers spoke of the ways in which they first contacted SANDS. Participants contacted the charities after they had time to initially process the deaths of their babies. Participants often used online search platforms, such as Google and the charities' websites, to find ways of contacting the organisations' peer support programmes. The SANDS website has a page that people who have been affected by baby loss can access (SANDS, 2022). Additionally, there are several links via which bereaved people can access immediate support using the Griefchat function. They could also find links to connect them to local peer support groups and other text-based grief support via mobile telephones which connects a bereaved parent with another bereaved parent for support (Fournier, 2016; Sutton, 2016). Text-based forms of peer support have become popular in supporting people who are experiencing emotional distress (Fournier, 2016). One participant Nicole was able to access help by phoning a number on SANDS' website that gave her information about a meeting in her local area.

"I looked them up, called them, spoke to somebody and then after that I found out about one of their meetings and I was sent to one of the meetings."- Nicole, Leicestershire, SANDS

Both Amelia and Abigail's journeys to access peer support began by using the SANDS' website. They were put in touch with befrienders who encouraged them to attend their first peer support group meetings.

"I was going to the support group meetings coz I googled SANDS and the lady there put me in touch with Ruby and it was just so lovely hearing about Ruby's experience and then her telling me that we hold all these support groups where other bereaved parents come"- Amelia, Leicestershire, SANDS

Abigail found that SANDS had a texting option which she found helpful as she was too uncomfortable to call the number. Although she was not prepared to speak to anyone, she felt comfortable texting a befriender named Julie. Abigail built a meaningful relationship with Julie through their text conversations. Abigail and Julie's text-based correspondence relate to current research on peer support programmes via text or video which have been piloted in neonatal intensive care units and have shown to support parents who prefer less in-person engagement (Dahan et al., 2022).

"I, you know, found SANDS' number and I texted them coz I was too scared to ring. You know, I sent e-mails and text messages and that was my form of communicating because I didn't wanna physically talk

to anybody, I wasn't ready, erm, and I certainly didn't want anybody to see my face. I got it hold of a lady called Julie who is just phenomenal. I just love that woman, she's like my godsend. She really helped in every single way. I mean I remember those times at like 2 or 3 o'clock in the morning I would text her about some, you know, how I felt, or I can't sleep or just anything." – Abigail, Leicestershire, SANDS

In this phase of the grief journey verbal and/or written communication was the first step for parents when searching for appropriate bereavement support. Table 13 presents a summary of the methods and sources of communication. Support from bereaved parents' social circles was important but declined over time and which meant that they accessed peer support through online forums. This is similar Aho, Paavillainen, and Kaunonen's (2011) findings.

Table 13: Sources of communication which encouraged bereaved parents to seek baby loss bereavement support.

Method of Communication	***Sources of Communication***	***Detailed Sources of Information***
Verbal Communication	*Healthcare Professionals*	*Midwives (bereavement and community)* *GPs* *Mental health providers*
	Social Circle	*Family*
		Befrienders
Written Communication	*Social Media*	*Facebook, Instagram, Twitter*
	Written material	*Pamphlets* *Documents from hospital*
	Internet	*Google* *Contacting charity directly via website or text*

8.5.6 Phase five: Oscillation of seeking support

Phase five of the RTHTG theory addresses the patterns that emerged from the data that explain how participants accessed baby loss peer support programmes. Findings from the semi-structured interviews suggest that parents' experiences of accessing peer support programmes oscillated between active participation and inactive participation. Bereaved participant mothers were more active in peer support programmes, which is echoed within the literature (Laakso and Paunonen, 2002). Some participants found their grief lessened after a few meetings. This limited interaction alleviated their emotional distress which meant that they did not feel the need to access further peer support programmes. Some participant mothers chose to continue participating in peer support groups years after their perinatal losses. Conversely, logistical barriers such as lack of childcare or transportation issues were reported which prevented participants from regularly accessing baby loss bereavement support; these issues would make it more difficult to bereaved parents to return to their peer support groups.

Visual data confirmed that participants benefitted from accessing peer support groups. All eight collages included positive phrases to describe their experiences of attending peer support groups. The participants integrated images of birds and elephants to symbolise how the group coalesced around similar experiences of loss. Furthermore, collage 5 contains the phrases ‘welcome to the club’, ‘space for change’, ‘leap of faith’, and ‘I can look forward to the future’ as ways to express her experience. Peer support groups offered parents a place where their pain was normalised because they were meeting with others who had known the pain from losing a baby. This was echoed by the creator of collage 6 who selected the phrase ‘it’s freeing to know everyone here is like me’.

8.5.6.1 Peer support groups

Within the literature, peer support programmes have been implemented for a variety of different mental health needs (Bartone et al., 2019). Peer support programmes provide bereaved parents with the option to have long-term support after the death of a baby (Aho, Paavilainen, and Kaunonen, 2011). This study only investigated minority ethnic bereaved parents who access baby loss peer support programmes as there is a paucity of evidence related to this group within the peer support literature. Fifteen participants accessed peer support through baby loss charities, whereas one participant accessed a monitored private Facebook group. Findings from this study complement what has been found within the literature (Friedman & Cohen, 1980; Diamond & Roose, 2016; Schoonover, Prokop, & Lapid, 2022). Shared experiences of grief and bereavement may facilitate trusting relationships between participants (Solomon, 2004). A systematic review (Bartone et al., 2019) which examined peer support programmes for bereaved individuals found people who attended this type of bereavement support felt less isolated and alone. Additionally, Daham et al.’s (2022) study on NICU peer support parent groups found that being part of a peer support community offered hope to ‘new’ parents that it was possible to adapt to a new reality of a baby being in NICU. Similarly, the parents who participated in this doctoral study reported engaging with parents further away from the initial loss of their child inspired newly bereaved parents, that one day their lives would keep going despite it feeling unimaginable at the onset of their child’s death.

Understanding one’s cultural values impacts on how social support will be interpreted (Fisher et al., 2014). It was important for Alice to see her identity as an Asian woman represented in their group’s facilitator. She needed to recognise her cultural identity within Ruby, the group leader. She trusted that Ruby would understand the issues she was experiencing with seeing her extended family after the traumatic loss of her child. If Ruby had not been an Asian woman herself, Alice stated she might have resorted to finding support through her family. How one chooses to express one’s grief is influenced by social and cultural factors (Bhugra & Becker, 2005; Ayebare et al., 2021), understanding the importance of cultural identity in supporting grieving minority ethnic communities is essential for peer support programmes to be successful. Alice felt Ruby understood the cultural dimensions that were sewn within the grief she felt losing her baby (Bhugra, 2004). A group leader who can recognise newly bereaved parents’ cultural norms within the grieving process may challenge the stigma grieving parents feel within their social circles (Ayebare et al., 2021).

“I was really fortunate that in that first meeting, even though, like I said, Ruby, you were the only other Brown face I could see. I felt like this was my family. These people understand me, these people know what I’ve been through, and I was so fortunate to have that and if I hadn’t, I feel like then I would have just gone back to the family support, which didn’t fit either, so I would’ve been stuck.”- Alice, Leicestershire, SANDS

Within peer support, there has only been limited work which explores the concept of matching ethnicity with peer support programme attendees and peer support leaders (Fisher et al., 2014), and yet diversity was featured within the visual data, indicating a need for adequate ethnic representation within baby loss charity programming. The word ‘diversity’ was featured on collage 2; collage 4 featured the image of an eye shadow palette to show the importance of diversity within baby loss groups. Collage 7 featured a large image of a and Black woman leaning on each other which the author selected to show how different cultures can support each other. Collage 8 has an image of a globe which represents how people all over the world can experience baby loss and come together to support each other.

Participants reported that they had accessed counselling at the same time as accessing peer support. Peer support programmes do not replace advice provided by a heath professional, but may complement that advice (Boyle et al., 2015).

“I was given counselling through my GP. I did a bit of SANDS in between when I had face to face counselling.”– Sheila, Warwickshire, SANDS and Luca’s Angels

Iris and Amelia responded better to peer support than they did to one-to-one counselling sessions. Both women felt they were able to be their authentic selves when they were with other bereaved parents compared to when they were with a professional counsellor. Feigelman et al. have found that peer support programmes foster newly bereaved parents' emotional growth and encourage ways in which they can form a new identity by weaving their grief into their lives (Feigelman, Jordan, & Gorman, 2009; Feigelman et al., 2012).

When she attended her counselling appointments, Iris felt as if she was being interrogated. She described how she felt there was a power imbalance between being a bereaved parent and a counsellor. Within a group setting, Iris felt more relaxed and that she was equal to other group members. The peer support group environment was collaborative and fostered discussions.

"I did explain to her [the counsellor] the differences compared to group and therapy. I can be myself, feel myself and in the group." – Iris, Kent, SANDS and PALS

Counselling may provoke a person's vulnerability by heightening the power imbalance between the therapist and patient (Dillon & Hornsteitn, 2013). Amelia felt more supported by having her husband by her side. A group setting facilitated her processing her emotions. She could cry without drawing attention that she was distressed. The easy-going nature of a peer support group challenged the distress she experienced whilst crying in a therapy appointment.

"I think for me counselling was a case of I could just sit there for a session and just cry and not say anything. Like, you know, a peer support group, like I said: a) my husband could come along with me as well, we could be in the same room together. B) you could sit there and cry if you wanted to but other people would talk around you."- Amelia, Leicestershire, SANDS

Peer support programmes gave these sixteen participants the opportunity to connect with other bereaved parents. Even when their participation was limited, being exposed to other families' stories gave these parents hope for the future. 'Veteran' bereaved parents attending peer support groups fostered hope by providing emotional support, practical information, and education which new parents might have found useful (Hall et al., 2015).

"I felt like I'd got the answers that I needed for that one that, you know, for that time and then, erm, I kept in contact with another couple of people, and then that was it."- Nicole, Leicestershire, SANDS

As parents' needs changed and they needed less in-person support, participants shared that they still kept up to date with various throughout the year by baby loss charities. Memorial services during Baby Loss Awareness Week and Christmas were often mentioned as highlights of bereaved parents' events. Services of remembrance offer parents the opportunity to come together with other bereaved parents and to publicly acknowledge and remember the lives that are lost. Services around Christmas were particularly helpful considering how difficult Christmas is for families who have experienced perinatal loss (Conway & Valentine, 2019).

Connecting with other parents may reduce self-stigma (Hundt et al., 2015). Peer support is a generally accessible intervention because it is facilitated by the community effected by the phenomenon (Fisher et al., 2014; Boyle et al., 2015). Peer support leaders like Ruby are a valuable resource because they act as mentors for newly bereaved families (Ardal, Sulman, & Fuller-Thomson, 2011; Hall et al., 2015). Within this small study, Ruby was the person who gave me access to six other participants. Compassionate group leaders like Ruby must balance how to respond to participants' emotional experiences and their involvement in terms of their own experience of baby loss (Boyle et al., 2015). Wahl et al.'s 2018 study on a nursing peer support programme reports that compassionate leaders are people who carry out compassion as an action. Research carried out by Dillon and Hornstein (2013) on hearing, voices that peer support groups showed that a strong group leader is not dependent on one's understanding of social work or counselling. Instead, a group facilitator must be a good listener and be unprejudiced about what people are willing to share (Dillon & Hornstein, 2013). Hundt et al., (2015) found peer support programmes for veterans experiencing PTSD offered a unique form of social support which they couldn't receive from people who were not veterans. When applied to the context of this study, it is critical to address the social isolation that often accompany people who are emotionally distressed (Hundt et al., 2015). Ruby had first-hand knowledge of baby loss and encompassed the skills needed to help bereaved parents process their pain. Her time spent as a group facilitator and befriender inspired her to develop her own charity to support bereaved parents in Leicestershire.

Within the visual data, flocks of birds (collages 3 and 4) were featured to show how parents bonded together to create a safe space to discuss loss. Peer support programmes help new members feel their experiences are valid and worthy to be heard (Dillon & Hornstein, 2013). Furthermore, attending peer support groups enabled parents with the ability to speak openly about the loss of their baby. An image on collage 3 of two birds interacting together talking about a baby confirms that it was important for parents to speak about their children.

8.5.6.2 Leadership Opportunities within peer support programmes

Parents in this study reported a desire to give back to the baby loss community to gently welcome newly bereaved families to a reality they hadn't anticipated. The participants who shared their experiences of leadership opportunities corresponds with the literature that finds volunteer opportunities increase bereaved parents' community engagement levels (Cacciatore, Blood and Kurker, 2017). Within the baby loss literature, bereaved parents of perinatal loss saw volunteering as a way to benefit from their own loss and heartbreak (Wada and Park, 2009; Beck and Watson, 2016; Cacciatore, Blood, and Kurker, 2017). In the context of this study, it was important for the mothers to feel their involvement was directly related to grieving families.

"I wanna help support other people and have other people help support me in my life and in my family so, yeah, that's super important to me. I am happy to bake a cake. I'm happy to do whatever but there's something about translating that kind of action into I wanna do direct support for families. I feel like it's super important for me to put my voice out there and, you know, if I, if I'm too scared to talk about it, I can't expect anybody else to put themselves forward."– Carrie, Sussex, SANDS

"Helping other bereaved families or mums or whoever along their journey and basically sharing my experience with them of what happened to me is key, but then giving that hope as well that, you know, what? It does get better as time goes on. It doesn't get better; it gets easier as time goes on."- Amelia, Leicestershire, SANDS

Daphne wanted to use her experience attending baby loss peer support groups to act as a trustee of a developing baby loss charity Ruby was leading. She was able to use her skills working in law to the new charity's advantage.

"Going to that support group around people who actually understand me without feeling judged and everything else is the reason is why I'm actually, erm, I actually sit on the board of trustees now for this new charity that we've set up with Ruby."- Daphne, Leicestershire, SANDS

For most participant parents, this was their first opportunity to participate in research. Considering the population sample is an underrepresented group within health research (Redwood & Gill, 2013; Smart & Harrison, 2017; Fernandez Turienzo et al., 2021), it is important to recognise the importance of the research participants' contributions to diversifying literature in this field. Dominic shared his views on the importance of not only participating in research but also implementing research in practice. As an active participant on the All-Party Parliamentary Group (APPG (Bates, 2021), he felt dissatisfied about the implementation gap which he felt existed between the empirical evidence and policy implementation. He felt that it was important that findings were not only published but that they were also implemented within policy and practice.

"If people don't have the knowledge, let's give them the knowledge. If more research needs to be done, let's do the research. You know, I'm tired of everyone going back to the MBRRACE report and talk about the MBRRACE report. Cool with we've spoken about the MBRRACE report. Now, what have we done based on this report?"- Dominic, Greater London, Dope black Dads

Phase five of RTHTG theory indicated that participants found ways to interweave their lost baby's legacy within their new identities as bereaved parents. Finding ways to support other bereaved families may help parents find meaning in their loss and serve as a means to continue the bond with their baby who died (Cacciatore, Blood, and Kurker, 2017). Within the literature, volunteering may be beneficial to a bereaved parent's psychological wellbeing because it may give a bereaved parents a sense of purpose especially later in life long after the initial loss (Huo, Kim, & Wang, 2022). Moreover, participants in this study found ways in which they could serve the baby loss community which may help build their bond with their lost baby and is also reiterated in the literature (Cacciatore, Blood, and Kurker, 2017). Parents who participated in this study who were further along in their grief journey understood the nature of baby loss and recognised that a newly bereaved parent's needs may oscillate depending on where they are with their grief journey. Having a keen understanding that experiences of grief related to baby loss fluctuated (Stroebe & Schut, 1999), meant veteran parents were able to meet the needs of newly bereaved parents by offering gentle insight and to provide them hope without placing expectations on newly bereaved parents. Ultimately, the participants who volunteered or took on a leadership role within their respective charities challenged the cultural expectations which argued baby loss should be kept silent (Cacciatore, Blood, and Kurker, 2017).

8.5.6.3 Barriers which impeded parents' participation in peer support programmes

Bereaved participants reported that they were generally satisfied with the peer support groups. This was measured by their statements during the semi-structured interviews. However, there were barriers which prevented participants from accessing peer support in the long-term.

8.5.6.4 Men's connection with peer support

Compared to participation rates of the women in this study, the three participant fathers participated less often. Furthermore, participant fathers did not appear to be as willing to attend peer support programmes as the participant mothers. Of the three, one father (Dominic) organised and led a peer support group for fathers. Arthur attended a men's group run by his church. Whilst it was not a formal peer support for bereaved people, he felt it still qualified as a peer support group because men shared the struggles they were experiencing within the group. Men within Arthur's peer support group were encouraged to speak about struggles within their professional and personal lives. Vern had very little contact with peer support programmes. He felt connected through Sandra's work with Aching Arms. These three participant fathers' experiences provide insights which is mirrored in the literature that men engage less with peer support opportunities compared to women. In Laakso and Paunonen-Ilmonen's (2020) study, bereaved mothers participated in peer support grief groups more than bereaved fathers, because mothers bonded with other bereaved parents more than the fathers appeared to do. Dominic shared that bereaved fathers felt more inclined to participate when they had their own space to discuss their grief. As a result of gender stereotypes, Dominic shared that it was difficult for men to show their feelings on grief. Armstrong's qualitative study on grieving bereaved fathers found that participants reported they didn't want to talk about their feelings or the loss they endured with anyone than their partners (Armstrong, 2001) which suggests bereaved fathers may isolate their grief from their families and friends. Because there were only three fathers who participated in this study, the results may not be representative of the broader bereaved father population; however, Dominic's opinion of gender stereotypes is important to recognise as a factor that may complicate how men express their grief. Although it may seem appropriate for men to speak openly about their mental health, it is critical to acknowledge Black men's mental health outcomes are different to white men's mental health outcomes. The convergence of race, gender, and class correspond to a higher risk of psychosocial issues for Black men (Watkins, Walker, & Griffith, 2010).

In the UK, minority ethnic communities are less likely to receive a referral from their GP to access mental health services (Arday, 2018) which raises further questions on how to support grieving fathers from a medical perspective. Within the psychosocial literature addressing Black men's mental health, Black men often experience pressure to follow gender stereotypes which defend traditional masculine norms (Gordon et al., 2013; Watkins, 2019). A significant traditional masculine norm is not showing one's emotions or emotional weakness (Watkins, 2019). Applied to this doctoral research, it is evident that Dominic felt he was obligated to prescribe to conventional cultural norm of keeping his grief self-contained and withheld from others (Watkins, Walker, and Griffith, 2010).

