A Qualitative Exploration of the Experience of Bereavement Amongst Gujaratis in the South Asian Community

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Abstract

Background: Research indicates that bereavement care for specific ethnic groups is inadequately addressed, largely due to a lack of awareness and knowledge of individuals' personal faith and culture. The COVID-19 pandemic has underscored the urgent need for improved attention to bereavement. This study explores the Gujarati population's bereavement experiences in the United Kingdom (UK), an area with limited existing research. By gaining insights into their diverse experiences, we can evaluate existing bereavement models and assess their applicability, ultimately aiming to enhance support for this community.

Methodology: A qualitative research design was selected, guided by a Critical Realist (CR) epistemological stance. Consultation was integral to the process throughout the study's development and interpretation of findings. Participants were recruited using purposive sampling through community organisations. Twenty Gujarati individuals shared their bereavement experiences in oneon-one interviews. These interviews were recorded, transcribed, and analysed using Reflexive Thematic Analysis (TA) to identify common and differing themes, thereby deepening our understanding of their experiences.

Findings: From the data, five primary themes and twenty sub-themes emerged. The main themes encompassed: understanding bereavement and its process, the aftermath, coping with grief, the cultural influence on grieving, and support during bereavement. While participants generally followed a similar mourning process known as *Besvanu*, their experiences of processing and understanding bereavement varied. Different coping strategies were identified, with some being helpful and others unhelpful. The interplay between culture and religion was evident, and cultural nuances significantly impacted individual bereavement experiences. Generational differences in views and values were noted among participants, potentially due to acculturation. Many individuals were unaware of

available bereavement support and had not sought it due to societal stigma. Existing models showed some applicability but were limited as they did not fully account for cultural nuances and religious beliefs.

Implications: The Gujarati population may struggle to know of available bereavement support services, highlighting the need for better promotion to enhance accessibility. Bereavement and mental health services gaining better understanding of cultural nuances and religious beliefs, would allow them to support individuals from Gujarati backgrounds more effectively. This includes recognising that traditional bereavement models may have limited applicability for this community.

Keywords: South Asian; Gujarati; Qualitative; Thematic analysis; Bereavement; Experiences

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"Those we love don't go away; they walk beside us every day. Unseen, unheard, but always near; still loved, still missed, and very dear." – Alex Maclean

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Chapter One: Introduction

Chapter Overview

The first chapter will introduce the research highlighting the researchers epistemological, ontological, and personal positions. The key terms are defined and an overview of literature relevant to the research is presented.

1.2. Positioning research

This research focuses on individuals' experiences of bereavement from a South Asian (SA) background, particularly within the Gujarati community. Interviews for this research were conducted in the UK between September – November 2023.

1.2.1 Ontological and Epistemological Positions

Epistemology is how one views the nature of knowledge, it refers to what can be known about said reality (Marsh et al., 2017). Epistemology is thinking about questions such as what knowledge is and what is counted as knowledge and investigates how claims considered to be knowledge, are justified (Ejnavarzala, 2019). Ontology is understanding the nature of reality (Al-Ababneh, 2020) and relates to human-related conditions that are linked to social, cultural, and political contexts (Ejnavarzala, 2019).

This research takes a critical realist (CR) epistemology stance. I chose this epistemology, as CR looks at the analysis of experiences of participants to understand a description of the real world (Lawani, 2020). Lawani (2020) states that CR aims to look at underlying causal mechanisms, to obtain knowledge, to then understand how things work. The CR stance helps suggest policy recommendations that are practical and help address social issues (Fletcher, 2017).

1.2.2 Personal position to the research

Taking a CR stance, I understand that bereavement can have multiple meanings to individuals and different meanings will be made on how they interpret a loss of a loved one. Personally, I believe that after an individual passes away, they are reincarnated, and the soul is still very present. My preference for working through bereavement is to experience my emotions privately for myself and celebrate the individual rather than mourn in the initial stages of Besvanu (mourning period). However, I acknowledge that others would have different views of this, which can be impacted by different experiences of upbringing and exposure to culture and religion.

Reflexive awareness is considered an integral part when conducting qualitative research. It helps the researcher to critically self-evaluate their position with regards to the research and is achieved by paying analytic attention to the process and outcome (Dowling, 2006). Acknowledging my own experiences, values, assumptions, and beliefs, helped me, to judge the authenticity of the findings and helped to enrich the process (Palaganas et al., 2017) . Reflexivity has been criticised to be selfindulgent and narcissistic, when it appears that the voice of the researcher is more dominant than the voice of the participants (Bukamal, 2022; Finlay, 2002). However, it is still seen as a powerful tool because the process can help researchers to monitor their biases (Finlay, 2002a) and it can raise awareness to whose voice is being dominant (Hertz, 1997).

Reflecting on my experience of bereavement, I have found it difficult to disentangle religion from culture and understand the cultural expectations placed on individuals from a Gujarati background. Many individuals I know who have experienced a bereavement in the SA community have spoken to me about finding it difficult to follow through certain rituals, as they felt that they did not understand the significance of the specific rituals and customs. This lack of understanding has made it difficult for people to process the loss or be able to grieve. Those that I have spoken to were not aware of services that could support them, and when I was asked if I knew about any support

services, I was unsure what was available. This made me question why I did not know about the available support especially when bereavement is a common event that people experience at different points in their life. I felt that how bereavement, loss or grief is experienced, depended on a person's exposure to culture and religion.

As a trainee clinical psychologist, I acknowledge that psychologists have the power to help advocate for change and act as a voice for the underrepresented. I am aware that the voices of the SA community are marginalised. Part of this research is to help services become aware of how they can be culturally competent in understanding bereavement experiences for this population and be able to support them.

An insider researcher is when a researcher is conducting research on a group, person, or community in which they share the same characteristics (Yin, 2015). Research suggests that insider researchers can obtain a greater depth of understanding from the data that is collected, because they are able to build more of a rapport with participants. This enables participants to feel comfortable and therefore more willing to share their experiences (Dwyer & Buckle, 2009).

I identify as a person from an Indian Gujarati background hence I am approaching this research as an insider researcher. Being able to understand the culture that is being explored can promote a natural flow of social interaction , which can encourage a close relationship with participants and bring a level of trust that encourages speaking and rapport building (Bonner & Tolhurst, 2002).

Alternatively, from a positivist perspective, research is only considered objective if the research is conducted from an outsider perspective (Chavez, 2008; Hellawell, 2006). Research that is conducted by an insider researcher could be criticised for not holding the same standard of rigor because the personal position the researcher may hold may be considered too "close" (Brannick & Coghlan, 2007).

1.2.3 Language

This thesis is written mostly from a third-person perspective; however, my personal reflections of the process are written in the first-person.

1.3 Definition of key terms

1.3.1 Bereavement, grief, and mourning

Bereavement and grief are often used interchangeably within research and can be inconsistently used (Zisook & Shear, 2009), thus there is a need for these terms to be defined for the purpose of this research. 'Bereavement' is described as experiencing a loss or a state caused by loss, many types of losses can create a state of bereavement (Abi-Hashem, 1999). The term 'Grief' is described as emotional, cognitive, functional and behavioural responses to a death: it is also important to note that the term can be broadly used to explain other losses experienced such as loss of opportunity or loss of functional ability (Zisook & Shear, 2009). Mourning is also suggested to be a common term used with grief and bereavement due to its interconnectedness and interdependence (Bowlby, 1980; Abi-Hashem, 1999).