"I think I think man only I think that definitely has to be a man only space. To break that down, purely because when you've got women present, the group men always feel like certain men feel like they need to act up to it, and they need to be and they don't want to seem weak."- Dominic, Greater London, Dope Black Dads

Arthur shared that he had learned that he needed to adjust to his new identity as a bereaved father. He had difficulty expressing how the loss of the baby had impacted him compared to his wife, Jade.

"I would always say to people, it's just part of life. You got to move on. And then they'll refer back to Jade was more inclined to talk about the impact [of the loss]. And I think I don't know why I did that. Maybe because I just probably didn't know how to express how it has affected me." – Alan, Kent, Men's church group

The world recognises the physical pain of the mother because she carries the pregnancy and has to give birth, whereas the grief of the father largely goes unrecognised (O'Leary & Thorwick, 2006). Consistent with other studies, participant fathers shared that they felt more prepared to tend to the needs of their partners than to their own pain (McCreight, 2004; Nguyen, Temple-Smith and Bilardi, 2019; Jones et al., 2019). It's not uncommon for bereaved fathers to struggle to find balance between supporting their partners and expressing their grief (Jones et al., 2019). In the literature, pregnancy loss has been situated within gender relations and roles; bereaved fathers tend to hide their grief in an effort to 'be strong' for their partner (Samuelsson, Radestad & Segesten, 2001; Bonnette & Broom, 2011). From a feminist lens, it appears that the socio-cultural expectations of how a man grieves is constrained within cultural expectations (Versalle & McDowell, 2005). In Western cultures, perinatal loss is often disregarded as a 'nonevent' (Markin & Mano, 2018). Often stigmatised from actively grieving any loss, men find it difficult to show their grief to their partner and their communities (Wilken, 2006) because of traditional concepts of masculinity which perpetuates men from seeking help to not appear weak (Miller, Temple-Smith & Bilardi, 2019). Cultural expectations around the ways in which bereaved fathers should grieve may amplify the silence of men's experience of baby loss (Miller, Temple-Smith & Bilardi, 2019).

Vern commented that he connected to his grief through Sandra's work with Aching Arms. He regarded Sandra's participation within the organisation, and he was proud of the commitment she had to support newly bereaved families. He saw his role of supporting the household to lessen his wife's household duties so she can focus on her trustee role at Aching Arms. Although this was not typical of the culture from which Vern and Sandra originate, it is interesting to note that Vern carried out a woman's duty to take care of the household. However, the literature on gendered grieving patterns show it is not uncommon for men to perform problem-solving approaches to grief which uses distraction to avoid confronting painful emotions related to their loss (Obst et al., 2021).

"I support in taking care of the kids and making time for her. I facilitate her so that she is effective with the time that she devotes there and, erm, through her work I am connected. I feel connected through Sandra."- Vern, Greater London, Aching Arms

Sandra reported that Aching Arms was trying to encourage the participation of bereaved fathers, on the board of trustees so that it was more inclusive of all bereaved parents. Including more male voices in the baby loss charity sector may help validate their grief journeys since their experiences are often not heard (Nguyen, Temple-Smith, and Bilardi, 2019).

"At Aching Arms now we have a father who's, err, a member of board and he's a trustee and this is something we are quite aware of in and focusing on doing some like directed action, erm, in using the fathers experience so that it can, can, can speak to other fathers." – Sandra, Greater London, Aching Arms

Amelia and Alice participated in the semi-structured interviews without their husbands. They shared that their partners were supportive of their involvement with their peer support group, and yet they did not attend the groups themselves.

"Even now a lot of times, Victor, my husband, he'll be like I'll come along but, like I said, we both can't go together. He often says I'll come and something always comes up."- Amelia, Leicestershire, SANDS

"He's happy that I'm involved with the charity and, you know, he feels that it helps me deal with our loss as well."- Alice, Leicestershire, SANDS

The general narrative within the data demonstrated that men felt compelled to support their partners' needs to attend peer support programmes rather than attending the groups themselves. In Obst and Due's (2019) study which explored service provider's experience of supporting fathers impacted by perinatal loss, men felt they had to return the family to routines which were consistent with their previous daily lives. In the visual data, there was one image which referenced a couple coming together from the mother attending her peer support group. Collage 7 featured the phrase 'love again' above a heart-shaped image of a couple holding each other. The mother who created this collage said her husband's encouragement to attend the support group helped build a romantic connection between the two of them after losing their baby.

Care following pregnancy loss is often woman-centric meaning it may exclude men from participating (Obst and Due, 2019). Within the data it was noted that participant fathers felt that they could access the peer support groups their wives participated in if they wanted to, but they did not attend the peer support groups often or at all. Whilst pressure from the dominant Western culture tells men to be 'strong' (Kavanaugh, Trier & Korzec, 2004; Jones et al., 2019), findings from this study recommend that bereavement support from the healthcare providers and baby loss charities is offered to men whilst they are in early grief so they can access support if they need it later on in their grief journeys.

8.5.6.5 Impact on attendance by subsequent pregnancies

A rainbow baby is a baby born after perinatal loss (Lake, 2020). A subsequent pregnancy however created challenges for two bereaved mothers in terms attending the peer support group. Pregnant mothers who attended peer support groups felt they no longer belonged in a bereaved parent group. Even if negative comments weren't said out loud to the expecting mother, these women felt shame that they were attending a group when they were having another child.

Peer support groups can provide support to women who are expecting rainbow babies in a safe and therapeutic environment (Smith, Davidson, and Roberson, (2018). One participant mother, Iris, attended a pregnancy after loss support group specifically for women who were expecting a baby after their initial loss. Another participant, Sheila, attended a regular peer support meeting whilst she was pregnant with her rainbow baby. She no longer felt welcomed by the group members, despite the fact she was a grieving parent like other group members.

"I was expecting my rainbow baby. I asked how, erm, how do people cope when they're having a rainbow baby. There were women there who had just lost their baby and I was talking about having a rainbow baby. So, it wasn't received very well, and I felt like I'd said something that I wasn't supposed to." – Sheila, Warwickshire, SANDS and Luca's Angels

Ruby, a peer support facilitator, shared in the focus group that she facilitated a meeting between two new expecting mothers who had suffered from perinatal loss. These women were patients at a clinic that specialises in supporting families who have a history of pregnancy loss. Ruby found bereavement support work rewarding when bereaved parents met through her peer support group. Through her work, Ruby facilitated bereaved parent friendships. She saw connections between parents to bring people together and out of grieving in isolation.

"I did one group last night, a virtual one and there were two mums on that, but they are coming into the group via their Rainbow clinic as well now. It was great because these two mums met for the first time, but the likelihood is they will swap numbers and, you know when they have their babies, they'll keep in touch, which is just lovely." – Ruby, Leicestershire, SANDS

It is not possible to compare the findings of this study to the literature because there is a gap within the research documenting women who choose to attend baby loss bereavement support groups during their subsequent pregnancies. The mothers who attended PALS groups shared they had positive experiences in groups specifically designed for expecting mothers. Participants described how they felt safe in a group where other people had similar fears related to their pregnancies after loss. This area of baby loss bereavement support warrants further research.

8.5.6.6 Logistical constraints

Participant parents found it difficult to attend peer support programmes when it conflicted with their other commitments which often related to childcare. This was not surprising considering it was difficult to attend an event that did not cater for children. Paid work and volunteering commitments also made it challenging to regularly participate in peer support programmes. Maya shared that she had young children which deterred her from attending a peer support group, as this would involve childcare arrangements in order to enable her to attend an evening session. Similarly, Jade found daytime events difficult to attend when she had other commitments, for example picking up her child from school.

"My youngest was three or four years-old then and the other one was twelve? I couldn't leave them in the evening to go for counselling or group, so it just didn't work."- Maya, Yorkshire, Online group

"Yeah, they even sent me an invitation at the end of last year, and I think was a networking event with teas and coffees. It was just unfortunate I couldn't go because I think it was in Maidstone. I had baby J and the timings meant I would be late for picking up my other child from school."- Jade, Kent, SANDS

In a 2014 NHS review on pregnancy loss support, it was found that national charities are linked to an NHS choices website, however, local charities were often not included missing. The report (NHS England, 2014) recommended adding an internet postcode search function which could facilitate connecting parents to groups within their respective post codes areas. Beyond this one report, within the literature reviewed for this study there was a lack of empirical evidence which examined how parents choose to access local baby loss bereavement support. Carrie, a SANDS group facilitator, said it was important for her to access bereavement support in her neighbourhood. Having a group within her community was a prominent factor that inspired her to attend. She commented that when Black and Asian parents had to travel far to attend a group, this deterred them from attending.

"The fact that there was group nearby was certainly a big factor. And I didn't have to travel super far, you know, and that there were people also connected to my hospital who understood as well. So, that was super important. I only went to my group because it was super close to me. In a community that's far away from Black people or Asian people, they're not gonna go, they're not gonna go if it's not close"
– Carrie, Sussex, SANDS

This may be a contributing factor in terms of minority ethnic parents limited participation in support groups. Mayland et al. (2021) conducted a systematic review which reviewed facilitators and barriers for the UK's minority ethnic population to access bereavement care. This 2021 article was a response to the disproportionate impact COVID-19 had on minority ethnic populations at the time. Within their review, authors found a study which compared Black Caribbean populations to white populations experiences of bereavement. Compared to white populations, Black Caribbean communities reported practical financial support to be needed more than bereavement support interventions (Koffman et al., 2005). Whilst research on minority ethnic populations accessing bereavement support is limited, this study (Koffman et al., 2005) could support Carrie's statement. If families are in financial distress, it is unlikely they will travel to attend a support group when there are other pressing needs.

8.5.6.7 Summary of phase five

From the semi-structured interview data, there was a general narrative about factors that facilitated or impeded bereaved parents from accessing baby loss support. Through their social circle connections, participant parents were encouraged to contact perinatal loss charities to seek out opportunities to participate in peer support programmes which would mitigate the emotional distress they felt following the loss of their babies. Whilst not all bereaved participant parents within this study took part in a peer support programme over a long period of time, all participant parents indicated that they were positive about their time spent connecting with other grieving parents. Within the wider bereavement literature, connecting with other bereaved people is perceived to be helpful when individuals grieve (Cacciatore, 2007; Aoun et al., 2018). When the bereaved parents' grief journeys progressed on from their initial loss, their need to participate in a peer support programme also diminished. This would lead to participants processing their grief alone or informally within their social circles. When bereaved participant parents felt a need to return to peer support groups, they indicated that they felt welcomed to attend after their absence.

Within the data some participants reported barriers which prohibited them from regularly attending peer support groups. Participant fathers struggled not only to attend baby loss support groups, but also to find a space where they felt they could share their emotions. Although the participant father sample in this study was small (n=3), the findings demonstrate that men felt responsible to care for their partners, which meant they were supportive of their partners attending baby loss peer support groups whilst they cared for the children. As was noted earlier, men are stigmatised for grieving the loss of their baby out loud, so fathers kept their pain to themselves (Aydin & Kabukcuoglu, 2020). To avoid processing their grief, fathers tended to devote themselves to work (Bonnette & Broom, 2012). However, it should be noted that participant fathers felt that they could attend a group if they chose to access these services.

Phase five of the RTHTG theory proposes that the bereaved parents' grief journeys oscillate between needing support from people within the baby loss community and those within their own social circles. Findings from other studies (Cacciatore, 2007; Umphrey & Cacciatore, 2011; Gold et al., 2022; Jones, 2020) confirm oscillation of seeking bereavement support and not seeking support as an important part of the grief journey. As the pain from the loss becomes less sharp, parents typically accessed less baby loss support. Instead of participating in peer support programmes, they stayed connected to their babies by attending memorial services and taking on leadership positions within the charities they supported.

Findings from this study which influenced phase five of the RTHTG theory suggest baby loss charities support grieving parents by publicising strategies that parents can use to access in-person and online peer support groups. I recommend that there be inclusive marketing towards bereaved fathers who often feel they cannot express their grief. Equally, parents who are further on in their grief journeys should be encouraged to attend peer support groups at times when they need additional support from the baby loss bereaved community.

8.5.7 Phase six: Transforming Pain to Power

Phase six of RTHTG seeks to explain the factors that influence bereaved parents to become more engaged in baby loss leadership opportunities. Participant parents indicated that they found ways to continue their bond with the baby they had lost. Perinatal loss transformed the participant parents in a way they did not anticipate when the loss initially occurred. Findings from the verbal data suggest that participants wanted to find ways to support other parents experiencing perinatal loss.

8.5.7.1 Continuing bonds with children

Investigating continuing bonds with children addresses the fourth research aim which seeks to explore the ways through which minority ethnic communities grieve the loss of a child to stillbirth and what ceremonies/rituals and support are considered culturally appropriate. Participants within this study described the ways in which they processed their loss and found strategies to continue the bond with their babies (Klass, 1996; Neimeyer, 2014; Jones et al., 2021). In the data participants indicated that they attempted to find ways to integrate their baby within their lives. In the interviews, participants shared they included having photographs of them in the home, speaking about the baby to other children in the family, and acknowledging the deceased child's birthday. In the visual data, there were visual images that commemorated the lost children. Collage 1 included an image of a colourful birthday cake. The mother who created this collage disclosed her family still celebrates the baby's birthday every year. Collage 3 included the baby's birthdate because she also celebrated her child's birthday. Additionally, Collage 6 included the first letter of the baby's name; the creator of this collage shared she has photographs displayed in her home to include the baby in the family home. According to Jones et al. (2021), parents who felt empowered to share their relationship with their baby with others had better mental health outcomes. Participants shared including their deceased child in their daily lives helped keep the baby's memory alive; by cultivating active relationships with their child, they have facilitated healing and post-traumatic growth (Walsh, 2007).

Making meaning from perinatal loss reduces the symptoms of anxiety and depression (Jones et al., 2021). These findings align with the results of phase six of the RTHTG theory. Here, participant parents described that they had been on a journey in terms of their loss and had found ways to adapt to a normal they had not planned for. Furthermore, their identifies had been transformed (Neimeyer et al., 2006) and changed the instant they lost their baby (Cacciatore, 2007). Through the loss of their baby, participants were forced to re-examine their own expectations of their parental roles (Niemeyer, Klass,

& Dennis, 2014). Dominic and Amelia described how they interwove their child's legacy within their daily lives.

"What I found is especially Black fathers, once you've been through it, you just don't give a shit about anything else. You're just like, I could do anything I want to do. Nothing is going to break me because I've already been broken and put back together, and I've made it through to the other side. The relationship between my daughter and myself, my dead daughter, is one of the most dynamic relationships I think I've ever had. Because every year it just grows into something that's bigger." – Dominic, Greater London, Dope Black Dads

"It's just a case of, you know, trying to just accept and deal and move on with what's happened and just sort of make him be part of my life and he is. Like I said, there's not a day or a moment where I don't think about him and what's happened but at the same time it's just living this new normal and just accepting and just moving on really."- Amelia, Leicestershire, SANDS

Finding meaning as a response to trauma and loss is critical for a bereaved person to heal (Neimeyer, 2001), because it helps reconstruct a new normal in which the griever adapts to an altered reality to what they once imagined (Walsh, 2007). The death of a child induces a time of reflection which often shifts beliefs and values (Cacciatore, 2007). Growing through traumatic loss, such as these parents did, produces glimmers of hope that their lives may be full again (Walsh, 2007).

8.6 Summary of Road to Hope through Grief theory

The findings from the semi-structured interviews and collage-making activity demonstrated that there was a general pathway that these minority ethnic bereaved parents accessed to find baby loss bereavement support. The overall goal of this chapter was to outline and guide the reader through the RTHTG theory which is a conceptual theory which explains this process (Charmaz, 2006). Methods of data analysis are grounded in the researcher's theoretical assumptions who developed the methods and the assumptions of the researcher conducting the research (Mauthner & Doucet, 2003). As a feminist researcher, I conducted the analysis through a feminist approach which means I consider women's and other marginalised populations' lived experiences as a justifiable form of knowledge, respect and examine my reflexivity in the research process, recognise the context of how knowledge is produce, acknowledge power and privilege exist in the world, and call for transformative social change (Routledge, 2007; Plummer & Young, 2010). Not being a bereaved parent, I viewed the participants as experts on perinatal loss. This is a central epistemological view within feminism which argues that marginalised communities should have the power to 'give voice' to their lived experiences (Mauthner & Doucet, 2003). Validity of the findings are dependent on whether the researcher can demonstrate how the conclusions were reached (Mauthner & Doucer, 2003). This chapter included quotes from the research participants whose insight was fundamental in constructing this theory. As a feminist researcher, I interpreted the semi-structured interviews in conjunction with the visual data to derive meaning to develop the six stages of the theory (Plummer & Young, 2010).

Since the mid-1990s, feminist researchers have used grounded theory within their studies (Plummer & Young, 2010). A constructivist grounded theory approach (Charmaz, 2006) was applied to the study, because it was more methodologically appropriate as an interpretive theory on a study on grief and bereavement compared to other forms which are grounded in positivism (Plummer & Young, 2010; Holtslander, 2014). Constructivist grounded theory (Charmaz, 2006, 2014) was a suitable philosophical fit to my own experience as a bereaved person which allowed me to include my insight. Charmaz recommends the researcher to be reflexive throughout the data analysis and theory development process (Holtslander, 2014). Because Charmaz openly acknowledges subjectivity within the research process and within the construction of grounded theories (Charmaz, 2006), I could include facets of my own experience of grief and bereavement. I wrote memos and created reflexive collages throughout the research process which facilitated the creation of the theory. The theoretical findings which developed into this theory are grounded in the verbal and visual data. It's for these reasons that I argue the RTHTG theory meets Charmaz's (2006) criteria of a constructivist grounded theory which is to be original, credible, relevant, and modifiable.

Participants revealed perinatal loss changed the trajectory of their lives. It took time for them to adjust to the brutal reality of not bringing home a live baby from the hospital. Some participant mothers had to physically recover from traumatic births which impacted on how they felt interacting within their social circles. Participants reported that they needed an initial period to privately process their grief. Whilst it is not uncommon for people to isolate after a traumatic bereavement (Chappel, Ziebland & Hawton, 2015), it is important to acknowledge there may be an implication that my finding was applicable to specific minority ethnic populations. In a study by Garcia et al. (2020), researchers explored stillbirth bereavement in Asian and white British mothers living in Luton, England. Within their findings, the issue of privacy was culturally important to Pakistani and Bangladeshi communities. A major finding from the study showed that grieving the loss of a baby was not common in Pakistani and Bangladeshi cultures which made the mother feel unsupported by her community, so often the losses were concealed and not disclosed (Garcia et al., 2020).

Participant parents shared that when they felt ready to seek support from their communities, they were often encouraged to seek specialised support through baby loss charities. Parents in this study reported their social circles were the biggest contributing factor for them to seek out bereavement support. This was mirrored in the wider literature where immediate support from family and friends was sought out by bereaved parents (Kavanaugh, Trier & Korzec, 2004). Toller (2011) found that parents felt emotionally supported when their networks were willing to talk openly about the deceased child which helped grieving parents cope with their loss. In their book on effective bereavement support, Dyregrov and Dyregrove (2008) argue bereaved people are more likely to seek support when their loved ones support them in that mission.

Participants in this study felt that baby loss peer support programmes offered grieving parents an opportunity to engage with other parents who had also experienced loss. As time passed, participants felt they did not need to rely on peer support groups as they had initially followed their loss. This meant they were able to process their loss themselves and within their own social circle. However, some participants commented that they felt they were encouraged to attend peer support meetings and events even when they were no longer regularly active within the group. Memorial services were a favourable event where bereaved parents could gather together to remember their children around different points in the year. There was a narrative which emerged from participants which indicated that they wanted to support others who were experiencing similar loss within the baby loss community. Consequently, participants found opportunities to facilitate baby loss support groups, create their own charities, participate in volunteer, and trustee roles, and participate in research.

There is no guidance which enables an effective peer support programme, nor any guidelines that accommodate the different needs of parents who experienced baby loss. Throughout the development of this theory, there has been limited evidence on how to best support minority ethnic families who experience perinatal loss. Additionally, there is scarce information on minority ethnic populations attending baby loss peer support programmes which further perpetuates the gaps within the research. Often, minority ethnic families' perspectives go unreported in research (Burchard, 2014) which make it difficult to generalise the findings to include different cultures. Even systematic reviews are limited to disclosing the sample populations within the studies (Burden et al., 2016).

The bereaved parents who contributed to this study loved their baby who was stillborn and wanted to maintain a relationship with them, which often occurred by volunteering within baby loss support groups. This gave meaning to their baby's legacy and supported other newly bereaved families. Although the experience of grief is universal, variations exist across cultures (Klass,1999). Improving bereavement care for families affected by stillbirth must be culturally sensitive to be inclusive to minority ethnic populations where discussing baby loss is considered taboo (Burden et al., 2016). The RTHTG theory indicates that there is a conceptual process that explains how minority ethnic parents access bereavement support. Data from the semi-structured interviews and collages built a theory that was co-created (Charmaz, 2006) by minority ethnic parents and for minority ethnic communities.

Accessing baby loss bereavement support was a fundamental step for the sixteen participants to begin to heal from the immense loss of their child. Finding meaning within their loss helped parents adapt to their grief journey (Cacciatore, 2007,2013). The RTHTG theory provides a pathway concept that can help healthcare practitioners and charities understand how to better connect minority ethnic families with baby loss peer support programmes in an effort to make baby loss support more inclusive.

9 Researcher Reflexivity

9.1 Introduction to reflexivity and autoethnography

A researcher's capacity to understand another is dependent upon how well she knows herself (Pitard, 2017). The purpose of this chapter is to present the personal collages I made whilst I conducted the data collection and developed my thesis, as a means of examining my reflexivity using creative methods (Mcintosh, Webb, & Walk, 2006; Kumsa et al., 2015). Throughout my doctoral studies, I have experienced several major life challenges which have impacted me personally and professionally. My own experience of loss has affected how I processed the data, and who I am as a researcher. Despite my own emotional distress related to these events, I believe I have developed a nuanced understanding of what grief and bereavement is, which has enabled me to work in this sensitive field with empathy and compassion.

This chapter begins by introducing the concepts of reflexivity and autoethnography. I then consider my personal history and how it has influenced my research identity (Castello et al., 2021). Finally, I present the collages I made during this research project which documents my experience of researching grief and bereavement whilst grieving the loss of my first marriage, and the deaths of my mother, my uncle, and my grandmother within a three-year time frame.

9.2 Defining reflexivity

Reflexivity is a term that is often used in qualitative methodology, but poorly defined (Palaganas et al., 2017). When I began my research, I noticed that the term 'reflexivity' and the act of 'being reflexive' was frequently used within studies (Dowling, 2006; Jootun, McGhee & Glenn, 2009; Palaganas et al., 2017). Additionally, I observed that within the published doctoral theses that were available online, that there was little attention paid to how researchers defined reflexivity and how they incorporated it within their studies beyond a brief discussion within the introductory chapters. Whilst there were many texts (Finlay, 2002; Watt, 2007; Hsiung, 2008) on reflexivity and resources detailing how to include it within qualitative research (Mitchell et al., 2018; Dodgson, 2019), there were few definitions of it that matched my pragmatic-feminist-transformative research paradigm (Wuest, 1995; Franks, 2002; Rosiek, 2013). Reflexivity as a tool is fundamental within qualitative research (Morse et al., 2002; Lamberts, Jomeen, & McSherry, 2010). However, many definitions of reflexivity within the literature are simplistic (Holmes, 2010). When reviewing these, the definition I aligned with most was a combination of several different aspects these included: reflexivity as the act of being self-aware during the research process (Jones, 2013; Dowling, 2006; Lambert, Jomeen & McSherry, 2010) and which examines the role the researcher plays within conducting qualitative research (Gouldner, 1971 as cited in Dowling, 2006). To be reflexive, researchers must acknowledge their subjectivity whilst carrying out research (Palaganas et al., 2017), and recognise that a researcher's "social background, location and assumptions affect their research practice" (Hesse-Biber, 2007, p.17). The researcher must critically reflect on the lived experiences and how that unfolds within the research process (Hesse-Biber, 2014). Reflexive researchers should clearly acknowledge the relationship that exists between participants and the researcher (Jootun, McGhee, & Marland, 2009). As a feminist reflexive researcher, I recognise the relationship built between the researcher and participants "is sensitive to the important 'situational' dynamics that exist" (Hesse-Biber, 2014, pp. 201). The rapport built between the participants and me enabled the development of an active partnership between participants and researcher (Palaganas et a., 2017). In return, the relationships built with these sixteen bereaved parents influenced how I approached examining my reflexivity (McFadyen & Rankin, 2016).

9.3 Autoethnography

Autoethnography originates from ethnography which is a form of qualitative inquiry (Ellis, 2004). This methodology has grown within the humanities and social sciences (Spry, 2011). Like reflexivity, through autoethnography, the researcher becomes an active participant within the study and analyses how she relates to the phenomenon being studied (McIlveen, 2008). It coalesces autobiography and ethnography, combining writing about the personal and the relationship to culture (Tilley-Lubbs, 2016). However, it goes beyond writing an account of one's life story. Researchers who use autoethnography strive to portray 'aesthetic and evocative thick descriptions of personal and interpersonal experience' (Ellis, Adams, & Bochner, 2011, pp.277). Including personal stories allows researchers to make sense of their experiences (Poulos, 2008) which can be therapeutic (Ellis, Adams, & Bochner, 2011).

Under the umbrella of autoethnography, there are many forms of writing and representation within this method (Spry, 2011). It may be implemented through a variety of different modes such as visual, audio, and written methods (Ellis & Bochner, 2000; McIlveen, 2008). Performative autoethnography is the convergence of creating art and knowledge (Spry, 2011). Using different mediums, a performative autoethnographer can make research findings more engaging and accessible (Ellis, Adams, & Bochner, 2011). Performative autoethnography calls upon the researcher to demonstrate their heart within their research (Spry, 2011; Holman Jones, 2009). Spry (2011, p,54) comments that 'Performative autoethnography represents the connection between the personal experience and cultural assumptions, between the word and the body, and offers the researcher healing through enacting these connections.

Spry's (2011) work on performative autoethnography offered me an opportunity to tell my story utilising collage which resonates with my personal experience of grieving the loss of my mother. Furthermore, I implemented collage as a performative autoethnographic method to articulate how I connected with my participants' experiences of grief and bereavement and the larger social issues within perinatal loss and accessing bereavement support (Inati et al., 2018; Helps et al., 2020). Researchers who use performative autoethnography methods tell their stories through new ways which help to fill the gaps within the existing qualitative methodology literature (Spry, 2011; Brown & Nash, 2010; Adams & Jones, 2011).

9.4 Combining reflexivity and autoethnographic lens into this thesis

Carolyn Ellis and Art Bochner (2006) encourage researchers to focus on the elements of emotional autoethnographic writing. Ellis continues this in her 2007 work and states that "this requires us as researchers to act from our hearts and minds, to acknowledge our interpersonal bonds to others", (Ellis 2007, p. 210). Within this chapter, I found inspiration from the autoethnographic method personal narrative (Ellis, Adams & Bochner, 2011) which helped me to document my experience of grief and bereavement and in doing so triangulate with the study's data (McIlveen, 2008). Autoethnographic personal narratives opens the researcher's world to readers and provides context in terms of how the study was carried out (Ellis, Adams, & Bochner, 2011). As a method, autoethnography challenges traditional qualitative research concepts (Ellis, 2009; Adams & Jones, 2011). Even more unorthodox in health science research, performative autoethnography requires the researcher to be vulnerable to the scrutiny of the researcher's own critique and that of the reader (Spry, 2011). Spry's 2017 work explores how performative autoethnography connects the researcher with the participants. She writes that performing autoethnography calls upon the researcher to critically reflect about how the researcher relates to the participants from a critical social lens, which creates a 'wilful embodiment of "we"' (p.48) through the performance (Spry, 2017). Together, reflexivity and autoethnography have qualities that anticipate that the researcher will become personally vulnerable and will think critically about the phenomenon being studied (Adams & Jones, 2011). Implementing performative autoethnographic principles into research bridges lived experience to theory (Dawson et al., 2022).

Reflexivity involves active listening so that the untold stories and silences within the research process are noticed. Autoethnography however, employs personal storytelling to bear witness of the phenomenon being examined so that the story can resonate with others who have experienced that phenomenon (Adams & Jones, 2011). Applying autoethnographic practice within a doctoral thesis to represent reflexivity has been recommended in qualitative research (Humphreys, 2005). In this doctoral study, the arts-based method of collage was utilised to tell the story of my grief journey whilst being reflexive and examining the influence of my grief journey and how I frame my own experiences to the experiences of the research participants. The purpose of this chapter is to offer a lens through which the reader can observe the pain and contentment associated with studying a subject that is closely related to the researcher.

I consider this doctoral thesis a fusion of health sciences pragmatism (Long, McDermott, & Meadows, 2018) and a transformative paradigm (Mertens, 2007) which recognizes the value of incorporating arts-based participatory methods (Romm, 2015; Groot & Abma, 2021). When I began my doctoral studies, I was in the final stages of a divorce which I thought was going to be the most profound personal event I would face. I was not prepared for how my life would change throughout the course of this four-year period. Now, I have studied and written a thesis on grief and bereavement, a topic which I have come to know intimately. During the four years as a doctoral researcher, my mother died in 2018, and my grandmother and uncle died in 2021 during the second COVID-19 wave in Minnesota. Like others who have recently experienced the loss of loved ones, perhaps related to the COVID-19 pandemic, I struggled to make sense of my experiences of grief and bereavement. It has been challenging to articulate the trauma associated with the deaths of three prominent family members and the lingering emotional distress in a professional way that sounds genuine and heartfelt. I have an acute awareness that being vulnerable may be seen as unprofessional or weak as a researcher (Rice-Evans & Stella, 2017), nevertheless; it was my vulnerability that facilitated sensitive conversations where there was a reciprocal understanding of witnessing each other's grief (Sherry, 2013).

The recurring questions I wrestled with during my doctoral course were: 'how do I convince readers from health backgrounds that my own experience of death and bereavement is worth investigating and considering in terms of how I conducted data collection and analysed the data? How do I integrate reflexivity through an autoethnographic lens when autoethnography is often receives push back in health sciences?'. I wrote this chapter to go beyond writing about what reflexivity is within the literature and how to apply it, to show the collages I created about my own experience of grief and bereavement in conjunction with the work the research participants produced. Additionally, I document the different forms of bereavement support (including peer support) I have sampled throughout the last four years, and what I have learned about accessing support during my own grief journey.

Within this chapter, my aim is to magnify the importance of reflexivity when researching sensitive topics such as grief and bereavement. It aims to show readers the value of using autoethnography to explore reflexivity in a more thorough way that can facilitate the researcher to create new knowledge and to acknowledge the researcher's positionality of the phenomenon being studied.

9.5 My personal experience of loss

It is essential to distinguish how my experience of death and grief is different to the participants' experiences. The death of a parent is intrinsically different from the death of a baby, and yet the mutual experience of profound loss facilitated the interviews and collage-making activities (Rowling, 1999; Dickson-Swift et al., 2006). Knowing there was a mutual understanding of grief and bereavement helped me to feel confident that I had experience and knowledge of loss which I could use when conducting research in this field (Mitchell-Eaton, 2019). I was raised knowing I had siblings who were stillborn. Additionally, my aunt and my grandmother never hid the loss of children they had experienced when pregnant. I had grown up with my family's collective experience of baby loss and understood that these children's lives mattered. Although they were no longer alive, these babies were loved and remembered. The birthdays of my siblings, cousins and uncle were noted throughout the year. Throughout my childhood, my mom took me to the cemetery where the babies were buried; I was included in honouring them by visiting their graves. I have never feared death or cemeteries because grief was normalized in our family's story.

The relationship I had with my mother was complicated. As a child of an alcoholic, I was often the parent in our relationship (Omkarappa & Rentala, 2019). I took responsibility for her wellbeing at a young age and continued to care for her within a parental role when I became an adult. It was not until she received a court ordered for a year-long treatment programme in 2012 that she received appropriate care and treatment for her alcohol dependency and poor mental health. However, despite successfully completing the intensive treatment programme, she quickly relapsed and began to drink again. In 2014, she was declared psychiatrically disabled and unfit to care for herself by the state of Minnesota (Minnesota Department of Human Services, 2022). With my mom's new disabled status (Minnesota Department of Human Services, 2022), the state of Minnesota provided her with housing, healthcare, mental health programming and a monthly income. My grandmother and I considered the state's judgment to be positive because it provided additional support for us when caring for her.

My mom died from sepsis related to pneumonia on Christmas Day, 2018. It was the first year of my doctoral programme, and I had not planned to fly home to celebrate the holidays. I received a call on 22nd December from a number I did not recognise and spoke to the doctor caring for her. The doctor informed me she didn't expect my mother to recover from the infection because she was rapidly deteriorating. Understanding how vulnerable she was due to her poor mental and physical health, I prepared myself that I would lose my mother at a younger age than was normally expected. I did not anticipate she would die from something unrelated to her substance misuse or poor mental health. I flew from London to Minneapolis on 23rd December to say goodbye to my mother. As her designated next of kin, and the eldest child, I was responsible for deciding when to end life support. It felt like an unbearable responsibility to hold, and a horrendous decision to make. Ultimately, her condition declined, and the right decision was to remove the life support equipment.

My role followed me beyond her death when my grandmother and I had to clear the apartment where my mother had lived. Even after she died, I was charged with caring for her belongings. When I was cleaning her apartment after she died, I found some of the artwork she created. I remember her as being a highly creative and charismatic person. Her innate talent coupled with the abilities she learned during her time at university made her a competent artist. She was exceptionally skilful in drawing with charcoal. Her bedroom had several pieces of art she created hung on the walls. One of those pieces is the collage below. I do not know when she created this collage, nor do I know what the purpose of it was. I suspect it was an activity that was part of a mental health day programme she was required to attend to maintain her disability funding.

Figure 58: Collage I found in my mom's apartment in December 2018

This collage offers a glimpse of who she was and the images and phrases that represented her at the time of its creation. She openly acknowledged her addiction with the phrase 'my life as an addict' (in yellow writing on the left side). The viewer can see she struggled with her body image through the phrases of 'my size does not define me' and 'I love my body now'. The designer Ralph Lauren was included in the centre of the collage which is an indication of how much my mom enjoyed fashion. Kate Middleton is featured on the right half of the collage because my mother was devoted to following the royal family. She was a fervent animal lover which is why she included all the images of cats and dogs. The image I find most poignant is the one of the celebrities who died when they were young, as my mother also died at a young age.

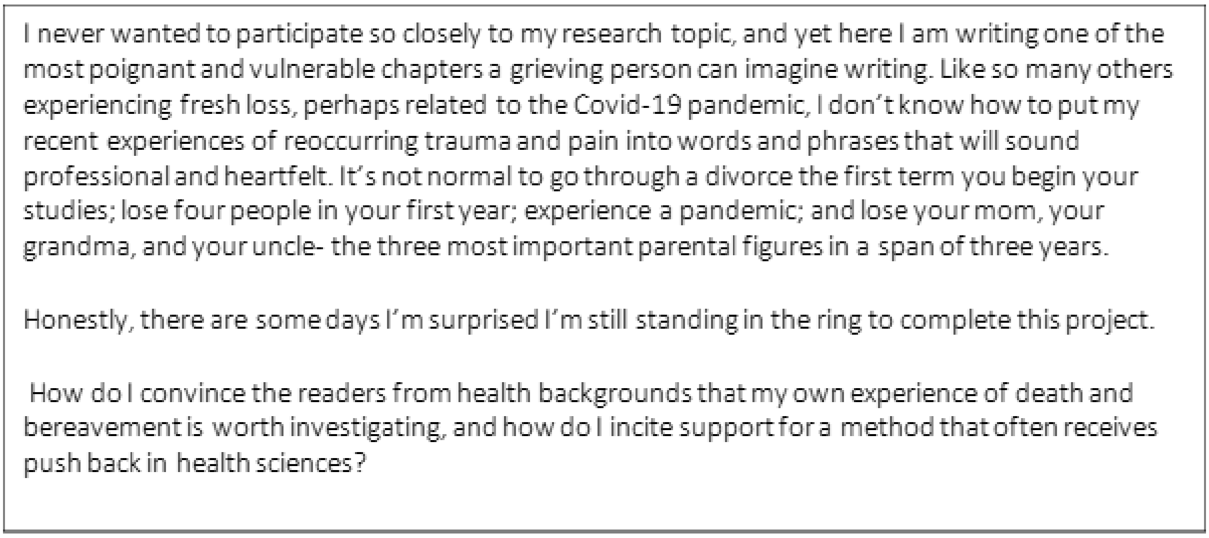
Whilst this collage does not portray an encompassing portrait of who my mom was, it does confirm that she was someone who was had poor mental health and yet was creative. The collage that she created verifies meaningful aspects of her identity and lived experience of mental health concerns (Mohamed, 2012). Each image and word she selected to be included within the collage told a story of who she was through her art (Stallings, 2015). As a bereaved daughter, this collage strengthens the positive aspects of her personality that I miss most about her.