The term 'Mourning' is used in the literature to describe an individual who presents externally how they are feeling internally (Abi-Hashem, 1999). Two meanings have been shared within the literature; one describes mourning as coming from a range of conscious or unconscious activities and internal processes of the mind, and the second refers to mourning being an appropriate cultural response to grief (Abi-Hashem, 1999; Silverman 2004). For individuals who follow mourning in a way that is

culturally accepted, their authentic feelings may not be presented accurately. This may be due to the potential disapproval from others who follow the same cultural customs (Wolfelt, 1988).

To explain how death impacts a life of an individual, family, or community through the definition of terms is difficult, because a person's reaction to loss cannot be defined without understanding the interpersonal, social, cultural, and religious connections involved (Silverman, 2004). In this thesis, taking a CR stance, bereavement is described in three ways; the loss of a loved one, a process of acceptance or, an understanding of their loved one being reincarnated which Thrane (2010) explains gives comfort. Some individuals, see loss as a part of life and there is a different relationship between death and living (Abi-Hashem, 1999). Within this thesis, terms will be used interchangeably due to the complexity of understanding the experience of bereavement and it being difficult to pick a term or combination of terms which explain the complex phenomena of grief.

Within this thesis, I acknowledge using the term 'death' less because of my own beliefs around understanding death as the soul being immortal and a view of a connection with a loved one being everlasting. Death to me has felt that I am cutting the connection off and is insensitive when speaking to individuals about a loss. Majority of the participants also did not use the term 'death' so I have chosen to use 'passed away' or 'loss of a loved one' to be sensitive towards the experience individuals have faced.

1.3.2 Religion Culture and ethnicity

Parkes et al (2015) states that the word 'religion' comes from the Latin *religare* which traditionally meant 'to bind', which includes a body of ideas which help to bind a society together. The Collins (2024) dictionary defines 'Religion' as a "belief in a God or Gods and the activities that are connected with this belief, such as praying or worshipping in a building such as a church or temple".

'Culture' is now considered to be dynamic and changeable, involving a flexible system of values that include different worldviews that people live by (Fernando, 2012). It relates to a system where different parts of our identities are defined helping people to negotiate their lives (Fernando, 2010). Culture is also interchangeably used with ethnicity, which refers to different groups who might share the same religion, same cultural system, language, and identify with the same nation or state (Spencer-Oatey, 2012).

The term 'Culture' is also used to explain different traditional behaviours, which are particular to a society or a group of societies, a particular race, a certain geographical area or a certain period of time (Brumann, 1999). Usually, definitions that have tried to define culture believe that culture includes something which is learnt by a group of people or shared. However, it can have many definitions dependent on the content of the culture (Birukou et al., 2009). The relationship between culture and religion is an on-going debate; religion is suggested to be determined by culture but also influenced by culture (Beyers, 2017).

Culture also intertwines with religion due to the difficulty of separating both terms. Individuals have different views on how one should display emotion when grieving, for example: some believe wailing is important at the time of death because it allows individuals to release pent-up emotions (Scheff, 2001), whereas there has been contradiction of displaying grief emotions in religious texts such as the Bhagavad Gita (Gupta, 2011). This highlights the different perspectives that individuals and communities can have.

This thesis explores culture as a changeable entity meaning multiple perspectives such as differences between Western and Eastern culture and highlights how culture and religion is difficult to disentangle.

1.3.3 Black Asian and Minority Ethnic (BAME)

The term BAME has commonly been used in research and within reports from the Office of National Statistics (ONS). The acronym attracted controversy leading to the term being discontinued, as it was not all-encompassing (HMG, 2021). BAME has been found to create divisions and exclusions, resulting in perpetuated racism (Patel & Fatimilehin, 1999), and maintenance of whiteness (Di Angelo, 2011).

The term BAME is not used in this thesis and is only referred to in the keywords for the systematic literature review (SLR) and in quotes from authors, who previously used the term in their research. In line with guidance from the Racial Disparity Unity (2021), 'ethnic groups' is used when referring to the SA population and where possible, if specific communities are mentioned they are identified (RDU, 2021).

I noticed myself feeling uncomfortable with using the term BAME, as I have felt singled out when this term has been used. The term does not capture individual Asian communities rather it groups them all together which can lead to misinterpretation. I also do not see individuals from different ethnic groups as a minority but as a majority and have found the term minority to create a divide and promote racism.

1.3.4 Gujarati culture

It is important to note that there are differences within the Gujarati population. More than other national populations, Indians are suggested to have a substantial number of intragroup differences, and as a population are divided into many different groups: for example, region, caste, origin, religion,

language group (Poros, 2010). In the state Gujarat, the official language is Gujarati which is spoken by 60.3 million people (Shantilal, 2013) and they are commonly referred to as Gujaratis.

With migration, acculturation and cultural diversity, differences of views can be present within families and between generations. There can be differing levels of compliance to tradition between generations (Lee & Mjelde-Mossey, 2004). Within Western countries, individualism is promoted, and the values which are commonly followed are: autonomy, self-reliance, personal achievement, and independence. Alternatively, SA communities are collectivist, focusing on family cohesion, conformity, solidarity, interdependence with group priorities and families being valued over the individual (Chadda & Deb, 2013; Skillman, 1999; Peterson & Bush, 2013; LaLonde et al., 2004). Collectivist families can be close, resilient, have traditional gender norms, follow obedience to older members and have an emphasis on family harmony. However, this can lead to unexpressed conflict, stress and in turn somatisation (Chadda & Deb, 2013; Zagelbaum & Carlson, 2011).

To sustain ethnic and cultural identity, whilst living in a different culture, migrants continue to practice sacred rituals and rites of passage (Van der Veer & Vertovec, 1991; Bankston & Zhou, 1995; Kurien, 1998; Guest, 2003; Min, 2005). This has been confirmed in research specifically focussing on the Gujarati community (Barot, 1980; Mukadam, 2003; Mawani, 2006). Hindu religious practices, at times, may be altered depending on local particularities (Zsófia, 2016). Academic studies have shown that people adapt to various aspects of local culture, if their religion is a minority, which then builds dual identity (Numrich, 1999; Yang & Ebaugh, 2001). This phrase is used to describe cultures living in a different context, altering cultural practices, which can be applied to the Gujarati population living in the UK.

This thesis will focus on the Gujarati community, who predominately originate from Gujarat and speak Gujarati, and are living in the United Kingdom.

1.3.5 Hinduism and death

The term 'Hindu' originates from a Persian-Arabic label for dwellers of the Indus area (Firth, 2005). Hinduism is described by many as the '*Sanatana dharma'*, the eternal tradition or religion. Hinduism is the oldest of the world's living religions with over three hundred million followers, the majority of which are believed to be living in India (Morgan, 1987).

Firth (2005) explains that Hinduism does not have a specific framework; rather, it is a diverse umbrella that holds a family of beliefs and practices. There are specific beliefs on attitudes to death which are common: transition to another life through the process of reincarnation, being with God in heaven, or absorption into Brahman (the ultimate reality). Certain rituals are used which are a set of actions that have symbolic value, they can be prescribed by a religion or by the traditions of a community (Srivastava & Barmola, 2013). The worldview of those who identify as Hindu is that there are different factors which can directly determine an individual's life. These include the current and future outcomes through samsara (the cycle of rebirth), karma (universal law of cause and effect) and an individual's actions including one's own thoughts (Srivastava & Barmola, 2013).

In the Hindu scriptures, it is taught that the end goal of human life is to achieve liberation (Moksha) and when this is reached the individual will become one united with a spirit called 'Brahman' (Morgan, 1987). There is a particular notion around having a 'good death', which follows a model on how to die. The Bhagavad Gita (Holy book) says that those who think of God at the time of death and love God will go straight to him (Firth, 2005). Firth (2005) suggests that many individuals focus on this passage as the key to a good death and a bad death is usually feared.