9.6 Processing loss upon loss

My Uncle Bill died in January 2021 from Glioblastoma. Due to the Covid-19 pandemic, he was not treated with the care he would normally have received. He was misdiagnosed several times with Covid-19 and a stroke until the cancer was discovered during exploratory brain surgery. The holidays were quickly approaching when we learned of his terminal diagnosis. My aunt chose in-home hospice care, so our family could be with him in his final days. If she had opted for palliative care in hospital, only my aunt would have been able to say goodbye because of the visiting restrictions put into place during Covid-19. Losing my Uncle Bill was a devastating loss for the family. My uncle was my father figure; he married into the family when I was 14 years old. He was as active in my life as a parental figure as he was in his own children's lives. He was the last man in the family living in Minnesota and was responsible for carrying out home improvement projects and tending to emergencies. His death has had a significant impact on our family which still persists just over a year after his death.

Eight months after the death of my Uncle Bill, my grandma died in September 2021. She was a fit, active, and healthy 86-year-old. Unfortunately, she died from sepsis caused from pneumonia which was the same as my mother. Despite the similarities in how they died, I was more prepared to say goodbye to my grandmother than I was to my mom. My grandma had lost my grandpa to lung cancer in 1988. When my mom died in 2018, my grandmother assumed the role of a bereaved mother alongside her older identity of a widow. Her personality changed when my mom died. For the following three years after my mom died, she mourned the death of her youngest daughter. I felt my grandma lost interest in living; grief had consumed her and appeared to become a permanent part of her personality. There was a distinct change in her demeanour when my Uncle Bill died earlier in 2021. As a Christian, she believed she would see her loved ones again and held onto the hope that there was an afterlife. Her death was sudden and unexpected, and yet my family and I find comfort in her having strong faith.

It was gruelling to grieve for these two deaths simultaneously; each death required its own grieving period (Mercer & Evans, 2006). However, I have not had the capacity to address my own grief whilst writing the doctoral thesis and getting married again. Losing multiple people in a short time span may impact on the likelihood of a bereaved person experiencing complicated grief (Wallace et al., 2020) which may produce or intensify PTSD symptoms (Kentish-Barnes et al., 2015). I intentionally wrote about my uncle and grandma's deaths in this chapter because both have had an impact on my well-being and my attitude to grief and bereavement. Whilst I have not had the time nor space to fully process my grief related to their deaths, I know that there will be time after my doctoral studies have finished when I will be able to process the impact of their deaths. Below is an excerpt of a research journal entry which captures how it felt processing so much loss while being immersed in the field of grief and bereavement.



I never wanted to participate so closely to my research topic, and yet here I am writing one of the most poignant and vulnerable chapters a grieving person can imagine writing. Like so many others experiencing fresh loss, perhaps related to the Covid-19 pandemic, I don't know how to put my recent experiences of reoccurring trauma and pain into words and phrases that will sound professional and heartfelt. It's not normal to go through a divorce the first term you begin your studies; lose four people in your first year; experience a pandemic; and lose your mom, your grandma, and your uncle- the three most important parental figures in a span of three years.

Honestly, there are some days I'm surprised I'm still standing in the ring to complete this project.

How do I convince the readers from health backgrounds that my own experience of death and bereavement is worth investigating, and how do I incite support for a method that often receives push back in health sciences?

Figure 59: Journal entry of February 2022

Although their deaths have personally shaped me, I consider their deaths outside the remit of influence for this study. The reason is that I finished collecting data from the participants before my Uncle Bill and Grandma died, and therefore their deaths did not affect the analysis of the data. As part of my examination of my own reflexivity, I have included them in my personal collages to mark their deaths as part of my experienced during my doctoral programme and as a tribute to them.

9.7 Collage as a tool to examine reflexivity

From a feminist perspective, researchers should have the capacity to draw upon the methods they use to examine their reflexivity (Franks, 2002). Putting this concept into action, I implemented the same creative method of collage-making as the participants to examine my experience of grief and bereavement through an autoethnographic lens to explore my grief journey. I have developed an appreciation of how autoethnography integrates the humanities and social sciences (Bochner & Ellis, 2002; Bochner & Ellis, 2003). By combining humanities and social health science research together I consider myself to be an “artful scientist”, (Brady, 1991 as cited by Bochner & Ellis, 2003). I combined some of the characteristics of autoethnography with Facet Methodology and Pragmatic Feminism. The act of creating a collage enabled me to visually present my grief which I considered to be more profound than writing about it. I aligned collage-making to Facet Methodology (Mason, 2011), as making a collage is a creative act which is a hallmark of this research method (Muir, 2022), as the act of making a collage requires the artist to be inventive and imaginative (Ferro, 2022). From a feminist perspective, collage has empowered me to share my grief journey instead of hiding my experience of loss (Franks, 2002). Arts-based research can be used to tell a story (Bochner & Ellis, 2003), and the creation of the collages provided a relatively inexpensive alternative with which to construct a visual story rather than simply writing about my story.

Creating my collages required me to travel through time and space to reconnect with the acute grief I initially experienced after the deaths of my family members. I created the collages four times a year during the data collection, analysis, and the writing of the thesis period. My memory has been impacted by my grief. I can remember how I felt during my losses more than the actual timeline of the events. I used photographs of my family members to further reconnect with my grief journey and my memories of them. The collage exercise entailed that I had to intentionally set aside time to think, reflect and to create. Each collage marks a specific time during this period and documents the deaths of my Uncle Bill and my grandmother. Although their deaths did not have an impact on the data collection, I wanted to include them in my reflexive exercises to honour how their deaths have had an impact on me.

The impact of COVID-19 on grief and bereavement discourse was astonishing. Within healthcare, grief and bereavement care are ranked lower than other priorities (Hay et al., 2021). However, the Covid 19 pandemic underlined the importance of having policies in place to support grieving families (Pearce et al., 2021). For the first time since my mom’s death, I felt I could speak openly about my grief without feeling estranged from people. Grief was a global phenomenon (Walsh, 2020), which would help to normalise sorrow and the loss of loved ones whether it was from social distancing measures or deaths caused by the virus (Imber-Black, 2020). Deaths from Covid-19 were unanticipated and happened quickly (Mayland et al., 2020), and augmented the risk of the griever suffering from prolonged grief (Pearce et al., 2021). There were countless images which circulated through the media showing people who were severely ill and in critical care, which is where my mom (2018) and later Grandmother (2021) both died. Mourning rituals were disrupted by social distancing regulations which meant families had to grieve away from their communities (Morris, Moment, & deLima Thomas, 2020). Nevertheless, it became more acceptable to discuss the impact of grief and bereavement during the Covid-19 pandemic than it had been previously (Murphy, 2020).

Within the collages, I used images that served as metaphors to expand the meaning of my experience of loss. I was inspired by the bereaved participant mother who included photographs in her collage. I began to include photographs within the later collages. Collages were constructed from the same magazines that the participants used, however, I included different materials I had access to, such as an American calendar, Christmas carol programmes, and sympathy and wedding greeting cards. In March 2022, members of the Canterbury Christ Church University community were invited to present creative works documenting their experience of the pandemic and I submitted all six of my own collages to the University Covid-19 exhibit hosted by the Chaplaincy. I received positive feedback from the Chaplains about showing my vulnerability in my art. In addition to contributing to the exhibition, I gave a seminar on the power of using collage as a research method to the postgraduate student body. I didn't recognise that I brought someone in the audience to tears during my presentation. She later thanked me for my honesty in discussing my personal experience of grief and how my grief journey could connect to other areas of grief and bereavement research.

9.8 My reflexive journey through collage elicitation

In summer 2019, I received a bursary to attend a weeklong qualitative creative methods course at the University of Manchester. At the time of the course, I did not know that I was going to enjoy creative methods because it was the first time that I had been exposed to this type of research methods. The collage below was created in a thirty-minute timed challenge during the short course. The instructor asked us to create a collage which described our research topic. It was difficult for me to find images and texts that directly related to the topic of perinatal loss, so I chose words and images I thought might describe the experiences potential participants might had had when accessing bereavement support. The output I created appears severe in comparison to the research participants' collages. The images I selected to represent baby loss are largely black and white. Conversely, the collages the participants made are bright and colourful. The items the research participants chose to represent baby loss were different than the items I chose. The discrepancy between my collage and the participants' collages lies within my naivety around the topic of pregnancy loss. At the time when I created the collage, I had only read literature within the baby loss field. Participants' collages were more complex than I had anticipated

Because the task was a thirty-minute activity, I spent time finding words and phrases to correspond to grief and bereavement. The supplies that were provided had very little content related to maternal or baby health despite the diverse range of magazines that were provided. To construct Collage 1, I used scissors and Sellotape to attach the items to the piece of paper. I included this collage (see below) within this chapter because it was the first attempt to experiment with creative methods. It highlights the themes I anticipated I would see from the data as a result of my experience as someone who has two stillborn siblings. Admittedly, the collage is grim and does not portray the vastness of my grief journey. It was interesting to compare the participants collages to collage number one, because they were radically different to what I had envisioned the data would reveal.

Figure 60: Collage 1, June 2019, Ceative Methods short course at University of Manchester

Figure 61: Collage 2, December 2019, submissionof creative piece for Social Research Association Conference

Collage 2 relates to the first anniversary of my mom's death (25 December 2019). The story told in this collage conveys my experience as an international student missing the comfort of grieving with my family. I incorporated words and images of Christmas to signify how the holiday has changed. Instead of looking forward to it, it had become a season that I feared. I chose text emojis which detail the waves of feelings I felt while initially processing my early grief. To represent my American identity, I included several strips of the American flag and the image of the United States in the left-hand corner because the picture showed where Minneapolis was located. I also selected the word 'alien' because I still feel estranged from the culture in which I live. The life I have built in the United Kingdom has never co-existed with the life I had with my family in Minneapolis. Until this year, no one from my family has visited me in the UK. At times, I felt like I lived two distinctly different lives; one in America and one here in the UK. I integrated images of my student identity by including a desk, keyboard keys, a notebook, and the word 'underpaid'. Despite my status as a doctoral student, I chose these images because there were times where I felt stuck compared to my friends' lives. My American friends were secure in their careers; many began to have families. I felt silly starting a doctoral programme at thirty years old when my friends were planning how to save for a mortgage. The phrase 'wheel of misfortune' acknowledges how unfair it feels to experience a life of instability and emotional distress compared to other people who have never experienced such hardship. Despite the resilience I developed over my life's course, learning to live without my mom has felt particularly challenging and difficult.

Collage 3 (below) was constructed in March 2020 at the beginning of the Covid-19 pandemic.

Figure 62: Collage 3, mid-March 2020, Londond, Data collection period.

I created this collage as both a tribute to my mother and to mark what was happening globally at the time. Mother's Day in the UK was quickly approaching, and I was reminded of how the significance of the day had changed. The phrase 'do keep your distance' was selected to signify how I felt grieving the loss of my mom when most of my contacts were preparing to celebrate Mother's Day. Instead of a day to celebrate, Mother's Day became a day to commemorate my mom's memory. She was a fan of Marilyn Monroe, so I was pleased when I found an image of the actress in a magazine to add to the collage. I also included the word ‘beauty’ to honour my mom. The background of the collage featured a pink birthday cake with her initials ‘ck’, because she was born in early April.

At the time this collage was generated, the Prime Minister had ordered people to stay at home. I felt restless and nervous about the possibility of a national lockdown taking place. I was researching ways I could fly back to Minnesota to be with my grandmother. Daily news coverage included very ill people in ICU which generated memories of my own mom’s death. I represented the impact of the Covid-19 pandemic by including the words ‘clean’ and ‘colds & flu’. At the time the virus began to circulate in the UK, there was discourse on how the virus was like normal colds and flus. I selected the images of a hand holding bars of soap and the phrase ‘in trusted hands’ to denote the NHS guidance to wash hands for at least 20 seconds (NHS, 2020). I selected an image of a woman working on a laptop while seated cross-legged to demonstrate the adjustments people made when working from home. To further represent changes to work life, I included the words ‘work’ and ‘play’ which were constructed on keyboard keys. I felt the effects of being inside the flat for most of the day. The lines between where work ended and where leisure began soon blurred.

‘Stressed’, ‘burnout is fast’, and ‘I have always had grit and determination’ were chosen to demonstrate how I felt as a second-year doctoral student. In early March 2020, I had just received ethical approval to begin recruiting research participants, and felt recruitment was going to a difficult task as the national lockdown was imminent. I had completed two interviews prior to the lockdown, and I feared that I would not be able to recruit other participants. I worried I would have to change the design of the study, as I was unsure whether participants would want to create collages remotely.

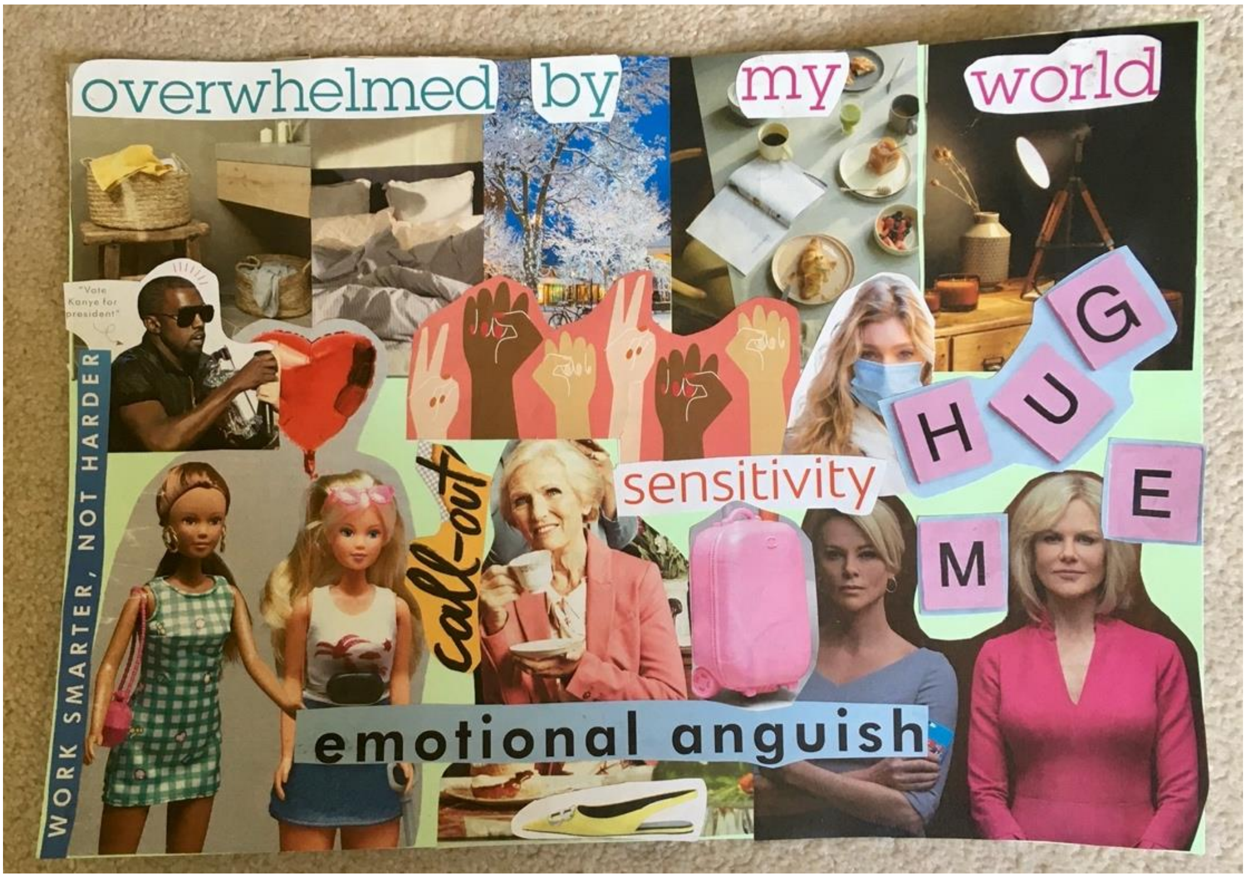


Figure 63: Collage 4, June 2020, Minneapolis, Data collection period

I flew back to Minneapolis on the 10th of April 2020 to care for my grandmother. Because she was an independent widowed woman who lived by herself, she did not fear catching the virus. She assured me she would take precautions and take care to avoid meeting people, however, I wanted to go home to be with her and care for her. I made Collage 4 at the beginning of June, and it chronicles what was taking place in the United States at that time. An African American man named George Floyd was murdered by a white police officer in south Minneapolis which is less than ten miles away from where my grandmother lived. His murder initiated national and international protests. The central image of the hands giving the peace sign and protesting is symbolic of the demonstrations that took place across Minneapolis. I also included the words 'call-out' and 'sensitivity' to highlight the never-ending struggle for racial equity in America (Dai et al., 2021).

I incorporated other images that marked what was happening in June 2020 by including the rapper Kanye West who was campaigning as an independent Presential candidate. The Covid-19 virus was at epidemic levels throughout the state of Minnesota. I selected the images at the top of the collage to demonstrate that my grandmother and I spent most of our time indoors. Although we did not often engage with the outside world, I felt overwhelmed by the responsibility that I had to keep her safe.

Even though I was preoccupied with caring for my grandma, I felt compelled to find a way to continue with my studies. I wanted to continue my education. I chose the phrase ‘work smarter, not harder’ to acknowledge that I used that time in the first wave of Covid-19 to publish an article on my study’s methodology with my first supervisor. The article was accepted by the British Psychological Society for a special interest issue on creative methods in qualitative research (McCloskey & Wier, 2020).

I positioned the image of the T.V. cook Mary Berry in the centre of the collage to represent my grandmother. She was the centre of my world. I included the image of the two Barbie dolls (on the left side of the collage) to represent my sister and me. On the right side I included two blonde women to symbolise my two aunts. I acknowledged the impact of Covid-19 on daily life by including an image of a woman wearing a medical mask and ‘hug me’ because I missed having physical contact with my other family members. My grandmother and I did not see anyone inside our home for three months fearing that someone would accidentally bring expose her to the virus. ‘Emotional anguish’ is positioned above a yellow shoe. It is pasted across the family members to demonstrate that we were collectively grieving the loss of my mom in our own ways. These images represent my mom’s missing presence within the family unit. She loved shoes; most of her clothing still resided in our home. The last image is of a pink suitcase which I selected to symbolise that I had to return to the United Kingdom to pursue my doctoral studies which created tension between my grandmother and my aunts. My grandmother supported my wish to return to the UK whereas my aunts wanted me to stay and care for my grandmother. Ultimately, I returned to London in July knowing that my decision was not fully supported.

In the summer of 2020, Covid-19 restrictions were relaxed, which enabled people to meet in-person once again. From August to September 2020, I collected the second cycle of my research data. As the rate of positive cases of Covid-19 accelerated in autumn, I decided to conduct the semi-structured interviews and collage-making activity remotely. In early November, national restrictions were reintroduced in England. This lockdown limited contact in terms of meeting people not within a designated “support bubble” (Danon, Lacasa, & Brooks-Pollock, 2021). I resorted to collecting the rest of my data remotely. In addition to finishing my data collection, my family was given devastating news. In November 2020, my uncle was diagnosed with stage four glioblastoma. Despite the risk of travelling to the US for the holidays, I understood how precarious his health was and I longed to be with him. It would be the last time I would see my Uncle Bill alive.

Figure 64: Collage 5, December 2020, Minneapolis, Analysing data

Collage 5 depicts my time spent in Minneapolis over the holiday season. My grief is the central theme of this collage. The background is a page from an American calendar that hung in my grandmother's kitchen. The 25th of December 2020 marked the second anniversary of my mom's death. I chose the image of candles and placed them over the course of Christmas to mark the importance of the day (these are in the centre of the collage). 'Our family tragedy' is at the centre of the collage to illustrate that our entire family is missing a member during the festive holiday season. The hands shaped as a heart are symbolic of the enduring love that I felt towards her despite her poor mental health and alcohol addiction. She was not a good mom by societal standards, but she was *my* mom. As a tribute to my mom's interest in the royal family, I included an image of Princess Diana and Prince William and his children. Prince William has spoken openly about his grief journey, and how he keeps his mother's memory alive for his children which is what I hope to do for the family I might have in the future.

The phrase 'my mother's legacy on mental health' is placed over an image of a little girl and an adult woman tying the child's shoe. I selected this picture to represent the impact that my mom's poor mental health had on my own career aspirations. I wanted to study maternal mental health to help other women like my mother. On the bottom left corner of the collage, there is a woman holding a happy face mask whilst she texts someone on her mobile phone. Within my grief journey, I have felt I had to ‘mask’ how I felt about the holiday season to not upset other’s festive feelings. It has been challenging to learn how to manage my emotions in terms of honouring my grief and participating in holiday gatherings. The phrase ‘find your quiet place’ represents the need I felt to respect my grief by spending time alone and reflecting on my mom’s life and legacy. I chose to incorporate ‘changing the narrative’ to emphasise how grieving the death of a loved one lasts beyond the initial shock of the loss. Conversely, I selected the phases ‘Finding joy & staying sane!’, and ‘I am strong enough. I didn’t always know that’ to represent the resistance I felt in terms of practicing gratitude. Despite December being my season of grief, I was thankful to be home with my family and to be in my hometown where my mom’s memory existed, unlike in London where no one had ever met her. My family mourned her death whilst we watched my uncle’s health decline rapidly.

Related to the two earlier 2020 collages, I integrated images of current events that took place at the time the collage was created. I included an image of Minneapolis and pasted the word ‘roots’ on top of the photo. National protests calling for systemic change in race-based violence and police brutality (Weine et al., 2020) continued. A memorial and a mural were constructed outside the Cup Foods corner shop where George Floyd was murdered. The words ‘pandemic adjustments and an image of a medical team wearing surgical masks represent the second wave of Covid-19 which instigated national lockdowns in both the US and the UK (Looi, 2020). These restrictions meant there were no international flights, which delayed my return to London.

Figure 65: Collage 6, April 2021, London, Analysing Data

I was in Minneapolis from mid-December 2020 until early April 2021 due to several flight cancellations. Collage 6 was created in June 2021; I had resumed my studies and was analysing the data sets from the semi-structured interviews. This collage has three distinct sections which are separated between my past which largely features my family (left panel), my present experience as a postgraduate student (middle section), and the future I hoped to create (the right panel).

The left portion of the collage features several photographs of my mom, my Uncle Bill, my grandmother, and my sister. This section narrates my experience of grieving my new loss in conjunction with grieving for my mom. Uncle Bill died in January 2021 from glioblastoma; he died two months after his diagnosis. The nature images of the northern lights and the barren trees were indictors that the winter was my season of grief; they are also images that are visible in Minnesota. Another Christmas passed that largely centred around loss. For this reason, I pasted 'the perfect Christmas' upside down near the photograph of Bill. There was no such thing as a perfect Christmas, or a good one. His death disturbed the balance of our family. We no longer had a male relative living nearby. I chose a photo of him that was taken at my first wedding when he accompanied me during the father and daughter dance. At the top of the section, I included an image of a woman with her mouth removed with a quote above it which says: “how we present ourselves to the world is part of our identity” to demonstrate how I felt silenced by my loss. It was difficult to not speak about him, and yet I did not want to share another experience of grieving with the world.

Bill’s passing made it difficult for me to focus on my studies. I lacked the concentration I needed to complete the data analysis. I did not want to speak about the complex nature of grieving new and old losses. I worried about the health and safety of my family which is why I included the photographs of my grandmother and my sister. I included a photograph of myself when I was two years old to symbolise the relationship I had with my inner-child and the emotional wounds I held from my childhood. Like this young girl who struggled to find coping mechanisms to continue her schoolwork despite the turmoil at home, I felt that I was balancing a life between my personal and professional identities. There was a continuous battle between becoming a perinatal grief expert and grieving the loss of two parental figures.

The middle panel documented my feelings towards my postgraduate research journey and how conflicted I felt carrying on with my studies knowing my family was adjusting to another loss. I wrestled with my identity as a researcher with lived experience of grieving close family members and carrying out perinatal loss research. This is the reason for including ‘the confidence that comes from having lived should be valued’ caption. A photograph of a mural of George Floyd was placed at the bottom central portion of the collage. This image refers to the time I spent reflecting on my position as a white researcher researching minority ethnic communities and whether I was the right researcher for this doctoral project.

Because I was behind in my research project compared to my friends pursuing doctoral studies, I struggled with ‘imposter syndrome’ which is positioned in the middle of the collage. Imposter syndrome is well represented within the literature pertaining to early career researchers’ mental health and wellbeing. Sverdlik, Hall, and McAlpine (2020) define imposter syndrome as a doctoral student’s negative self-image. Doctoral students with imposter syndrome struggle to acknowledge their successes; students feel they’re living as frauds within the system and will one day show how undeserving they are to work in the academy (Sverdlik, Hall, & McAlpine, 2020). Imposter syndrome sufferers attribute their accomplishments to be from luck or other external factors (Bothello & Roulet, 2019). Whilst I knew I earned my scholarship, and worked hard to study for a doctorate, there were times that my self-confidence waned. With every loss, I struggled to see the value of continuing my studies when my family in America was grieving. Despite facing my own version of imposter syndrome, I included an image of a heart and the quote ‘you’re doing this for other women, too’ to convey that I did find joy and purpose in the work I was doing despite the existential crisis that occurred within me. Contrary to the left and centre panel, the right panel was intentionally designed to feel lighter. This panel included words and images which inspired me to live a life independent from grief. I picked images that were symbolic of spring, such as, flowers, healthy leafy trees, a greenhouse draped in sunshine, and Easter eggs. The season of spring is the antithesis of winter and my personal season of grief. Through my grief journey, I found that as the seasons changed the days became longer and I could cope with my grief better than at Christmas time. ‘Lighten up’ was the tone of this panel because I wished to feel light-hearted and at ease within myself. An image of St. Paul’s cathedral, the Love Walk Street sign, and ‘completely at home in London’ aimed to remind myself that as much as I missed my family in America, I had created a life in the UK that was also my home.

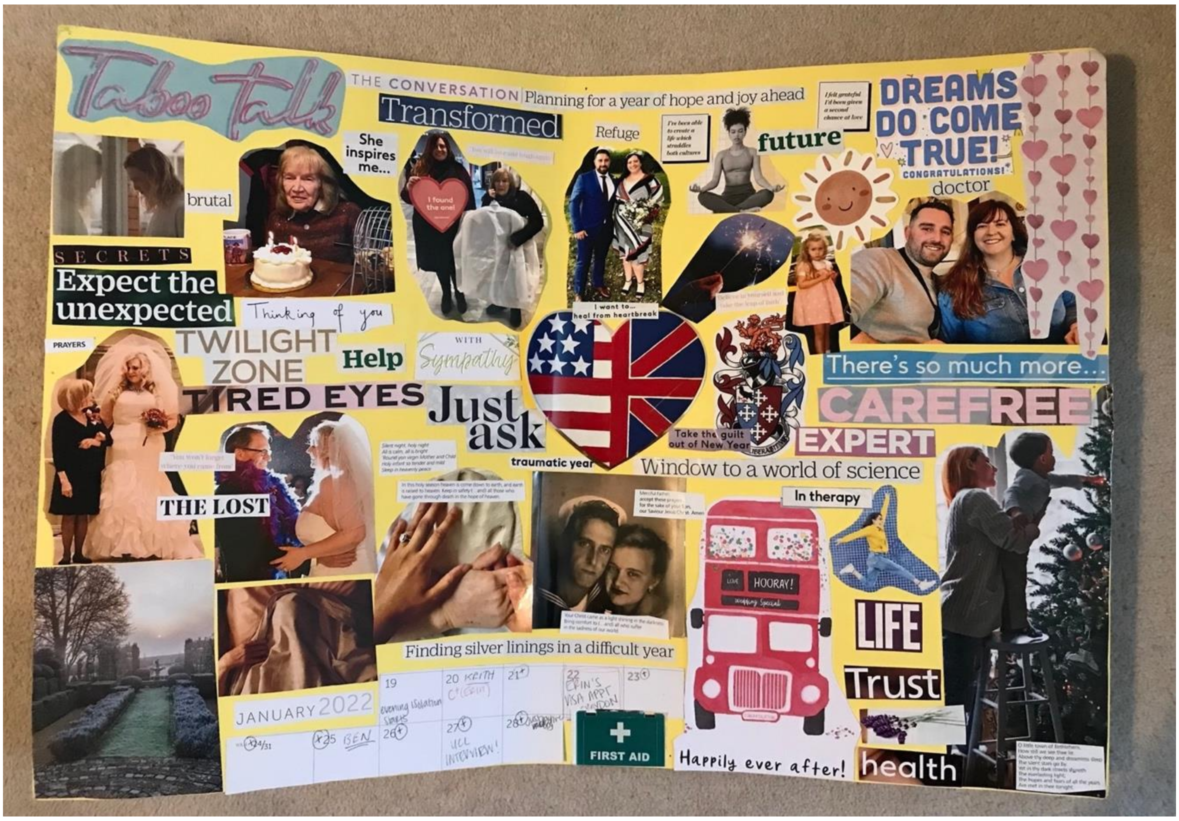


Figure 66: Collage 7, Feburary 2022, London, writing the thesis.

The final collage of the reflexivity series is the most personally significant one. In late September 2021, I received a call from my aunt to notify me that my grandmother had been admitted into hospital with sepsis related to pneumonia. Mirroring my mother’s death, my grandmother also died in the ICU only two days after I arrived in Minneapolis. Due to the ongoing Covid-19 pandemic, there were restrictions in place to limit the number of family members who could be with her as she died, and how we could plan her funeral. Only our immediate family could say goodbye and be with her once the life support had been removed. Furthermore, we were only permitted to have a small funeral which meant our extended family and community were not able to say goodbye.

Her death meant I had lost my last and most important parental figure. My life would never be the same. I was parentless and I felt abandoned. I cut out pieces of the sympathy cards I received which included 'thinking of you' and 'with sympathy' which are on the left side of the collage. I included three photographs of my grandmother as a tribute to her, and another image of me as a little girl to display how the inner child in me longed to be loved and cared for by her once more. Near the wedding photograph of my grandparents, I included a photograph I took when she was in hospital. It is a picture of my sister's hand, grandmother's hand, and mother's handprint which we created when our mom was in the ICU.

I selected 'taboo talk' to denote my experience of losing all my parental figures over a three-year period. Many people could not imagine being an orphan at the age of 34 years old. The statement 'Expect the unexpected' acknowledges how unpredictable life and loss are. No one in my family had anticipated that my grandmother would die eight months after my Uncle Bill. The sudden and acute grief I felt from my grandma's death felt familiar, as if I was in a 'twilight zone'. I had experienced early grief before and learned how to care for myself in the aftermath of a loved one's death. The words 'Tired eyes' and an image of a person with the covers over their eyes depicts how physically taxing grief felt to me.

This collage's focal point is a heart comprised of the US and the UK flag which symbolises that my life is divided between two countries. The left side represents my family and my American identity, and on the right corresponds to my life as a newlywed married to an English man and creating a new life in the UK. My partner, Rob, and I were married in Crewe, Cheshire only four days after my return from the US. I placed a photograph of us on our wedding day above the American and British heart. Underneath is a caption that says 'I want to heal from heartbreak' which encompasses how it feels to live with the hope that life will not always be as arduous as it has been during the last four years. The quote 'I've been able to create a life which straddles both cultures' refers to the commitment I have made to maintain my relationships with my family in America whilst building my own community in England.

I met Rob six months after my mom died. Although he has not experienced the loss of anyone close to him, he has adapted and learned how to support me in my grief journey. I included an image of the sun smiling, because Rob's love made me feel bright and carefree. Paralleling the sympathy cards, I received from my friends and family, I included images and congratulatory messages from the greeting cards we had received. The phrases 'Dreams do come true!', 'I felt grateful I'd been given a second chance of love', and 'happily ever after!' acknowledges the beginning of my second marriage with Rob. I never anticipated falling in love amidst the sorrow and emotional distress I had experienced because of losing members of my family. My relationship with Rob gave me hope that we could build a healthy family system in the future.

As traumatic as the last four years have been, I created this collage specifically to be a beacon of hope that I would enjoy my life and celebrate Christmas again. I pasted an image of a mother decorating a Christmas tree with a child which reminded me that one day I will hopefully make my own family holiday traditions which will be detached from my grief. I went to the Canterbury Christ Church University Christmas carol service in December 2021, and I have included the University's crest and lyrics from the songs we sang at the carol service to reference my faith in God even though I have experienced profound loss.

On the collage I have highlighted my new year's resolution to finish my doctoral studies with the words 'doctor', 'expert' and 'window of a world of science'. The phrase 'In therapy' underlined my commitment to learning how to manage my cPTSD symptoms and adapt to the new ADHD diagnosis. The January dates on the collage demonstrate when I became ill with Covid-19, which further impacted on my ability to progress with my studies. Regardless of the obstacles I have faced, on the collage I have included the image of the woman jumping to show that in the face of adversity I have persisted.

9.9 Summary of the chapter

Conducting research is a personal activity because a researcher's positionality and personal experiences contribute to the research process (Palaganas et al., 2017). The purpose of this chapter was to explain how I used collage to document my experience of grief and bereavement through an autoethnographic reflexive lens (Wiesner, 2020; Song, 2022). Performative autoethnography can be a means for the researcher to be playful by experimenting with physically embodying the research process through a performative act such as creating collages (Bochner & Ellis, 2003) This was integral to implementing Facet Methodology (Mason, 2011) within this thesis. Furthermore, I believe that within research, multiple realities exist and therefore there are multiple ways of understanding the experiences of grieving the loss of a loved one. Loss presents itself as the absence of a body (Spry, 2011), however, using a visual medium where I could incorporate photographs of my family further developed my story as a bereaved daughter.

My reflections are woven within the timeline of events that took place from 2018-2022.Through the medium of collage, I recognised the importance of using my voice as a bereaved daughter to become a better perinatal loss researcher (Matthews & Servaty-Seib, 2007; Tan & Andriessen, 2021). It was my intimate knowledge of grief that facilitated the emotional rapport I built with the research participants (Gair, 2012). I was inspired by the collages the eight bereaved participant mothers made. I connected with the use of nature images to depict grief; participants chose autumnal and winter scenes. For example, I identified that my season of grief was winter since that was the time of year when my mom died. I also found that using spring and summer images were representative of the hope I felt for the future. In addition to using seasons to depict emotional states, I felt motivated to include images of my family members for example the one my mother included of her family on her collage.

The arts-based method of collage has been an enjoyable research method that has facilitated the telling of my grief journey. It has deepened my understanding of reflexivity and has allowed me to spend time connecting to my grief in a creative way (Eldridge, 2012). I was thankful that I was able to create regular collages as a token of remembrance for my mom, Uncle Bill and my grandmother. It was an insightful exercise in terms of my grief journey and the larger world events that influenced my research plan, whilst documenting the progress I have made during my doctoral studies. I hope my experience of implementing collage encourages other qualitative researchers to use visual mediums to examine their reflexivity and research identity.

10 Conclusion

10.1 Introduction to the chapter

The sixteen parents who participated in this study had not anticipated they would not take their baby home from the hospital. They never imagined that they would take on the identity of a bereaved parent and thought that they would be a parent to a living child (Haylett & Tilley, 2018). Parents who participated in this study reported that their identities and senses of purpose had changed as a result of the loss (Riley et al., 2007). Stillbirth affects one in every 225 pregnancies in the UK; this figure equates to over 2,630 babies were stillborn (Tommy's, 2022). However, these statistics do not represent the psychological impact bereaved parents face following the loss of a child. To find solace from their grief, participants took part in baby loss peer support programmes where they met other bereaved parents. The literature showed peer-to-peer support programmes have been successfully implemented to help people coping with poor mental health, substance misuse, and those who have experienced grief and bereavement (Repper & Carter, 2011; Bartone et al., 2017). Within the semi-structured interviews and the collage making activity, participants articulated that connecting with other bereaved parents during their grief journeys helped them to process their own loss. Whilst the experiences of attending baby loss support groups varied between participants, the sixteen parents agreed that accessing baby loss bereavement programmes enabled them to move forward on their grief journeys.