At the time of a loved one passing away, the Gujarati community have a mourning period *(Besvanu),* which lasts between 12 - 15 days, commonly 13 days in India (Firth, 1997). This is when the final rites are conducted, but this can change depending on the community from which the loved one who passes away originates. To help preserve how rites and practices are done within India, individuals try to practise the way it has always been done (Mawani & Mukadam, 2016). During this time, of mourning, there will be family chanting, singing prayers and conducting rituals, as well as the cremation process. Portions of the religious texts may also be recited such as *Bhagavad Gita* or *Garuda Purana* (Firth, 2005).

This thesis focuses on how individuals from a Gujarati background living in the UK understand their experiences of bereavement. For some Gujaratis, following religious practices and cultural expectations are significant aspects of processing a loss, but for others, this is not the case.

1.4 Models around grief, loss, and bereavement

There are many different models used to explain the grieving process that are based on Eurocentric views and principles and are used in literature to explain the process an individual may experience when a loss occurs. This thesis will explore whether these models are culturally appropriate and can be applied to Hinduism teachings to explain the bereavement process in the Gujarati community living in the UK.

Kubler-Ross's (1969) five-staged model of grief is explained and frequently accepted as a guide for the grieving process (Avis et al., 2021). The model suggests that when experiencing a bereavement, a person experiences five different emotions: Denial, Anger, Bargaining, Depression and 'Acceptance'. (Kubler-Ross, 1969). The model is suggested to be fluid across the stages, although some have misused this model and misinterpreted it as linear process (Corr, 2019). Although Kubler-Ross and others have emphasised that experiences of the stages are flexible, critics have felt that the concept of stages have

been applied in a rigid way and explain potential harm if individuals follow the model in a prescriptive rather than descriptive way (Tyrrell, 2023). The model is suggested to not explain all types of grief. Interviews that lead to the development of this model were undertaken with terminally ill patients, which may limit the applicability (Avis et al., 2021).

Some Hinduism teachings explain the larger goal of accepting death, rather than ruminating in grief; they would explain *Besvanu* as a time when an individual should feel the above emotions. It could be suggested that the *Besvanu* period fits with Kubler-Ross' model (1997) of grief, as both the model and Hinduism teachings speak to acceptance as being part of the grieving process.

The Dual Process Model (DPM; Stroebe & Schut, 1999) was one of the first models to approach bereavement as a continuous process. Stroebe & Schut (1999) state that DPM allows for the bereaved individual, to be able to go back and forth between loss-orientated work (concentration on processing and dealing with loss itself) and restoration-orientated work (attending to life changes such as dealing with arrangements of life such as finances). Individuals from a Gujarati background are expected to mourn for the first few days following a loss; it is then culturally promoted that an individual accepts the death and moves on. Therefore, the DPM model may have limited applicability as individual from the Gujarati community, would have less flexibility to be able to go back and forth between the two processes.

Another model is the Continuing Bonds (CB) theory (Klass et al., 1996) which explains the significance of the relationship between the person who has passed away and the person who is mourning their death. This theory recognises that a relationship can be ongoing after a loss and does not suggest an individual should move on by severing ties to be able to work through their grief. The theory suggests that expressions displayed in the initial stages of bereavement appear when an individual is searching to reclaim the loved one that they have lost (Field et al., 2005).

In the literature, there has been some debate about whether CB expressions are adaptive or maladaptive (Field et al., 2005). Field et al. (1999) investigated grief-specific symptoms six months post-loss; they found that CB expressions, such as keeping possessions of loved ones or using special belongings of theirs excessively, had maladaptive consequences (e.g. hearing the loss of a loved ones' voice which would cause distress), they suggested that individuals should be encouraged to use possessions less. However, other research suggests using loved one's belongings can provide comfort as it can evoke positive memories and promote a sense of closeness, which can help an individual and continue transitioning to a new identity of self with integrating the past (Klass et al., 1996). In the Gujarati community, meaning-making of death and processing bereavement is closely linked to the CB theory, as rituals that are followed are about remembering the soul of the individual who has passed away. It is also common to remember the deceased on Shraadh (the day of remembering ancestors), where ceremonies are undertaken to help ensure the well-being of the loved one's soul in their afterlife (Bhuvaneswar & Stern, 2013). The family may also partake in memorial services such as making the loss of a loved ones' favourite food at the one month or one year anniversary (Bhuvaneswar & Stern, 2013).

1.5 Mental health and grief

After an individual experiences the loss of a loved one, the majority of individuals are known to develop debilitating symptoms of grief, which can impact on one's functioning and health (Boelen & Prigerson, 2007). Thus, it is important to consider the impact of bereavement on mental health. Mental and physical health problems are thought to be more likely to occur in individuals who experience high levels of prolonged grief disorder (Chen et al., 1999; Prigerson et al., 1995; Prigerson et al., 1997). To date, there has been no specific research exploring how bereavement affects individuals from a SA Gujarati background and the impact this has on their mental health.

When compared to other ethnic groups, the SA population is repeatedly underrepresented within mental health services (Sheikh & Furnham, 2000) and the data demonstrates that little is known of the experience of mental health within the Indian Gujarati community (Patel & Shaw, 2009). Commonly the research conducted on SA populations is combined with many subgroups such as Bangladeshi, Pakistani, and Indian populations, and is understood to be similar across these groups (Nisha, 2016). This does not allow differences to be understood or acknowledged within and across the subgroups (Gerrish, 2000). The need to understand differences of experience in mental health in individual communities has been raised by researchers (Gerrish 2000; Patel & Shaw, 2009; Nazroo et al., 2002, Parveen et al., 2011; Patel, 2016).

Due to the lack of research available for specific subgroups, this thesis aims to add to the evidence base by understanding the experiences of bereavement from a SA Gujarati community living in the UK and learn how mental health may be impacted as a result.

1.6 Gaps in bereavement care and research

Within healthcare policy and practice, bereavement care is commonly considered low priority and unrecognised. However, since the COVID-19 global pandemic, end-of-life and bereavement care have gained more attention (Pearce et al., 2021). Research has highlighted that for every death that occurred in the COVID-19 pandemic, nine people were affected by bereavement (Verdery et al., 2020).

A systematic review conducted by Mayland et al (2021), highlighted barriers including 'unfamiliarity and irregularities' in services, which related to healthcare professionals, as well as bereaved individuals from ethnic groups. Individuals from ethnic groups were not aware of the support available. The review found that staff had received limited training on cultural knowledge and nuances, and that the format of support was not accessible. Overall, the review, shed light on the lack of evidence for bereavement care for those from a specific ethnic group and found that facilitators

lacked an understanding of the social support networks within these communities. The review suggested that the lack of awareness about bereavement care may stem from healthcare professionals not being aware of the existing support systems available to ethnic groups and the importance of consideration of personal faith.

Interestingly, only six of the 185 participants across studies included in the review were classified as Indian, highlighting the lack of research within this subgroup. It suggests a naivety amongst researchers as they generalise the findings from different subgroups to form one outcome. The review emphasised the importance of implementing a co-designed approach, to help build a suitable model and format for bereavement care in ethnic groups.

1.7 Rationale for research with SA Gujarati individuals

To provide adequate support and interventions cultural competence is necessary. Interventions are more helpful if they are co-produced with ethnic groups following consultation (Selman et al., 2022). To better support ethnic groups, it is recommended that there is benefit in collaboration with specific cultural faiths (Selman et al., 2022). For example, by working with faith leaders, clinicians can become knowledgeable about beliefs and practices and be culturally sensitive in their approach to providing support (Bledsoe et al., 2013; Rogers et al., 2012; Thomas, 2012). A study conducted by Selman et al (2022), investigated access to support across 147 voluntary and community bereavement services before and after the COVID-19 pandemic. The findings showed that before the pandemic, 67.3% of individuals who attended bereavement services had unmet needs and 49% of this population were from ethnic groups. From the qualitative findings, there was a disproportionate impact relating to the lack of engagement in bereavement services by ethnic groups. Individuals had reported experiencing disruption to mourning practices, which affected their process of grieving; it was also evident that there was a lack of culturally appropriate support available.

The National Institute for Health Research (NIHR) is working to include voices from historically underrepresented groups in research, emphasising the importance of building relationships and trust (NIHR, 2021). This thesis aims to contribute to inclusive research by representing these individuals. Further research on individual communities is crucial for clinicians to offer culturally sensitive support. Therefore, this study will explore the bereavement experiences of the Gujarati community.

1.8 Conclusions

Overall, research has demonstrated that there is a need to understand how to develop bereavement services that are culturally competent and accessible to those from ethnic groups. Barriers have been outlined such as a lack of cultural awareness and sensitivity, a lack of accessibility, and an inadequate support format. The need for research within populations that are underrepresented is highlighted by NIHR. To address barriers in bereavement support, this thesis will explore SA experiences of bereavement, using a systematic review (Chapter 2) and focus on the specific differences within the Gujarati community in relation to bereavement through a qualitative research methodology (Chapter 3).

Chapter two: Systematic Literature Review & Research Aims

2.1 Chapter Overview

This chapter outlines the systematic literature review (SLR) that was undertaken to critically appraise literature relevant to this study. The SLR presents the aims, methodology, and a quality evaluation of selected literature, as well as a thematic synthesis of the findings from the literature review. The SLR is then summarised and critically reviewed, linking the findings to the study's rationale and aims.

2.2 SLR Aims and objectives

A SLR is a rigorous and structured approach to reviewing existing research on a specific topic or question. The method involves identifying, appraising, and synthesising research, following a process that allows it to be replicated (Siddaway et al., 2019). It concludes by making future recommendations for further research (Fink, 2019).

Initially, the SLR question asked '*what are the South Asian experiences of bereavement within the UK?'*. However, due to limited data in the UK from a brief scope of the literature, the context was broadened to all countries, thus the question became *'what are the South Asian experiences of bereavement?'*. The systematic review synthesized the evidence on bereavement support for SA and addressed the question *'what are the experiences of bereavement and support needs for South Asian individuals?*'. Specifically, it identified barriers and facilitators to bereavement support as this topic has been shown to be under researched with this population (Mayland, 2021).

Firstly, the PROSPERO register was checked to see if any systematic reviews had been done on experiences of bereavement within the SA population: records showed that no reviews had been conducted or were being conducted. The review protocol is registered on the PROPSERO register: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=473061

2.3 SLR Methodology

A pragmatic approach was used to guide the review, using the established methods outlined in the Cochrane Handbook for Systematic reviews (Cochrane, 2023). The approach included a preliminary scoping of the literature, the adoption of a search strategy related to the research question, the screening of studies to assess against the eligibility criteria, the extraction of data from the studies selected, an appraisal of the quality of findings, a synthesis of qualitative research through thematic analysis. The review is reported according to PRISMA reporting standards (Page et al., 2021).

2.3.1 Preliminary Scoping

A preliminary scoping search was conducted initially to ensure there were no other related systematic reviews, this included but was not limited to: Prospero, Google scholar and the Cochrane Library. To define the research question, the PICOS framework tool was used (see Table 1; Joanna Briggs Institute, 2011) to explore key search terms and unpick the research question. PICOS is an acronym for Population, Intervention, Comparison, Outcomes, and Study types. This tool is usually used for quantitative methods (Miller & Forrest, 2001) and was adapted to use with qualitative methods. The tool was used to specify the participants, the type of intervention, to identify any comparisons and outcomes. Participants included individuals from a SA background of any age.

Participants were excluded if they did not come from a SA background. Intervention and comparison were not applicable to the research question. The outcomes looked to explore bereavement experiences of those from a SA background, identify support systems available and the barriers and facilitators that may impact support for individuals from this background.

Table 1 – PICOS

Summary of PICOS

Participants	Intervention	Comparison	Outcomes	Study types

South Asian background, any age.	Not applicable	Not applicable	Understand key themes of how bereavement is experienced for individuals who are from a South Asian background. Explore current support systems available. Understand barriers and facilitators that may impact support for individuals from this background.	Include studies that are: Qualitative, primary studies and grey literature Exclude: Quantitative studies, opinion pieces, narrative book chapters, systematic reviews / scoping reviews etc). Studies related only to healthcare worker experience. If participants are not South Asian and if studies are not in English.

2.3.2 Search strategy

Using PICOS and the University of Hertfordshire (UH) library's search planning form, the search terms were developed. Broader terms for the search were used initially, which resulted in a high number of results, and some were identified as not relevant to the research question. The outcomes were then discussed with the supervisory team and UH library consultant, and it was decided to investigate bereavement reviews to assist in the refining of search terms. Following this process, the key terms were refined and Medical Subject headings (MESH), which are terms that are in the National Library of Medicine controlled vocabulary thesaurus, used for indexing articles in the database PubMed were explored to make sure all terms were captured. The final search strategy is shown in Table 2.

The SLR was conducted from September 2023 to December 2023. Databases were searched on 26 October 2023 and included Scopus, Medline, PsycArticles, first 20 pages of Google Scholar (these specific databases were selected after consulting with a member of staff from the UH library services and scoping research on this topic on Google Scholar to see where research in this area was

published). The reference lists of papers that were identified as meeting the research criteria were screened to identify whether any relevant papers had been missed. Email alerts were set up in case any new studies that met the search terms were published. An additional search was conducted using the Kings Fund Database, which retrieved six further studies. However, they did not meet the inclusion criteria, so they were excluded.

The search was limited to studies published in English, but there was no restriction on the year published, grey literature or country due to the topic area being under-researched. The search terms (see Table 2) were used to search the databases. To help the searches capture the appropriate papers, Boolean operations 'AND' / 'OR' were used. An Asterisk was used to capture any spelling errors, hyphenated words or derivatives (e.g., bereav* = bereavement, bereaved).

Table 2

Summary of search terms

Key terms	**Search terms**
South Asian	OR india* OR bangladesh* OR pakistan* OR nepal* OR afghanistan* OR maldiv* OR bhutan* OR "Sri Lanka*" OR "ethnic minority" OR "minorities ethnic" OR "ethnic minorities" OR "minority ethnic" OR "global majority" OR buddhi* OR hindu* OR muslim* OR cultur* OR cross-cultur* OR multicultur*
	AND

Bereavements	OR bereav* OR "Loss of loved one" OR grief* OR mourn*
	AND
experience*	“mental health experience” OR wellbeing OR emotion* OR "Help-seeking" OR "Lived experience" OR "Meaning making" OR support OR "Health equity"
	AND
Qualitative	OR interview

2.3.3 Screening and eligibility criteria

After searching across the three databases and Google Scholar, the initial search yielded 1680 papers. An online software tool called Covidence was used to screen the papers. Once imported, Covidence found 551 duplicates, and manually I had found three, which were then removed. The title and abstracts of the remaining 1126 were screened to determine whether they were relevant to answering the research question and fit the inclusion criteria (Table 3). It has been shown that by having two authors to screen papers it may reduce the possibility of relevant reports being discarded (Gartlehner et al, 2020), therefore, 81% of papers were reviewed by a peer, 21% by a supervisor and all papers were reviewed by me. After reviewing the papers, 188 appeared potentially relevant to the research question. A full-text review was conducted (37.23 % by a peer, 3.2% by a supervisor and all by me). 26 papers were included in the final review (see Figure 1; PRISMA).