The aim of this doctoral research project was to understand the pathways that minority ethnic families use when accessing bereavement support programmes. This study provides an original contribution to this important topic as it focuses on the experiences of minority ethnic families seeking bereavement support. This is important as within the literature, Black women have an increased risk (43%) of perinatal loss compared to white women (Quenby et al., 2021; RCOG, 2022). It is therefore essential that more research is conducted to explore ways in which to support grieving families from minority ethnic communities (RCOG, 2022). It is not sufficient to only investigate perinatal loss risk factors and health disparities; more research needs to be undertaken which examines appropriate bereavement support for communities who have a higher risk of pregnancy loss so that appropriate measures can be developed which facilitate those who have experienced perinatal loss and bereavement.

This conclusion chapter summarises the major findings from the thesis before presenting the strengths and weaknesses of the study. Finally, recommendations for policy and further research are considered.

The aim of this project was to explore the role of diversity representation in bereaved parents of stillbirth peer support groups through semi-structured interviews and a collage elicitation activity. The research questions to which arose from the aim of this project are the following:

2. What are minority ethnic parents’ reasons for participating or not participating in baby loss bereavement support groups across England?

From the interview data, there were two prominent themes which explained the ways in which parents decided to participate in peer support groups. The results showed that parents were stunned by their pregnancy losses. Before their own experiences of pregnancy loss, they were unaware of the baby loss charities existed. Several mothers reported they were encouraged to receive emotional support from charity led peer support groups by their GPs and midwives. Had their healthcare providers not persuaded them to seek emotional support, they would not have reached out to charities to find bereavement support groups.

Secondly, parents shared they participated in baby loss programmes because they did not feel they were receiving the appropriate support from their immediate family and friends. Well intended comments were reported as hurtful. Additionally, while social communities did their best to support the grieving parent, there were cultural norms that often dictated that baby loss shouldn’t be discussed which further exasperated parents’ experiences of grief. Participants felt they couldn’t speak about their babies, which amplified the silence around the experience of pregnancy loss. Attending peer support groups gave newly bereaved parents a safe place to discuss their experience of grief and bereavement with other bereaved parents. These programmes offered parents the opportunity to speak openly about their children.

Conversely, there were several barriers which contributed to parents not attending peer support programmes. Firstly, four mothers expressed they had received a sufficient amount of support from their peer support groups after a few sessions; they no longer needed to attend as their grief became less severe. Other mothers felt that they were not welcomed when they were carrying a subsequent pregnancy. They removed themselves from a general peer support group to avoid upsetting parents who didn’t have living children and found additional support in pregnancy after loss support groups which were designed to support expecting mothers.

The most common reported barrier centred around logistical complications. Bereaved couples rarely had the opportunity to attend peer support groups together due to childcare reasons. Often, it was the fathers who stayed home, which enabled mothers to attend peer support groups. Changes to the family’s schedule hindered how parents interacted with their groups; their attendance lessened with each adjustment. For one mother, there were no in-person baby loss support groups she could attend within her vicinity. Due to her family commitments and issues around childcare, it was not possible for her to travel to the nearest city to attend group. Instead, she found support from other bereaved parents on an online support group.

There were larger societal matters which deterred parents from accessing charity led baby loss bereavement support. Bereaved parents from lower socioeconomic status backgrounds may not have felt welcomed to attend baby loss peer support groups because they didn't identify with other parents attending the groups. Carrie, a SANDS group leader, witnessed how working-class parents didn't feel at ease mixing with parents from other socioeconomic classes. To feel included, parents needed to see they could comfortably socialise within the social space peer support groups provide. Other participants described how the use of language could negatively impact attendance by excluding non-native English speakers. Since peer support groups were led in English, people who learned English as their second or third language may not be able to adequately express their feelings related to their losses.

Participants also reported their experiences of racism within the healthcare system prohibited them from seeking out baby loss support. The parents who participated in this study were from different minority ethnic backgrounds, and all of them were aware that they had a higher risk of losing a pregnancy compared to white British families. Dominic, a bereaved father, shared that he distrusted the NHS and what he described as a lack of care for pregnant Black women. He also struggled to get a response from SANDS when he inquired about how he could collaborate with the organisation to share his experience of being a Black bereaved father. Iris, a Polish mother, described how she chose not to attend a SANDS meeting because she anticipated feeling excluded from the group. Whilst systemic racism did impede participants from taking part in peer support programmes, it is important to note that when parents did attend, they wanted to see a diverse group of parents to feel welcomed.

3. How do bereaved parents describe their experiences of attending peer support groups, and how do they find community within these services? Additionally, how do bereaved parents find meaning of their loss by participating in peer support services?

The collage elicitation activity provided rich data which illustrated the experiences of bereaved parents attending baby loss support groups. Throughout the eight collages, there were images and words which detailed mothers' journeys of accessing baby loss support. Collage participants chose images of flocks of birds and elephants to designate they felt they belonged in their peer support groups. Phrases such as: '*welcome to the club*', and '*freeing to know everyone here is like me*' demonstrated how liberating it was to be around other people who understood the physical and emotional pain of losing a baby. Peer support programmes were spaces where bereaved parents could feel safe to speak about their babies. Programmes also provided bereaved parents the opportunity to grow through their grief and to learn how to integrate their losses within their lives.

Participants incorporated images and phrases to denote how they made meaning from their loss through their participation in peer support programmes. Images of butterflies were prominent;

butterflies were said to be a sign of hope and metamorphosis. ‘*I can finally look forward to the future’* signified the emotional growth that took place in the participant’s peer support group. It was reported that parents who were further away from the initial loss kept attending the peer support group to mentor and support newly bereaved parents. ‘*Choose a caring community’* was selected to show the importance of being a part of a compassionate community and how it can positively impact grieving people.

4. Why do some parents take on leadership roles within these services? How does participating in leadership opportunities impact their outlook on their loss?

Eight of the sixteen participants decided to take on a leadership role within the peer support groups they attended or within the charity who ran the programmes. From their experiences of grief and loss, two mothers founded their own charities in honour of the children they lost. Three mothers served as trustees for their respective organisations. One mother now sits on a national maternity board which serves to enhance the state of maternity services. Finally, one mother and one father chose to lead their own peer-support groups. Parents who took on a leadership position said they felt valued by the organisation when they were approached to serve. The driving factor to take on additional responsibility was to help other bereaved parents’ grief journeys. These eight participants wanted to serve as a beacon of hope to newly bereaved families to show that living with baby loss was possible. They found ways to incorporate their deceased children into their family and wanted to share with newly bereaved parents that it was possible to be a parent to both living and deceased children.

Furthermore, there was a need to improve upon current baby loss support programmes specifically for minority ethnic families. Mothers like Sandra and Daphne used their professional training to support the charities of which they were patrons. Mothers who served in leadership positions shared they wanted to diversify baby loss support and make peer support groups more accessible. Asian mothers shared that attending peer support programmes where there were people from their own ethnic communities encouraged them to come back to another meeting. Whilst they found it would be an arduous journey to better serve minority ethnic families, two mothers shared it was necessary to support families where baby loss remained taboo.

5. What types of support are missing for minority ethnic families? What type of ceremonies and rituals are more culturally appropriate to support them through their grief journey?

From the interview data, support for bereaved fathers was largely missing from current baby loss peer support programmes. Both male and female participants said it was more socially appropriate for women to access bereavement support compared to men. This notion was supported by healthcare providers, who did not encourage fathers to access baby loss support. The three fathers who participated in this study shared they felt their grief was less important compared to their wife's experience of grief. At times, the lack of support for fathers created a wedge between the couples. Mothers and fathers shared those men often didn't fully understand the extent to which the loss of a baby impacted a woman's life because men couldn't experience pregnancy. Some participants shared they knew their partners were grieving but didn't know how to support their husbands.

Two mothers reported that their husbands briefly attended meetings with them. However, the data largely showed that men used social support within the couple's immediate social circles. It was important to have gender-separated spaces for mothers and fathers to grieve. Interestingly, Vern shared those men in Asian communities typically do not and would not discuss baby loss, yet he did want the opportunity to access formal baby loss support.

The most unexpected finding within this study was the lack of faith-based support for bereaved families. Within the dataset, there were participants who identified as Christians, Sikhs, and Hindus. However, no participants reported that they had accessed support within their respective faiths. Only one participant, Arthur, had access to a male faith-based support group which was not designed specifically for baby loss. I also noticed there was a dearth of faith-based support when I searched for baby loss support groups. The informal conversations I had with faith practitioners also showed there was extremely limited outside of immediate support for funerals. Participants expressed they wanted charities to build relationships with faith-based communities so spiritual support could be offered to newly bereaved families.

10.2 Contributions to the field

The use of arts-based methods has increased in health research (Coemans & Hannes, 2017). However, on further exploration I found that there is a paucity of research within the perinatal grief and bereavement literature. Whilst searching the literature I found only one study by Willer et al., (2018) that used the arts-based method of drawing the bereaved siblings' experiences of baby loss. Willer (2018) in another paper writes an autoethnographic account about her experience of pregnancy loss whilst being a mother and a researcher.

The field of perinatal loss has grown and continues to grow with new papers being published that document how parents grieve the loss of a baby (Farrales et al., 2020; Kishimoto et al., 2021), and ways in which healthcare providers can better served bereaved families, (Furtado-Eraso, Escalada-Hernandez, & Marin-Fernandez, 2021; Fernandez-Ferez et al., 2021). Nevertheless, no other studies were found within this discipline which utilised creative methods to explore parents' experiences of accessing baby loss bereavement support groups. This doctoral research project therefore makes an original contribution to this area by employing collage as a creative method to explore how parents access baby loss bereavement support.

It is my hope that this project will inspire other researchers to implement collage and other creative methods to further explore other areas of maternal perinatal mental health research. To do this, I have published in the British Psychological Society special edition on qualitative methods on the use of collage in grief and bereavement research. Additionally, I have led seminars on how to implement creative methods within the midwifery programme. Likewise, I have presented at conferences on perinatal loss, and I co-led a workshop on using creative methods for nursing and nursing assistant faculty members. Earlier in 2022, I showcased six collages I created during my experience of a bereaved researcher researching grief at an art exhibit at Canterbury Christ Church University. Upon successful completion of this doctoral programme, I plan on publishing the collage results findings. I would also like to publish on how I practised researcher reflexivity through the use of collage. Finally, I plan on creating an executive summary of this thesis to deliver to the charities and the participants that supported this project.

In addition to using collage, I selected facet methodology (Mason, 2011) as a new approach to investigate the phenomenon of baby loss bereavement support groups. Whilst facet methodology has been becoming more popular in the social sciences such as in physical health sciences (Phoenix & Bell, 2019) and psychology (Larkin et al., 2019) this appears to be the first study where this approach has been implemented in maternal mental health research. Mason's facet methodology (2011) is a practical method to research complex social issues (Mason, 2011; Muir 2022) because it supports the researcher to find connections between different *facets* of a research problem. On the surface, this research project might appear simplistic in that minority ethnic bereaved parents experience grief like white British parents. One would think that minority ethnic communities would share the same reasons for attending peer support groups as white British families. Instead, facet methodology illuminates the ways in which communities, cultural norms, stigma, and health inequality and racism influence the ways in which minority ethnic families access charity led baby loss support.

Facet methodology (Mason, 2011) invites the researcher to explore multifarious angles of a phenomenon (Muir, 2022). Mason (2011) doesn't support the idea that facet methodology will solve all the dimensions of the research problem, but it will offer researchers an opportunity to strategically explore facets of the phenomenon to find 'flashes of insight' (Mason, 2011, p.75 as cited by Phoenix & Bell, 2019). I was inspired by this way of thinking, because I didn't think existing literature which often used traditional methods of examining pregnancy loss and grief adequately explored the intersections of such complex experiences (Mason, 2011; Muir, 2022).

This project strove to display how a newer methodology which encourages playfulness could offer original insight into grief and bereavement research. Mason (2011) invites facet methodology researchers to experiment with mixing methods with critical reflection. Instead of hiding my researcher's personal experience of growing up in a family where baby loss was prevalent, I was able to incorporate it into this project as an additional facet of this phenomenon's gemstone. This research project was personal. I appreciated the holistic nature of facet methodology (Muir, 2022) in that I didn't have to exclude my own experience of baby loss outside of the data from the participants. I believe it empowered me to analyse the data from a compassionate viewpoint.

Facet methodology's flexibility doesn't demand there to be a strict formula into how methods are mixed (Muir, 2022); rather, it emphasises researchers to illustrate 'different ways of seeing' the phenomenon (Larkin et al., 2019, p. 192). Because Mason (2011) sees facet methodology as an *approach* rather than a firm method (Muir, 2022), I had the flexibility to design my research study which was conducive to combining the traditional method of semi-structured interviews with a collage elicitation exercise. The combination of these two qualitative methods created rich data which served to examine each facet of this phenomenon (Mason, 2011). The findings from this study were developed by researching how the different facets are entwined with each other (Muir, 2022). Facet methodology (Mason, 2011) encouraged me to creatively explore the experiences of minority ethnic bereaved parents, and can be applied to other areas (Muir, 2022) within maternal health research.

10.3 Strengths of the study

The combination of verbal data through the semi-structured interviews and visual creative methods of the collage elicitation exercise complemented each other to produce a rich data set. To my knowledge, this is the first study which utilises both creative and traditional research methods to explore the experiences of minority ethnic stillbirth bereaved parents accessing bereavement support. By using two methods instead of one, this research project has been innovative in its design and has generated knowledge in new ways (Chamberlain et al., 2011). This research study however offers a unique contribution to this area because it explores the experiences of a population of bereaved parents whose voices are often not heard within the literature, which is necessary to diversify the literature and to provide feedback to charities who serve bereaved families. When minority ethnic families are blatantly or inadvertently excluded from research, the Academy contributes to maintenance of health inequalities (Dodgson & Strutheras, 2005; De Freitas & Martin, 2015;).

I am pleased that I established community partnerships with charities who are interested in better serving bereaved minority ethnic families. I took time to research the organisations, and to meet with the executive directors, group leaders and other gatekeepers within the organisations to build rapport.

I developed trust with the organisations' gate keepers and kept them sent them updates about the project (Emmel et al., 2007). These organisations appreciated the significance of good bereavement support on the wellbeing of a grieving family. In addition, they also experienced how few minority ethnic families accessed their services and wanted to learn more about this phenomenon. Whilst I was only marginally successful recruiting from these charities, I still value the trust they bestowed upon this study.

An undeniable strength of this study is that sixteen bereaved parents took part as research participants for the first time. They shared what factors facilitated them accessing support and which factors served as barriers to access support. Understanding how different communities access bereavement support a research priority within the grief and bereavement field (Swords et al., 2022). Although it has been suggested that minority ethnic communities may not want to participate in stillbirth related studies because of the sensitivities around the subject matter (Tooher, Middleton, & Crowther, 2008), I found that was simply not true. Instead, they were never invited to take part in research before. My experience was consistent with Cronin et al. (2020) who found that when people from minority ethnic populations are invited to take part in perinatal research, they are as willing to take part as white European women.

Like the rapport I built with the charities, I took time getting to know the research participants by scheduling a meeting before I conducted the interview. This was an effort to make them feel comfortable with who I was and my own experience as a bereaved person. I encouraged participants to speak candidly to express themselves and their grief journeys; at times that meant they swore or began to cry. As a bereaved daughter, I understood that speaking about grief can bring about a range of different emotions. Whilst all participants were offered the opportunity to co-produce research through the collage making activity, only eight participants contributed to the arts-based method activity. Still, this is a success because this activity may have opened the participants' minds of what research can be. I received positive feedback from several of the mothers who wanted to bring the collage-making activity to their peer support groups.

I developed the Road to Hope through Grief theory which serves as an original contribution to the field and serves as a strength in this field of study were identifying pathways to accessing bereavement support is largely ignored. Within this thesis, I included a detailed account into how this theory was developed in hope that this improves the dependability of the research findings. Additionally, I included several memos I wrote during the data collection process to show how I processed the data and then analysed it. I consider using constructivist grounded theory (Charmaz, 2014) as a strength of the study. Charmaz (2017) writes researchers using constructivist grounded theory is a pragmatic approach to research social justice issues which is applicable to this study's objective in emphasising the experiences of minority ethnic families affected by stillbirth.

Constructivist grounded theory calls upon researchers to include their unique perspectives within the research (Charmaz, 2020). By using Charmaz's (2006, 2014, 2020) work on constructivist grounded theory, I was influenced to reflect upon my researcher reflexivity and to use my experience of grief and bereavement as a facilitating factor in conducting the research. I understood the sensitive nature of this field, and how to connect with other bereaved people (Aoun et al., 2018). Making collages as a way for me to examine my reflexivity and factors that influenced me as a researcher allows me to visually showcase my research subjectivity and how it affects the analysis (Charmaz, 2020). Furthermore, including my grief journey within the research challenges what's acceptable in research by challenging traditional ideas within research (Charmaz, 2020). The act of including my experience of grief helped me bond with the participants and legitimised my voice within perinatal loss field (Charmaz, 2020). I enjoyed learning about constructivist grounded theory and using it as a method for this project.

In summary, grieving the loss of a baby is a multi-faceted issue which deserves more research (Sharp, 2018). Aside from this study being the first in the field to explore how minority ethnic parents access baby loss bereavement support through semi-structured interviews and creative methods, the main strengths lie within the relationships I built conducting research, and the relationship I built with myself in examining my reflexivity.

I plan on presenting the findings of this study to the All Party Parliamentary Group (APPG) on baby loss of which I have been a member of since 2019. APPGs are topic informed groups led by Members of the Commons and Lords (UK Parliament, 2022), where individuals and organisations related to the issue come together. I want the findings of this thesis to represent the voices of families who are unable to attend these meetings, and to show the personal story behind the statistic (Best, 2012). My intention of sharing the findings of this study is to underline the importance of funding baby loss charities so they can continue to support bereaved families.

10.4 Limitations of the study

This doctoral study has been designed and undertaken with thorough consideration to maintain ethical rigour and the wellbeing of the research participants and the researcher (Velardo & Elliott, 2021). Nevertheless, there are limitations to this study.

The timeline of the project was severely impacted by the Covid-19 pandemic. Although the safety of the participants and researcher was prioritised, recruitment and in-person data collection were affected by national lockdowns and constraints of social distancing (Nguyen et al., 2020). I had planned to form more research partnerships with organisations in the north of England. However, this was not possible as the employees and organisational resources that served bereaved families were overextended. I had several of the representatives of the organisations who were contacted state that they were too concerned with managing their day-to-day duties to support the research project. During the first and second wave of Covid-19, I returned to the United States to care for my grandmother which further impacted on the study. Doctoral students who were caretakers were acutely affected by the pandemic and had to manage the dual responsibilities of caring for family members whilst continuing with their degrees (Boreson et al., 2021).