Table 3

Literature search inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
• Must include individual from a South Asian background with experience of bereavement (from anywhere around the world) • Any age • Primary studies • Qualitative	• Other backgrounds that are not South Asian • Any studies not in English • opinion pieces, narrative book chapters, systematic reviews or scoping reviews etc • Studies related only to healthcare worker experience

2.3.4 Data Extraction

Data was extracted from the final included papers: Author, date of publication, aims of the study, research methodology, theoretical underpinnings, region, sample size, sample characteristics, sampling method, data collection and analysis, summary of findings and strengths and limitations of the study (see Table 4 below). This was done on Excel. Due to time restrictions this was not checked.

Table 4

Included studies

Author(s) & Date of Publication	Aim(s) of study	Region	Sample size	Sample Characteristic s (age, gender)	Sampling	Research methodology / Theoretical underpinning s	Data Collection & Analysis	Summary of findings	Strengths & Limitations
Ahmed et al. (2020)	To understand the factors of perinatal mortality which are related to sociocultural context and local practices during pregnancy and birth	Pakistan	25	Female Age – Not stated.	Purposive sampling	Theoretical underpinnings highlighted.	In-depth interviews not Thematic analysis	Women in this study had significant reliance on herbal remedies during pregnancy and birth. Some women were sceptical of health care advice and medication and, in some	+ Deeper inquiry into cultural practices of woman who had experienced a perinatal loss. + Gave a voice to a sample of rural woman in Pakistan to explain their experience of

			cases, felt their losses. loss was due to this. - Women Some women were only also felt there selected in the was spiritual areas the lady causes or faith health related
			beliefs for why workers they recruited encountered a from. loss.

Asim et al. (2022)	The study objectives are to understand the lived experiences of women who had multiple stillbirths in Thatta, Pakistan.	Pakistan	8	Female 15-39 years old	Purposive sampling	Psychosocial model	Semi structured interviews Interpretative phenomenological approach	Experiencing multiple stillbirths has a devastating impact on women's mental and social desirability responses Experiencing + The multiple stillbirths isolated women in the household and the community. Different labelling if you have a stillbirth and have kids to just having a stillbirth with no kids.	- Small sample size - Key informants helped recruit, social wellbeing. + The multiple interview guide was pilot tested before conducting interviews + Recommendations given

			Health system support was absent to meet the needs of such women who experienced stillbirths. Religious and spiritual beliefs play a role in the lives of bereaved women.

Batool & Azam (2016)	The study objectives are to explore the bereavement experiences of women after miscarriage, including psychosocial experiences of women after the miscarriage of their first child.	Pakistan	10	Female Aged between 23 to 28 years,	Purposive sampling	Psychosocial model Interpretative phenomenological approach	Semi structured interviews	The main findings are the exploration of bereavement experiences after miscarriage, constant psychological and physical pain was felt after miscarriage through different factors. It highlighted the importance of cultural awareness in addressing healthcare needs, and the need for immediate recognition of the psychosocial	- small sample - inclusion of only urban and educated women + some similarities are also noticed within the Western culture + Highlights factors to think about when implementing health policy and including healthcare needs of women from different cultures, who undergo similar reproductive losses.

impact of
miscarriage
and support

	for affected women.

Chaudhry (2014)	The study aims are to understand the experience and mourning among survivors of armed conflict in Karachi, women's words.	Pakistan notes theory armed conflict in Karachi,	Unclear experiences - Specific of grief in the g of survivors'	Female Unknown age generalisabilit Pakistan,	Purposive Mohajir y is limited	Gender lens Feminist lens face of losses	In-depth interviews and observation Grounded women incurred during	The article explores women's constructions and to Mohajir the 1985-1999 phase of utilizing totalizing violence on their lives. The study reveals that memories, historical and recent, as well as identities, are intertwined in	- Lack of reflexivity women so the + Understandi ng of grief, and their attempts to manage that grief. women's

					narratives of grief as they mourn individual and familial losses along with collective disenfranchisement. Different coping mechanisms are observed among women of different age groups in the face of grief.		
Christou et al.	Afghanistan	42		Semistructured	Insights into	-	Limited

(2023)	Stillbirths reported to still be high in Afghanistan, aim is to understand local beliefs and perceptions of causes to stillbirths and understand what might contribute to		Recent stillborn baby participants comprised of women (n = 21) and men (n = 9) Female community elders (n = 3), community health workers	Purposive sampling	Kleinman's explanatory framework - understandin g how individuals and cultures perceive health and illness.	interviews Thematic analysis	perceived causes of stillbirth. The impacts of stillbirth revolved around the psychological effects and grief, the physical effect on women's health, and	success in recruiting women who gave birth at home, most had given birth in a health facility. - Reflexivity not

	prevention of stillbirth experience.	(CHW) (n = 5) and mid wives (n = 4).	the social implications for women and how they are perceived by communities. Prevention practices in pregnancy aligned with perceived causes such as religious rituals, selfcare, and superstitious practices. Respondents felt it was preventable but explained not receiving any information on how to ensure healthy pregnancy.	mentioned, potential bias + Recommendations given + Provide insight into perceived causes of and explanatory models for stillbirth that exist in Afghanistan

Das et al. (2021)	The study objectives are	India	N = 134 IDI	Mother, n = 47	Purposive sampling	Psychosocial model	In-depth interviews	The main findings are	- The study includes the
	to explore the social, emotional, and psychological impact of child death and stillbirths on parents and their families in the north Indian context.		FGD, N= 72 Community representatives - 12	Father, n = 46 Other family members, n = 41 Females (mother – n = 19, grandmother, n = 18) Males (father, n=18, grandfather, n =17) Other family members gender not classified, n=41			Focus groups Constructivist grounded theory	related to the impact of the bereavement experiences of bereaved parents and families and understanding the sociocultural practises in India and the impact it may have, such as the differential experiences of mothers and fathers, the persistence of severe grief among mothers.	contextspecific nature of the finding + Identify need of care, counselling and support for parents after stillbirth or child death

Davies. (2019)	Understandin g children's views on their family and personal relationships and the meanings they attach to	England, UK	N=28	White British = 24 South Asian = 4 9 boys 15 girls	Convenience sampling	Continuing bonds theory	Data includes in-depth observational field notes, two sets of paired interviews	The paper acknowledges the importance of family homes as a site for encountered embodied, sensory, and	+ Sample is comprised of children in middle childhood who has children's a death, where

	death and bereavement and how they remember the individual.						Analysis is not clear.	material engagements with death, bereavement, and remembrance. It signifies children's pasts and memories in understanding their experiences of death and bereavement.	research has been neglected + Range of deaths and bereavements (including pet) - Majority from white British background – hard to generalise findings to other backgrounds
Ekanayake. (2013)	The study aims to investigate the	Sri Lanka	N = 38	Female = N = 21	Purposive sampling	Lazarus and Folkman's Transactional	In-depth interviews.	Natural disasters cause immense	+ Men and women in sample and

	coping strategies that were adopted by survivors in Sri Lanka after the 2004 Boxing Day tsunami to deal with a range of	Male, N = 17 Aged 18-65 36 were Sinhalese, 2 Muslim, 34 Buddhist, 2 were catholic. No Tamil participant	Model of Stress and Coping	Thematic analysis, with elements grounded theory.	suffering among some affected of communities, survivors rely on their own coping resources and support from family, social	varied age range + Highlighted consideration for better understandin g for local cultural beliefs about misfortune,

psychological and social problems.	from the study area was found.	networks, and mental health, the wider community to manage emotional distress, extended supportive networks.	and health before designing any mental health intervention. - Selective group through sampling method
		Religious faith and practices, and cultural traditions also play a crucial role in facilitating recovery and sustaining	- Dominant narrative of Buddhism perspective for coping strategies, make it hard to generalise to other individuals from other faiths.

emotional well- being.

Professional mental health support and Western psychological interventions was limited, and survivors preferred to seek help

	from traditional and religious healers.

Garcia et al. (2020)	The study aims to explore the experiences of after stillbirth of Pakistani, Bangladeshi, and White British factors contributing to outcomes in Bangladeshi women in	Luton, England British Framework theoretical differences such as eating	6 British that impact mothers - small Luton.	Female = 6 2 = White + Highlights bereavement 3= Pakistani 1 = Bangladeshi adverse restrictions	Purposive sampling	Framework analysis for ethical decision making Not clear	Semistructured interviews.	Mostly there was similarities of between Pakistani, Bangladeshi and White and religious Cultural bias during pregnancy or religious views that contributed to decision making when	+ Culturally sensitive religious differences and similarities - recruitment differences

mothers and underpinnings were sample birth identified.

mothers, a bereavement to identify few cultural experience.

Pakistani and

			considering option to
			have postmortem examination was found. Regardless of ethnicity it was found that pregnancy related knowledge was limited which contributed to their decision making. All mothers described adverse impact on wider family and finding it difficult to speak about openly.

Ghosh & BK. (2020)	The study objectives are to understand the COVID-19	India observation,	15	Unknown unstructured	Purposive sampling	Not clear interviews.	Documentary evidence, narratives and pandemic on the mourning
The COVID19 pandemic has had significant ramifications	- Lack of reflexivity - Location on the of interview for mourning				participants		

	rituals of Hindu communities in Kerala and West Bengal, it also aims to understand the difference between a good and bad death. It looks at the differences that had to be adopted and how this impacted individuals.		Comparative analysis	rituals of Hindu communities in Kerala and West Bengal, leading to negotiations, reaffirmations , and reinterpretati ons associated with death and bereavement.	were not neutral + Gives insight into how Hindu death rituals get renegotiated, modified and reinterpreted across two vastly different regions of India, both of which have their local customs.
				The inability to conduct pre-liminal and postliminal rites personally became a challenge with duties being mostly performed by the	

crematorium staff.

	The pandemic has given rise to a new culture of funerals, including electronic cremations, swift rituals, and negotiations.

Gopichandran et al. (2018)	To understand psychosocial impact, coping styles and health system response to experience of stillbirths	Chennai, India	8	8 female, age range not known	Purposive sampling	Psychosocial model	In-depth interviews Thematic analysis	Women who experienced stillbirths suffered from serious forms of grief and guilt. Further factors which were challenging were the health system, health care providers, strained marital relationships, and financial burdens. Reasons for occurrence	- Interviews with woman were also at times with another family member accompanyin g them, so this can have influenced the interview findings - Inability to explore the grieving process of fathers,

included: superstitions, biomedical explanations, Highlight the others in their

+ Participants did not know researchers and blaming +

need for

		life.	training of the providers to create a sensitive work force to provide care for these women.

Gupta. (2011)	The study objectives are to explore Asian Indian American Hindu (AIAH) cultural views related to death and dying and to understand the similarities and differences among three generations of AIAH in the meaning of	America 40 From different regions of India (NorthPunjab, Gujarat, and the South)	Men – 21 Female -19 15 -78 years old age range. Majority participants in 60-78years (25) and middleaged 35-59 years (10).	Purposive sampling	Continuing bonds theory	3 Focus groups Comparative analysis	All 3 generations were believers in the afterlife and the karmic philosophy. However, they exhibited differences in the degree to which Hindu traditions surrounding death and bereavement have been influenced by	+ Highlighted beliefs and practices will differ based on the family's level of acculturation, religious beliefs, and availability of ethnic temples in the city or town in which they live. + Paper can help to

	death and their respective preand postdeath practices.						the fact that they live in the United States.	develop assessment and intervention - Small sample size in one setting
Hussein & Oyebode. (2009)	The study aims to explore the nature of continuing bonds between bereaved Pakistani deceased, it religious may enrich how are influenced to the deceased cultural beliefs, the	UK 10	Female – 8 Men – 2 Average age – 33.6 years old	Purposive sampling	Continuing Bonds Theory Cultural framework Grounded theory also the concept of process of bereavement, - mourning, and study's results through meaning is limited by religious and	Semistructured interviews	All participants reported a sense of continuing relationship with the influences deceased those impacted the bonds. such as the way of Extended family	+ Reflexivity + The study highlights how understandin g different Muslims living in the UK and highlighted significantly continuing understand relationships bereavement, - making. the sampling Transferabilit y of the of only British Pakistani

					Muslims,
	context an individual is in and how the relationship with the person they have lost affects, their emotions and functioning.			structures, communal gatherings and mourning rituals made it the norm for there to be conversations , reminiscence and shaping of shared continuing bonds.	given that Muslims living in Western societies represent many ethnicities in a setting of a variety of majority cultures. - Few men in study

Hamid & Jahangir. (2022)	The study examines the impact of COVID-19 on individual practises on death, dying, and mourning in Kashmir, among Sunni Muslims.	Kashmir, India	17	6 Female 11 Male Age range 2669 years old Sunni Muslims	Purposive sampling	Not clear	In-depth interviews Thematic analysis	The deceased mostly had died in isolation without loved ones being present. Mourning the loss felt challenging as support systems were not able to be utilised and the inability to perform final rites also had additional impact on the process of grieving.	+ Highlighted implications and recommendations - Interview done by telephone may have limited the responses given - Small sample size

Inman et al. (2007).	To understand the culturespecific bereavement and coping methods used by South Asian family members who lost a relative within the context of a major traumatic event.	America	11	Firstgeneration immigrants who lived in US for 120 years. 4 male, 7 female. Ranged in age from 27-59 years. 2 Bangladeshis, 8 Indians, and 1 IndianGuyanese. 8 participants were Hindus, and 3 were Muslims.	Purposive sampling	Transactional model of stress and coping (Lazarus & Folkman, 1984) Continuing bonds theory.	consensual qualitative research Structured Interviews	The study emphasizes the importance of understandin g how culture influences bereavement reactions and coping among South Asians who lost a relative in the 9/11 tragedy. It highlights the need to conceptualize coping within a collective, cultural, and religious context, it speaks to the bereavement process being impacted by traditional rituals not being able to be performed	- Potential bias with researchers being from same background - Mixed modality of data collection + Were reflexive about their biases towards their expectations + Clear Implications

			and not having their immediate families or ethnic groups around at this time. It also shows their is lack of culturally sensitive resources which is a major gap in services

Khan et al. (2022)	Explore the impact of COVID-19 on funeral customs, coping this loss and understandin g the affect on relatives of the deceased.	India 21 3 districts: Srinagar, Ganderbal, and Bandipora,		The average age range of participants were 22 to 66 years old. 11 males 10 females	Purposive sampling	Abductive research approach	Semi structured interviews Grounded theory	There was a communicatio n gap between those infected by covid-19 and wider public which made them anxious and afraid for their wellbeing and health. A significant change in ways of dying was noticed.	+ Participant feedback was sought to ensure validity + Highlighted impact of not being able to say bye to a loved one in a context such as covid-19, can impact likelihood of chronic bereavement.
								Ceremonies and rituals were toned coviddown or	- Specific to context of 19 abandoned.
Kim et al.		Nepal	49	Varied in age		Explanatory	Semistructured	Participating	- Findings