Although I was unable to collect data whilst I was in Minneapolis, I did use the time to publish an article on the methods used in this study (McCloskey & Wier, 2020). On completion of the data collection during the summer and autumn of 2021, I could not access the NVivo software programme to analyse my interview data because the university was closed. Because I couldn't download the remote NVivo software package on my personal laptop, I had to wait until students were allowed back to campus. As a first-generation doctoral student with limited financial means, it was problematic that campus was closed for as long as it was because it restricted the project from moving forward. Ultimately, I have received three extensions during my PhD to cope with the unforeseen delays related to the pandemic. If it wasn't for the support of my supervisors, I suspect I would have quit this programme due to the tension I felt between pursuing this degree and caring for my vulnerable family members.

I had planned to recruit between twenty and thirty participants for this study, but this was not possible due to the constraints I experienced when recruiting participants. Snowball sampling was employed during this study (Naderifar, Goli & Ghaljaie, 2016) which meant that the bereaved parents I had connected with during the first year of my doctoral studies helped promote the study and enabled the recruitment of other bereaved parent participants. This form of sampling may be a limitation of this study. For example, partnerships with NHS Trusts, may have enabled the use of theoretical sampling which is a specific form of sampling within grounded theory (Gentles et al., 2015). In theoretical sampling, the developing theory dictates who may participate rather than prearranging populations to include within the study (Draucker et al., 2007). In the context of this study, this may have meant that I was specifically recruiting minority ethnic stillbirth bereaved parents through NHS health records. This would have entailed getting ethical clearance from NHS trusts in addition to clearing the ethics committees at my university.

Although the participants were racially diverse, it is unclear whether they were diverse in other ways. All the participants were in heterosexual relationships. I did not explore their socioeconomic status, nor study the participants' education status. I excluded individuals whose first language was not English.

Including participants who were from diverse demographic backgrounds such as those whose first language was not English may have generated different data, and insights in terms of the research questions (Bowen et al., 2009). This study was conducted in the Midlands and southeast England and therefore the findings from this study may not be representative of others from non-white British communities who live elsewhere in the UK (Higginbottom, 2004). Moreover, my background as a white woman may have meant that I was considered as an outsider by participants who were from minority ethnic backgrounds. For this reason, it was important the data was validated by the participants through member checking (Motulsky, 2021). Member checking the transcripts served to enhance the robustness of the overall findings.

Parents whom I met before formally recruiting participants may have felt obligated to take part because I had met them through the baby loss support groups (Karnieli-Miller, Strier, & Pessach, 2009). To try and reduce a power imbalance which may have influenced parents to participate, I gave potential participants a week to reflect upon their decision to take part in research. I encouraged participants to have a conversation with me to learn more about the study and who I am as a researcher before we met for the interview. Additionally, participants may have felt compelled to participate because they had been encouraged by their midwives who were providing care. Participants may have felt their care was linked to the study because the bereavement midwives recommended the study (Karnieli-miller, Strier, & Pessach, 2009). Recommendations by their midwives may also have positively influenced participants to take part. Because this study was personally recommended to them, parents felt they could this research project was a good fit for them to contribute to research.

The study sample is too small to make any generalisations of the findings. However, qualitative studies often involve small sample size, so the number of participants is consistent with other studies and can be justified (Boddy, 2016). The discussion of sample size is dictated by the country of origin in which the research is conducted; compared to the US, sample sizes in the UK will be smaller (Boddy, 20160. It is important to recognise that this study provides valuable insight into how minority ethnic parents access baby loss bereavement support and offered participants an opportunity to tell their story. It was surprising to learn that none of these sixteen parents had every been approached to take part in a previous research study. Inclusion of bereaved minority ethnic parents is essential so that this area of perinatal mental health can be progressed, and ways developed which support service improvements for bereaved families (Luchenski et al., 2018). The aim of the research was to give a voice to parents whose grief and experiences often goes unreported and therefore having a small sample of bereaved parents as participants enables the aim of the research to be fulfilled in this regard.

Another limitation of the study was the gender representation imbalance in the collage-making activity. I wanted to engage both participant mothers and fathers in the arts-based exercise, however no participant fathers expressed interest in creating a collage. As a research method, collage has been used with male veterans who have experienced PTSD (Miller, 2010; Lobban & Murphy, 2018; Malhotra et al., 2021). I examined the art therapy literature where creative methods are often used as forms and had anticipated that the collage activity would engage the male participants because of the flexibility creative methods offers researchers to engage with participants across cultures, generational gaps and socioeconomic statuses (van der Vaart, van Hoven & Huigen, 2018). From the literature on men participating in arts-based research methods, I postulated that fathers would want to participate in a collage activity related to the loss of their baby, however this did not happen in this research study. It is possible that other creative methods would have been more acceptable to the participant fathers in this study. For example, photovoice may have been more interesting to male participants. In this method, participants take significant photographs to capture moments that are presentative of the issues that are being studied (Ball et al., 2021). The photographs serve as a prompt to create narratives about the phenomenon (Langhout, 2014). For example, Oliffe et al. (2020) used photovoice as a research method with twenty bereaved men to explore men's mental health seeking behaviours. Photovoice may have been used similarly in this study; instead, men would have taken photographs documenting their grief journey and choosing to access peer support programmes.

Other visual arts-based methods that might appeal to male participants would be those related to video and board games (Ball et al., 2021). Liao's (2017) study found that the arts-based research method of developing an online game created a collaborative digital environment where users could interact with the activity. The use of an online game helped to create new arts-based knowledge (Liao, 2017), and could have been an option for this study if there was further funding and more resources to develop an online experience. Implementing avatars in research social spaces has become an innovative way for participants to engage in research (Liao, 2017). In these online spaces, there are tools which participants can use to produce digital stories where they create a personal narrative of themselves using audio, photographs and video (de Jager et al., 2017). Burnell et al. (2017) found that using digital storytelling may be a useful way to encourage men to change seek mental health support for PTSD from their service time in the military. Digital storytelling may have been a useful method for this study, because it can be accessed via web or smartphone usage (Burnell et al., 2017) which would have been suitable for the second national lockdown of 2020, which was the time period when data was collected.

As I was the only researcher conducting this study, research bias could be viewed as a limitation (Chenail, 2011). However, I attempted to mitigate bias by firstly randomly checking the interview transcriptions with the audio to verify the transcripts were correct. Secondly, I encouraged the participants to review the interview transcription to see if they wanted to amend any statements. Member checking is a way to certify that I accurately represented the research participants and is an important strategy to validate qualitative data (Candela, 2019). Additionally, I tried to mitigate bias by following Charmaz's (2006) structured coding procedures. This meant that my research orientation was directed by Charmaz's work (2006, 2014) on constructivist grounded theory, and I also included the research participants' perspectives within my analysis. To reduce researcher bias, I incorporated collage as an arts-based method to triangulate the data and confirm findings (Greyson, O'Brien, & Shoveller, 2017). Data triangulation, where a researcher uses more than one research method generates a thorough set of findings compared to using only one method (Kuper, Lingard, & Levinson, 2008; Noble & Smith, 2015). Furthermore, I discussed how I analysed the data with my supervisors. Together we discussed what alternative explanations might have generated the findings that emerged from the data.

I acknowledged that I used a constructivist grounded theory approach which meant that I considered my own experiences of grief and bereavement within the findings (Neimeyer, 2006, 2010; Gillies & Neimeyer, 2007). My close relationship with grief and bereavement may have impacted the research process. Grieving is a multifaceted process (Carmack & Degroot, 2014) which meant it was challenging to separate my experience of grief from those of the research participants. Conducting bereavement research as a grieving 'insider' was emotional (Rowling, 1999), and was problematic at times for me in terms of managing my own feelings about grief and bereavement. I tried to illustrate how I practiced my reflexivity as a researcher *and* my experience as a bereaved person throughout the research process to guide the reader in terms of my thoughts during the data collection, analysis process, and my own experience of creating collages I have made as a result of conducting this study. For example, when I was in my personal annual season of grief November through January, I had to take extra care of myself. This meant that I took a break from analysing the data or writing this thesis.

Nevertheless, the theoretical framework that was implemented within this study does have the capacity to suggest similar findings that could be extrapolated when applied to other similar research questions (Mertens, 2007; Shariff, 2012; Mollard, 2015). Equally, the traditional and creative research methods employed in this study could also be utilised in other research areas (Mannay, Lomax & Fink, 2015; Jepson, 2019), which might generate results that are more representative of other marginalised communities who access baby loss bereavement support within the UK. Whilst I was inspired by participatory research methods, I did not conduct a participatory study because I did not include participants throughout the entirety of the project (Milligan, 2016). If I had more time to conduct a participatory study, I would have included the participants throughout the analysis and writing process. However, a doctoral timeline and limited funding is not conducive to include participants throughout the research project.

10.5 Recommendations

The chapter concludes by discussing recommendations from this study and how it relates to the literature and current policy. Whilst there are many considerations for future work, this section will address the main findings and how they apply to bereaved families and service providers.

10.5.1 Considerations for further research

Results which influenced the Road to Hope through Grief (RTHTG) theory support the suggestion that more research is needed that explores how virtual bereavement support can assist grieving minority ethnic families. In the development of the RTHTG theory, I noticed that as bereaved parents' grief journeys continued their grief became less severe. As a result, they accessed less in-person peer support. Depending on their personal seasons of grief, they would oscillate between seeking peer support and not accessing support. The participants shared they enjoyed knowing they could always access support if they became distressed and needed the support of from other bereaved parents. Whilst online peer support interventions have had some attention within the field (Gold, 2012; Bakker & Paris, 2013) and most recently with a smartphone application designed to offer bereavement support (SANDS, 2021), there is a paucity of evidence which examines how minority ethnic bereaved people access these services. The recommendation for further research into virtual baby loss support may also benefit people who live in isolated rural communities like research participant, Maya, who was unable to travel to access in-person baby loss support due to childcare responsibilities. Virtual bereavement support groups can support a wide range of people who may otherwise not access social support to process their grief (Beaunoyer et al., 2020), including parents who do not feel they need to access in-person support but would like the ability to access some type of bereavement support if needed.

Despite my efforts to try to recruit and include more men in this study, there were more mothers (13) than fathers (3) who took part. This may be because women are more likely to seek out bereavement support compared to men (Swords et al., 2022). However, it was clear speaking to both mothers and fathers that there was a lack of support for bereaved fathers. The impetus for the three men to take part in this study was to contribute to findings that included the viewpoints of fathers in perinatal loss research. Whilst the sample of male participants was too small to make any generalisations, it is important to note that each man preferred to meet other bereaved fathers in a group solely to men. As Dominic said in his interview, he preferred to meet and facilitate a father support group so men can be honest with their grief and not have to consider their partners' feelings. Men may find it challenging to express their feelings and often put their partner's needs in front of theirs (Ellis et al., 2016), so having male only peer support groups are invaluable for fathers to process their grief. Similar to the experiences of the three dad participants, the literature shows that men's grief is less visible compared to how women grieve (Davies, Whitworth, & Murray, 2015). My recommendation is for charities to invest in male only peer support groups, and researchers investigating how male only spaces impact men's grief journeys. There is inadequate work published on bereaved father's support group experiences, especially of groups who are specifically designed for men (Davies, Whitorth, & Murray, 2015).

Several mothers who took part in this study shared harrowing accounts about the birth trauma they experienced whilst they were delivering their babies. Whilst they did not disclose a formal diagnosis of PTSD during the study, within DSM-IV criteria, the death of an infant satisfies diagnostic criteria for PTSD which is important because this diagnostic manual recognises the severity of losing a baby and the impact of trauma on a mother's mental health (Murphy, Shevlin, & Elklit, 2012). The literature showed an association between receiving a PTSD diagnosis after pregnancy loss has been documented in the literature for years (Engelhard, van den Hout, & Arntz, 2001; Giannandrea et al., 2013; Robinson, 2014; Rich, 2018). One study recently found Black and Asian families are at a higher risk of losing a pregnancy and birth complications compared to their white counterparts (Jardine et al., 2021). To complicate the matter even further, the national MBRRACE-UK (2021) report showed both Black and Brown women are impacted by implicit systemic racism within the NHS, which may exacerbate symptoms of PTSD (Diop et al., 2021). Although it was outside the scope of the study, it would have been interesting to explore how minority ethnic mothers with PTSD diagnoses access baby loss support groups. Considering the risk factor for perinatal loss, it is interesting to note how little information is available specifically looking at Black, Asian, and other minority ethnic groups' varied experiences of pregnancy loss is still largely unknown (Murphy & Cacciatore, 2017). Even more unknown is the rate of PTSD diagnosis related to perinatal loss within minority ethnic populations, who are considered to be at risk of experiencing pregnancy loss (Kersting & Wagner, 2022). It is for these reasons that I suggest there is further research into how Black, Asian and other minority ethnic communities suffer from traumatic births related to perinatal loss and the rates of PTSD which stem from their birthing experiences.

An unexpected finding within the data centred around the role of stigma attached to pregnancy loss within Asian communities. Asian mother participants shared that they felt stigmatised by their social circles because they lost their pregnancy and also stigmatised because they grieved the loss of their baby. After the birth of the baby, a mother would isolate herself from her community so she wouldn't have to feel different than other mothers within her community (Pollock et al., 2020). Women from minority ethnic communities are at risk of experiencing poor mental health after giving birth (Nilaweera, Doran, & Fisher, 2014) even when there is no pregnancy loss. Because experiencing stillbirth has been suggested to lower a mother's self-esteem (Wonch Hill et al., 2016) and the rate of suicide after the first year of birth is higher in women from Indian and Pakistani communities

(Nilaweera, Doran, & Fisher, 2014), it's imperative that there is more research exploring the experiences of Asian mothers who have lost a baby and suffer from community-based stigma in order to try and prevent poor mental health outcomes in this population.

10.5.2 Recommendations for healthcare providers

The participants' experiences of their healthcare providers and the healthcare they received differed. Whereas some mothers reported having caring GPs, midwives, and hospital bereavement counsellors who recognised they needed bereavement care and could signpost where to access emotional support, there were other mothers who reported they did not feel supported by their healthcare team during or after the birth of their child. Even though this study didn't centre around stillbirth bereaved parents' experiences with their healthcare team, it is important to note that healthcare providers were one of the ways in which parents first learned about baby loss charities and subsequently charities' peer support programmes. The 2021 to 2022 NHS Mandate stated the NHS will continue to reduce stillbirth and neonatal deaths for minority ethnic women (Safety of Maternity Services in England, 2021). Whilst there has been success in reducing singleton stillbirth rates by 18% from 2014 to 2019 (Matthews et al., 2022), it is necessary to remember that not all stillbirths can be prevented especially when ethnic inequalities in rates disproportionally affect Black and Asian families (Maddox, 2021; Matthews et al., 2022).

For these reasons, I recommend healthcare professionals who interact with grieving families must be trained to work compassionately with parents experiencing perinatal loss and to confidently refer parents to appropriate groups. Almost all sixteen parents recalled receiving informational leaflets shortly after giving birth which were poorly received. Five mothers shared how distasteful it was to be given information so shortly after the delivery of their babies. They were unable to process new information and didn't want to read about accessing baby loss support. Downe et al. (2013) also captured how difficult it was for parents to understand bereavement support information given to them by healthcare providers. When stillbirth bereaved parents perceived their care to be insensitive, they became further distressed which exasperated their grief (Downe et al., 2013).

Although healthcare providers can't take away the pain of grieving parents, there are efforts they can make to lessen the intensity of acute grief to comfort parents (Ellis et al., 2016). There is still a need to improve the care given to stillbirth bereaved parents (Montacute & Bunn, 2017). Maternity staff must be trained in how to respectfully work with bereaved parents, which includes giving the couple space to process their loss without imposing new information on them (Siassakos et al., 2018). Care for families who experience perinatal loss can and should be improved (Mills et al., 2016). Investing in bereavement support training for maternity staff can prevent further detriment to grieving families (Siassakos et al., 2018).

10.5.3 Recommendations for baby loss charities

In terms of the current study there were charities with whom I developed community partnerships and who were supportive of this research project. There was recognition among senior level employees such as executive directors within the charitable organisations that services and supporters were typically white British families. Despite attempts to use different marketing approaches to promote diversity within the services they provided, minority ethnic families within the current study accessed these charities for support less often when compared to their white counterparts. One recommendation therefore that emerges from the data in this study is that baby loss charities should develop academic research partnerships with Higher Education Institutions to develop research projects that could benefit both parties. This would enable the generation of knowledge which could be shared with healthcare service providers who could signpost bereaved families where to find emotional support. Within this study, parents reported their GPs and midwives were helpful in encouraging them to access baby loss support. Within the peer support setting, new knowledge could prepare group leaders how to better support newly bereaved parents in their groups. Organisations and practitioners within the grief and bereavement field have a history of carrying out their own research (Sue Ryder, 2021), however their studies are often small scale and have fewer resources to allocate to research (Penny, 2020). The National Bereavement Alliance supports bereavement research conducted from a range of methodologies which address pre-existing research gaps such as the absence of bereavement experiences of minority ethnic people (Penny, 2020). Developing partnerships between academia and the third sector may lead to an increase in larger robust research studies that have the potential to reach more people (Turin et al., 2022).

10.6 Final Conclusion

Perinatal loss is a devastating and overwhelming experience; Along with the death of a baby is the loss of a planned future. This study explored the experiences of sixteen bereaved minority ethnic parents and the ways in which they accessed baby loss bereavement support groups. To investigate this phenomenon, a constructivist grounded theory approach was used in conjunction with the creative method of collage elicitation. In total, there were thirteen mothers and three fathers who took part in semi-structured interviews, and eight mothers who contributed to the collage-making activity. These two methods produced rich data. The Road to Hope through Grief grounded theory was developed from the semi-structured interview data and documents the ways in which these participants accessed baby loss peer support groups. Additionally, the collages produced vibrant visual data categories ‘nature of grief’, ‘seasons of grief’ and ‘symbolic growth’. A thematic analysis concluded that peer support groups were beneficial to grieving parents.