(2017)	The study objectives are to understand widows' perceptions and experiences of grief in Nepal, explore the existence of a PCBD-like construct in the Nepali context, and compare the local construct of Persistent complex bereavement disorder (PCBD) with the DSM-5 criteria.	Kathmandu, Lalitpur, Bhaktapur and Kavrepalanch ok districts.	24-60 years old. Female - 49	Purposive sampling	Model Interview Catalogue (EMIC) framework (cross-cultural psychiatry for understandin g and addressing the cultural dimensions of health and illness).	interviews Focus group discussions Grounded theory Comparative method for analysis	widows reported negative psychological reactions in response to bereavement, suicidal ideation was coming. Bereavement among widows was perceived to be complicated by several coexisting stressors that are atypical in high-income countries, including cooccurring psychological effects of armed conflict (e.g.	may not be generalisable to all Nepali widows - Participants were primarily of reproductive age + Recruitment of widows through organisation likely fostered more comfort and candidness in sharing sensitive and emotional issues.

			surviving torture), societal discrimination and economic hardship. Suicidality was highly salient among sample, 31% reported suicidal thoughts and plans and 62% reported attempts in the past year and their lifetime.

Maddrell et al. (2022)	To explore migrants' and minorities' memories and memorymaking associated with death, funerary and remembrance spaces and practices.	Huddersfield, Newport, Northampton and Swindon - All UK.	N=138 122 (15 focus groups). 16 key participant individual interviews	Migrants or those of migrant heritage from South Asia, the Caribbean and Eastern Europe, including those of the Baha'i, Sikh, Muslim, Christian and Jewish faiths). Gender – not stated	Purposive sampling	Place attachment model	Focus groups Individual biographical interviews from across the four case studies. Analysis not mentioned.	Memories of past practices, including post colonial marginalisatio n, changes in practices, and the strains of not being able to grieve in the homeland. It highlighted the pragmatic compromises and collaborative efforts to suggest improvement to how funerary provision can be inclusive.	+ Focused on lived experience + Large sample representing different backgrounds and faiths. - Different migrant minority groups so hard to generalise all findings applicable to those from South Asian background.

Mammen. (1995)	To understand the psychological response of Indian women to perinatal loss	Bangalore, India.	9	Female – 9	Purposive sampling	Not stated/ unclear	Unstructured interviews – ethnographic. Analysis not mentioned.	Seven of nine woman experienced significant psychological distress. Four out of seven described similar finding that are found in the west.	+ Highlights woman can experience significant distress experiencing perinatal loss + Suggests preventative programs for perinatal loss - Middle class population, hard to generalise
									- Small sample

Patel et al. (2022)	Aimed to understand how the restrictive COVID guidelines impacted the experiences of Hindu Gujarati bereaved family members and the differences in views regarding changes in funeral processes and restrictive guidelines.	Gujarat, India	10	Gujarati background Female – 2 Male – 8 Average age was 40 years old. (26 – 52 years old).	Purposive sampling	Not clear	Semistructured interviews. Content analysis	The main findings of the study showed there was difficulty in proper communication during hospitalisation, disrupted end-of-life and funeral rituals, and accepting the harsh realities related to the changes imposed.	- Majority male population - Interviews are done by phone, potential loss of contextual data. + Highlighted the impact of COVID-19 restrictive guidelines on bereavement process and impact on emotional distress it can bring + Clear recommendations
Paudel et al. (2018)	Explores the experiences and beliefs of families in remote	Nepal	42 – women experienced neonatal death or stillbirth	Age range 1635 years old. Female - 42	Purposive sampling	Religiocultural framework	In-depth Interviews Thematic analysis	Religiocultural interpretations have an impact on	+ Implications for future provision

villages of Nepal about perinatal sickness and death. Considers how healthcare provision may think about the implications of these beliefs.	9 – birth attendants 2 – female community health volunteers 2 support staff 1 - Auxiliary Health Worker, 5 - other stakeholders.	perinatal deaths such as acceptance of death as a because the culture that has been around and in Karma figures to also God as a work together factor in to reduce poor health and perinatal survival in the sickness.	+ Findings highlight need for medical health norm practitioners of and faithbased healers and religious belief	mountain villages. - Specific to individuals in the two mountain villages (purposively selected)

Roberts et al. (2012)	To understand how poor, rural central Indian women perceive and cope with stillbirths, experience	Central India	N = 31 Women with personal history of stillbirth – (n=15)	Focus groups: 15-49 years old). 2nd focus group – (older female).	Snowball sampling	Psychosocial model Intersectional Lense – gender	Focus groups Semistructured interviews	Perinatal grief is a significant shared experience among poor, rural central Indian women, Grounded theory despite being	+ Clear implications + Perceptions from both those who experience still birth and

perinatal grief and their social environment reacts and influences their experience.	Observers if stillbirth experiences (n=16, local healthcare providers)	Individual interviews: age range was from 15- 40 years old (mostly between 20 30 years old)		usually never talked about or recognized as an issue. The perceptions of stillbirthrelated grief emerged in three major themes, indicating the heavy influence of gender and power issues and local social norms on their perinatal grief experiences. Grief, social norms, and gender and power issues were predominant factors in the experiences of perinatal grief among	healthcare providers - Finding are relevant to a specifically rural lowincome women, generalisabilit y can be difficult.

	the participants.

Suhail et al. (2011)	This study looked at the nature of relationships of	Lahore, Pakistan	10	Pakistani background Muslim	Purposive sampling	Continuing bonds theory	Grounded theory approach Semistructured	Religion and culture were an important factor through the	- Small sample size - Mostly male

	Pakistani Muslims to deceased relatives, with a focus on the impact of religious and cultural beliefs on the ongoing link between the deceased and bereaved, and to understand the bereavement process.	Aged 19 – 59 years old (average 41 years) Female – 3 Male - 7	interviews	bereavement process. Religion provides a strong basis for coping and adjustment and culture allowed individuals to follow rituals and ceremonies to help them talk and reminisce relatives.	sample - Social Desirability + Helps to understand the phenomenology of bereavement and continuing bonds in Pakistan + Implications for counsellors and family therapists who can use religious affiliations to reduce the impact of loss and

	complicated bereavement.

Thomas et al. (2023)	To understand how the Sri Lankan and male – (resourceoriented cited was loss understandin g of conflict N= 103 6). model, provides a Semistructured of how the conflict impacted how useful framework interviews possessions has impacted this grief Study 2 for and absence community. Gives manifested (female – 36 understandin g of loved one guidance on how within and male 17). the complex and most communities can communities ways in which frequent be supported and to Age range not multiple losses coping when loss has identify the stated. that occur in a strategy that been different war context can was experienced. types of lead to highlighted losses such as human loss vs. material loss. Coping Prolonged findings - Majority mechanisms Grief Disorder where female was also investigated in response to or making - Interviews loss and post conflict conducted at ambiguous loss.	Northern Sri Lanka	Study 1 – 49 Study 2 – 53	Study 1 (Female – 43	Purposive sampling	Conservation of Resources theory significant distress).	Content Analysis	Most frequently was support seeking. Both studies had material loss was causing stressors worse, specifically linked to loss of personal and social resources	+ Allows us to gain an + Clinical implications participants single time point, might not have

		impacting mental and physical health.	allowed for rapport to be built

Warrier et al. (2019)	To explore the caregivers' experiences of the end-oflife stage of support for individuals and their caregivers	South India	7	Female - 5 Male – 2	Purposive sampling	Constant comparative method	In-depth interviews Thematic major themes comparative method.	The main findings of the study include the setting with a related to caregivers' experiences, accessible individual with MND deteriorating, particularly Highlighted with ambiguity and uncertainty. when Most care of faced with the terminally ambiguity and uncertainty. ill happens at home, people	- Small sample size - Was wellestablished multidisciplinary team, there is Disease at the palliative care in India + importance of emotional support

Psychosocial analysis using identification of conducting in a and sources model constant

the importance a lack of a with Motor of support uniform Neurone through the Disease at the advanced healthcare for end-of-life stages of an chronic stage.