This is a study which strictly explored the experiences of minority ethnic populations in England, who have a heightened risk of experiencing perinatal loss (MBBRACE, 2021). Due to the qualitative nature of this doctoral study, the results are not representative of each minority ethnic population in the UK. However, this study contributes and diversifies the field by further representing minority ethnic families’ experiences. More research into ethnic inequalities regarding stillbirth is necessary to reduce the rate of stillbirth and to improve services for bereaved families (Matthews et al., 2022). It has been documented that there is a disconnect from bereavement research into bereavement care practices and services (Neimeyer & Harris, 2011 as cited by Penny, 2020).

Grief can affect a bereaved person at any given moment. As a bereaved daughter conducting research in grief and bereavement, I understand the benefits of participating in a bereavement support group and being able to speak openly about deceased loved ones. It is crucial that bereavement service providers are equipped to support grieving individuals (Swords et al., 2022). I hope this study contributes to developing more appropriate baby loss bereavement care for bereaved parents, so that every grieving parent feels like they can find sustainable emotional support.

11 Epilogue

In June 2022, my husband Rob and I found out I was pregnant while on our honeymoon in Spain. It was our first day there when I took the test and saw a faintly blue line. The line was so faint that we had to hold it in direct sunlight to make sure what we were seeing was in fact a blue line. I called my closest friends. They were all thrilled to hear the news. My best friend was elated to be experiencing pregnancy at the same time. She sent me a message saying: "I'm so happy I get to experience this with someone". One friend texted me to say she couldn't wait to be an auntie. Being a researcher in the perinatal loss field, I told them to wait to feel those things because it was very early, and we didn't know if this pregnancy was going to be sustainable.

Regardless of how faint it was, or what I said to my friends, we became parents that day. I began saying 'us' and 'we' instead of 'I' and 'me'. Rob had bought the dream of being a dad and made a down payment on this embryo's future. We planned this embryo's future and discussed baby names. We took another pregnancy test two days later to make sure that the first test wasn't faulty. Like the first, the second test turned positive, this time bluer than the other. It confirmed that we weren't imagining a blue line and that our excitement wasn't for nothing.

The next day, I woke up with intense back pain and cramping. It felt like the beginning of my menstrual cycle. I realised I was lightly bleeding. I called for Rob across the hotel room and told him I was scared. I knew that something was wrong and anticipated that I would be at the beginning of a miscarriage. I recognised that the symptoms I was experiencing meant this was the beginning of an end to the future we began to plan.

Rob went to the reception to call for a doctor. About a half an hour passed before a stout German doctor arrived. The second she entered our room, the atmosphere changed. Her energy made me feel more nervous, and as a result I ended up crying even more than I was before she arrived. I could feel my anxiety amplifying; my other cPTSD symptoms were activated as well. I tried to hold back my tears to gain back some of my composure, but my body failed me. I've already gone past the point where my tears were retractable.

The doctor tells us that my symptoms might suggest it was an ectopic pregnancy and that I need to be seen quickly at a hospital. I know that this is rare occurrence, but I also know how unlucky I have been to experience so much grief and pain in the span of 35 years on earth. I start to accept that there will be more examinations and possible treatments at the hospital I don't want to endure.

She calls a medical taxi for us to be taken to a private hospital in Malaga. She escorts us to the resort's entrance where we will be picked up by taxi. The doctor tries to comfort me by saying: 'It's going to be okay, Erin. You are young. At least we know you can get pregnant. That's important to know and it will get better'. She's held my hand close to her body. In the moment, I didn't know if I believed her. All I knew is that these were the indirect words that confirmed that I was losing the pregnancy. She didn't say the word 'miscarriage' and she didn't need to for the message to be clear.

We arrive at the hotel after an hour-long journey to reach the private hospital in Malaga. We check in with the receptionist who is more speaking to Rob than she is to me. She can see that I am not in a state where I can rationally answer questions. We are told to sit in the waiting room with other people waiting to be seen. There were mothers, fathers, kids, and babies in the room with us.

We are sent to the gynae ward which is in a different building on the third floor. Shortly after the woman is seen, we are called into the doctor's office. I'm relieved it is a female gynaecologist. Her English is very limited. I did my best to answer the questions she asks me 'when was your last period', 'how far along are you?', 'when did you start to bleed?', 'do you have any health conditions we should know about – diabetes?'. I tell her I have cPTSD. I keep saying 'I'm scared'. She doesn't say anything to alleviate my fears. Rob sits in a chair next to me and doesn't speak because he is frozen in the moment

The doctor guides me to the exam table. Rob stays in his seat. After what seems like an eternity, the exam came to an end. She says she did not see an embryo on the screen, but she still needed to do blood work to confirm that I was experiencing a pregnancy loss and if the pregnancy could have somehow ended up in the fallopian tube to cause an ectopic pregnancy. The blood work confirms that I was pregnant, however; the results are not indicative of an ectopic pregnancy. She tells me to make an appointment with my GP upon my return to England for follow up care. We return to England the next morning where I sought out care with my GP and early pregnancy loss team at my local hospital.

Despite studying grief and bereavement related to pregnancy loss for four years, it was the first time that I bore witness to the physical sensations and the flooding emotions attached to losing a pregnancy. Whilst we were flying back to the UK, I reflected upon the birth stories parents told me during the semi-structured interviews. Whereas I was detached as a researcher from the incidents, I understood what a harrowing experience losing a pregnancy was. I was on the other side of the mirror. I now recognised the power of language and how hurtful it is to hear the 'at least' statements which were often discussed during our meetings. There were no platitudes that were going to make our suffering any better.

What is most distressing is that Rob and I will never experience a relaxed pregnancy. We will *only* know what it is like to have a subsequent pregnancy after loss, a rainbow baby. Never will we not worry what a new symptom may become. Any twinge or ache will signal that something is wrong, even if it isn't. We will always wonder what this pregnancy would have been and remember it on its due date which would have been the 11th of February 2023.

The miscarriage was a traumatic experience which has impacted my mental health by exacerbating my cPTSD symptoms, and ultimately the progression of this thesis. Instead of completing my studies in June 2022, I submitted this thesis in August. Thankfully, I have supervisors who support me holistically and understand the importance of taking care of oneself.

This loss feels intrinsically different than the other losses I have experienced over the course of this programme. Working in the field of baby loss was not a protective factor, although my experiences as a grief and bereavement researcher did try to defend me from becoming too hopeful that the pregnancy would be viable. I included my experience of pregnancy loss to validate the experiences of parents who haven't revealed their stories to the world but think fondly of their baby. I hope this is a small act of advocacy on behalf of the parents I've met during my doctoral programme to continue the conversation about pregnancy loss to normalise it within our culture, and to and to break stigma around miscarriage.

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Appendix A

Canterbury
Christ Church
University

27th January 2020 Ref: 19-005

Erin McCloskey

Email: e.mccloskey544@canterbury.ac.uk

Dear Erin

Project Title: Baby loss, grief, and the quest for community: A mixed methods study investigating stillbirth bereavement support pathways for ethnically diverse bereaved parents

Your application was reviewed by the Faculty of Health and Wellbeing Ethics Panel on 20th November 2019. The Panel agreed that the conditions set out in my email of 26th November 2019 should be met before final approval could be given.

As Chair of the Panel, I am content that these conditions have now been met in full and I am writing to give formal confirmation that you can commence your research. Any significant change in the question, design or conduct of the study over its course should be notified to me as Chair and may require a new application for ethics approval. You are also required to inform me once your research has been completed.

With best wishes for a successful project.

Yours sincerely

MBedford

Martin Bedford
Chair, Faculty of Health and Wellbeing Ethics Panel
Tel: 01227 922527
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Faculty Ethics Panel
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Professor Rama Thirunamachandran, Vice Chancellor and Principal

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Appendix B
Consent form

Canterbury
Christ Church
University

CONSENT FORM

Title of Project:	Baby loss, grief, and the quest for community: A mixed methods study investigating stillbirth bereavement support pathways for ethnically diverse bereaved parents
Name of Researcher:	Erin McCloskey

Contact details:

Address:

Erin McCloskey

School of Nursing, Midwifery and Social Work

Faculty of Health & Wellbeing

Canterbury Christ Church University

North Holmes Road Canterbury, CT1 1QU

Tel: *01227 767700*

Email: e.mccloskey544@canterbury.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential ☐
4. I agree to take part in the above study. ☐

Collage Creation

5. I understand the collage I create (or copy of the work) will be used in the researcher's portfolio and will be submitted for review panel. ☐

Name of Participant:	Date:	Signature:

Copies: 1 for participant

1 for researcher

Appendix C
Participant information sheet

Baby loss, grief and the quest for community: A mixed methods study investigating stillbirth bereavement support pathways for ethnically diverse bereaved parents

PARTICIPANT INFORMATION SHEET

A research study is being conducted at Canterbury Christ Church University (CCCU) by Erin McCloskey. I would like to invite you to take part in a research project. Before you decide to participate, you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and ask questions about anything you do not understand.

Background

Stillbirth is a silent public health crisis that affects families across the United Kingdom. In 2016, one in every 225 births ended in stillbirth; which is approximately 9 babies every day (Tommy's, 2018). Even as risk factors for stillbirth are identified through prevention research, the psychological consequences of stillbirth and therefore interventions have yet to become a priority (Froen et al., 2016; Bhutta et al., 2016). National charities within the baby loss field operate to support families affected by the death of a baby through various bereavement support efforts.

Despite bereavement support being available across the UK, not all parents who have experienced a stillbirth access opportunities provided by these organisations. The purpose of this study is to explore how bereaved parents from BAME (Black, Asian and other Minority Ethnic people) communities seek support through befriending programmes and support groups. This study examines the parents' journeys in selecting which group they feel is most appropriate for them.

There are three components to the project: (1) interviews with parents who have lost a baby to stillbirth; (2) an art exercise where parents will create a collage showcasing what their experience felt like in finding bereavement support; (3) and a research journal which I will keep throughout the project. The research journal will document my research experience and be used in the analysis. As I am a scholarship recipient, this study is funded by Canterbury Christ Church University.

What will you be required to do?

Participants in this study will be required to:

- Participate in a semi-structured interview discussing your experience in finding bereavement support, how you went about accessing support, and whether the support you received has been effective for you.

- You will also have the opportunity to take part in an art exercise to make a collage. A collage is a visual representation made of different materials to create a new whole piece of art. To create a collage, you may include newspaper clippings, ribbons, photographs, or portions of other artwork that are glued to a blank background. Incorporating collage into the research process provides parents with another format through which they can reflect upon their feelings which may not be accessible through the semi-structured interview.

To participate in this research, you must be:

- A parent who identifies himself/herself/themselves from an ethnic minority (Black, Asian and/or other Minority Ethnic) community
- Have experience of losing a baby to stillbirth which is defined at 24+ weeks of pregnancy
- Participates in a befriender programme or peer support group or have attended one within the last 5 years. You do not need to have participated in the group for a long time.
- Living in England

Procedures

You will be asked to take part in a semi-structure interview that will last approximately for 60-90 minutes about your experience of being a bereaved parent and how you chose to access bereavement support. We will discuss what motivated you to seek support from an organisation, and the benefits and challenges from seeking support from these charities or channels.

You will also be invited to participate in a collage making exercise. This will take place in a setting of your choice and which is familiar to you. Basic collage making supplies (paper, scissors, glue and some magazines) will be provided.

Feedback

Participants will have the opportunity to give their feedback during the research process to ensure the researcher is capturing their viewpoints correctly. Transcripts will be provided of the semi-structured interview to participants for them to review and to make sure the transcription captures the views and opinions of the participants accurately. At the end of the study, a short report of the study's findings will be made available to those who participated.

Confidentiality and Data Protection

In accordance with the Data Protection Act 2018 and General Data Protection Regulations (GDPR), and the University's own research and governance procedures data protection policies all data and personal information will be stored securely within Canterbury Christ Church University premises. No unrelated or unnecessary personal data will be collected or stored.

The following categories of personal data will be processed: consent form, the interview both through recording and typed transcripts, and collage (actual hard copy of the collage or a photo of it). Data will only be accessed by Erin McCloskey, Dr. Jacqueline Wier and Professor Douglas MacInnes, who are my supervisors.

After completion of the study, all data will be made anonymous and held for a period of 5 years. Data will be held on an encrypted devise that is password protected. Pseudonyms will be given in place of participants' real names in order to protect your identity.

Dissemination of results

The results of the study will be published in the doctoral thesis which is stored in the University library database. It is envisaged that the results of the thesis will be published in peer review journals and presented at an appropriate and relevant conference.

Deciding whether to participate

If you have any questions or concerns about the nature, procedures or requirements for participation do not hesitate to contact me. Should you decide to participate, you will be free to (i) withdraw consent at any time without having to give a reason, (ii) request to see all your personal data held in association with this project, (iii) request that the processing of your personal data is restricted, (iv) request that your personal data is erased and no longer used for processing.

Process for withdrawing consent

You are free to withdraw consent at any time without having to give a reason. To do this, please email Erin at e.mccloskey544@canterbury.ac.uk.

Any questions?

Please contact Erin McCloskey on e.mccloskey544@canterbury.ac.uk, 01227 767700. You may also contact Dr. Jacqueline Wier at jacqueline.wier@canterbury.ac.uk or Professor Doug MacInnes at douglas.macinnes@canterbury.ac.uk for further assistance.

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Appendix D
Interview Schedule

Title: Baby loss, grief and the pursuit for community: A mixed methods study investigating stillbirth bereavement support pathways for ethnically diverse bereaved parents

Date:

Time:

Place:

Interviewer: Erin McCloskey

INTRODUCTION

Introduce yourself

Introduce the study

a. What the purpose of the study is
b. Remind participant what themes will be discussed
c. How the study is implemented; interviews and introduce collage exercise
    a. Inform interviewee what will take place during the interview
        i. Remind interviewee that the interview will last for approximately 60-90 minutes long, but able to finish before that time for any reason
        ii. Can take a small break if requested

Introduce CCCU

Inform interviewee of confidentiality

Inform interviewee/respondent of anonymity

Inform interviewee of right not to answer a question if they do not wish to

Inform interviewee of right to stop the interview at any time without jeopardy

Gain consent for audio recording

a. Show interviewee the device

Gain consent (verbal & written) to participate

a. Provide consent sheet and pen for them to sign

QUESTIONS- More questions will develop as the interview continues

1. Broad questions
    a. Tell me about your experience seeking support through baby loss charities.
    b. What was your motivation to reach out to charities?
    c. Tell me what it was like attending a meeting/speaking to a befriender.

2. In-depth questions

    a. How important is it to access support from an organisation that is of the same faith as you?
    b. How important is it to access support that is ethnically diverse?
    c. Often in peer support programmes, mothers more often than men attend programming. Why do you think that is? What forms of support do fathers access peer support groups (i.e. football clubs) would be appropriate?

3. Clarifications and link to theory
    a. What changes would you suggest to organisations to encourage more ethnic diversity?
    b. What would make seeking support easier for parents? Whose responsibility is it to promote bereavement support services?
    c. Do you know what the National Bereavement Care Pathway is?

CLOSING

Concluding statement

a. Ask if there is anything else they would like to say before the interview ends

Thank the respondent for their time

a. Offer SANDS hotline number in case they need to seek emotional support after the interview

Inform them of what will happen after the interview

1. Offer an invitation to them to take part in the collage making exercise

Provide contact information if they need to contact the baby loss organization of their choice about the study or the following:

- Call 116 123 for Samaritans
- Text “SHOUT” to 85258 to contact Shout Crisis Text Line
- Mind.org.uk/information-support/helplines/
    - Infoline: 0300 123 3393

Appendix E
Recruitment form

Baby loss, grief and the quest for community: A mixed methods study investigating stillbirth bereavement support pathways for ethnically diverse bereaved parents

Lead Researcher: Erin McCloskey, Doctoral Student

Erin McCloskey and researchers from the School of Nursing, Midwifery & Social Work at Canterbury Christ Church University are recruiting participants for a research study looking at how minority ethnic parents access befriending programs or peer support groups after losing a baby to stillbirth. This study may help us to better understand how different ethnic communities access bereavement support, and help organisations better serve ethnic minority families who access their services.

You are eligible to participate in this study if you are at least 18 years of age or older and are:

- Parents who identify themselves from minority ethnic background
- Lost a baby to stillbirth which is defined at 24+ weeks of pregnancy by the NHS
- Living in England
- Currently participating in a befriender programme or peer support group or have attended one of these programmes within the last 5 years
- Able to provide informed consent

The study will take place across England. The study site will be determined between you and the researcher. Your participation will last up to 2 hours each day for a potential total of 2 days.

As part of participating, you will be asked to participate in a 60-90 minutes long interview where you will share your experience of seeking baby loss bereavement support. You will also be invited to make a collage which is a piece of artwork that is made from assembling different mediums (newspaper clippings, magazines, photographs, etc.) into a new whole piece of artwork. The purpose of the collage making activity is to document emotions and contributing factors (i.e. logistics of accessing support, need of child care, access to transportation) through a creative lens.

If you participate, there is no anticipated direct benefit. However, you will be contributing to research which will hopefully lead to the development of better informed services and care.

If you are interested in participating in this study, please contact Erin McCloskey at e.mccloskey544@canterbury.ac.uk.

Appendix F

Correspondence examples from charities

Hi Erin,

It has been great to have had the opportunity to have spoken with you a couple of times over the past few months and I know you also spoke with Sharon our Bereavement Support Coordinator at Tamba. I hope these discussions helped you to understand the complexities and unique situations our bereaved families are in when they lose a twin, triplet or more babies from a multiple birth pregnancy or they have lost a child who was a twin or a triplet.

We have many parents (over 500) in our online support group but we always like to offer our bereaved community the chance to be involved in research as this group can often be forgotten when it comes to baby loss especially when a family have lost a twin and have a surviving twin as they often say how mixed they feel emotionally and how they have lost the status of being a parent to twins.

For this reason, we would be happy to support the qualitative research project you are hoping to embark on. We will certainly promote the project to help with recruitment of parents.

If there is anything else you think we can help with please do not hesitate to ask

---

Dear Erin,

It was a pleasure to have met with you yesterday to discuss the role that our bereavement service plays in providing support to Muslim mothers who have had a stillbirth. The statistics we have, clearly demonstrate that BME communities do not engage as well with some of the national charities that offer bereavement support.

It is essential that we try to understand some of the factors underlying this. My experience so far has been that many Muslim women prefer to have a Muslim perspective incorporated into the support they receive and so they choose not to engage with some of the larger bereavement support charities. But it may well be that access to support is an important factor too.

For this reason, I would be happy to support the qualitative research project you are hoping to embark on and although we cannot guarantee that bereaved mothers will come forward, we will certainly try to promote the project to help with recruitment.

I wish you all the best with the project.