	+ Highlighted who received those who are palliative care
	showed to lucky enough feel more to receive confident with palliative care managing helps improve patient at their home which confidence highlights with managing more support patient at from home. institutions or hospice could be helpful.

Zakar et al. (2018)	The study objectives are mentioned are systemrelated factors which contribute to stillbirth and their underreportin g.	Pakistan	N = 373 Specific to understand and include the and health	42 women, 46 men for 88 – a total of groups (had experienced a stillbirth)	Purposive and snowball sampling	Psychosocial framework In-depth interviews. Focus group discussions	Stillbirth is frequently misclassified and underreporte d in Pakistan, Comparative analysis	- The scope of the study did not include older women who have a major say in decisionmaking regarding pregnancy.	Nowshehra, Mardan, Tando Allah Yar, and Thatta. Interviews (285 conducted with variety of stakeholders providers).	those experienced stillbirth was regions local seeking including terminologies medical care in health

cause.

Healthcare providers' and

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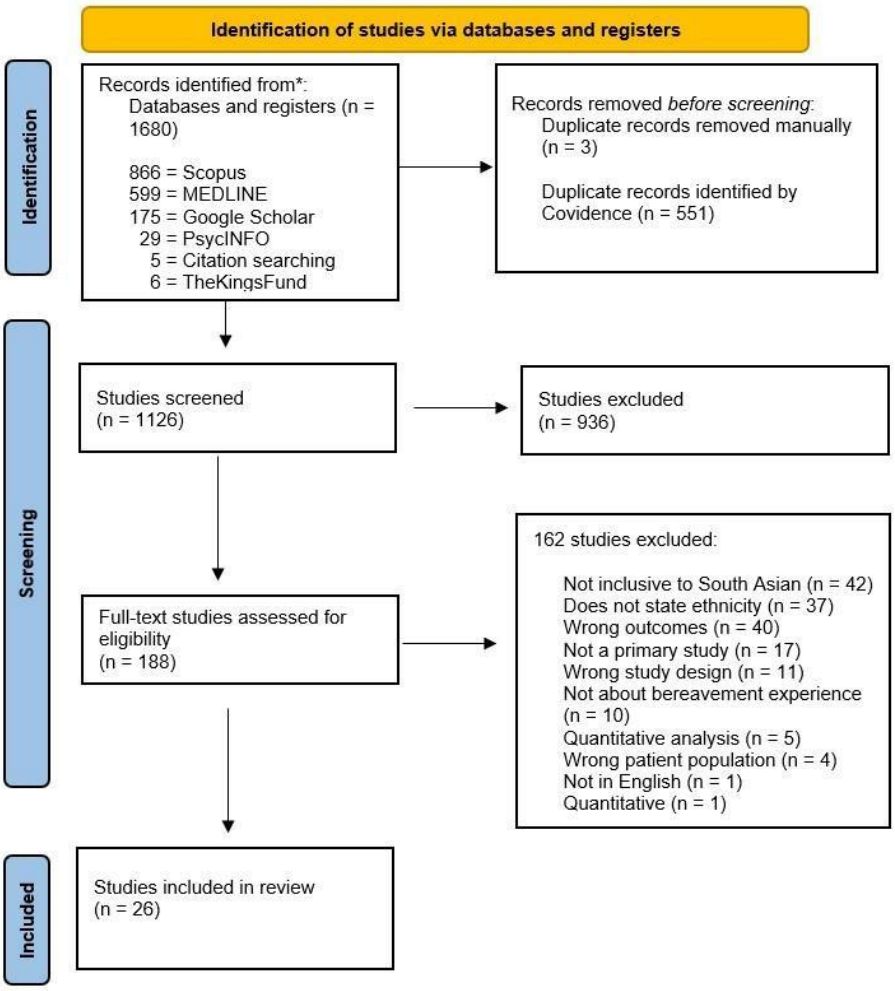
	the participants were some further limitations. + Helps to understand local context and what factors are influencing the under stillbirths. + Well triangulated using multiple methods of data collection. + Balance of male and female participants who experience d stillbirth	entoavoidbreportin g in Pakistan of ameandst

Figure 1

PRISMA Flow Chart



2.4 Study Characteristics

Twenty-six papers met the inclusion criteria, and the data was extracted and put into a summary table (see Table 4). Included studies were published from 1995 to 2023. The majority of papers focused on bereaved participants' experiences, however a few papers focused on both participants' experiences and healthcare providers' experiences (Christou et al., 2023; Das et al., 2021;

Gopichandran et al., 2018; Paudel et al., 2018; Roberts et al., 2012; Zakar et al., 2018). The majority of studies provided a figure for the number of participants included, except the study by Chaudhry (2014). Two papers also did not report the participants' gender (Ghosh & BK, 2022; Maddrell et al., 2022). Overall, the total number of participants' experiences included was 1982, across the 26 papers. Out of 1982 there were 1628 bereaved participants' experiences. Of the studies which provided gender information, 494 were female experiences and 251 were male experiences. There were approximately 354 stakeholders and healthcare providers' bereavement experiences across the 26 studies, one paper did not clarify the difference between participants' bereavement experiences and healthcare providers' experiences (Ghosh & BK, 2022).

The papers varied in context to bereavement experiences. Out of the 26 papers, six papers related to general bereavement, nine were related to contexts such as war, end of life, or COVID-19 and 11 were related to stillbirth and miscarriages. Four papers were based in the UK, two in America and 20 papers from SA countries (India, Pakistan, Sri Lanka, Afghanistan, and Nepal). The relation to the individual that passed away varied between studies, which included children, parents, partners, family relatives. Participants came from different religious backgrounds (Muslim, Hindu, Buddhist and Christian).

The age of participants across the 26 papers ranged from 15 to 69 years old. Twenty-three papers used purposive sampling to recruit participants, one study used convenience sampling (Davies, 2019), and two used snowball sampling (Roberts et al., 2012; Zakar et al., 2018).

For the method of data collection, many of the studies used either semi-structured or unstructured interviews and focus group discussions (FGD). A few studies also used documentary evidence and observation (Chaudhry, 2014; Davies, 2019; Ghosh & BK, 2022). Data analysis across the studies varied; seven used thematic analysis (Ahmed et al., 2020; Christou et al., 2023; Ekanayake et al., 2013; Gopichandran et al., 2018; Hamid & Jahangir, 2022; Paudel et al., 2018; Warrier et al., 2019), seven used grounded theory (Chaudhry, 2014; Das et al., 2021; Hussein & Oyebode, 2009; Khan et al.,

2022; Kim et al., 2017; Roberts et al., 2012; Suhail et al., 2011) two used interpretative phenomenological analysis (IPA) (Asim et al., 2022; Batool & Azam, 2016), one used framework analysis (Garcia et al., 2020), four used comparative analysis (Ghosh & BK, 2022; Gupta, 2011; Kim et al., 2017; Zakar et al., 2018), one used Consensual qualitative research (Inman et al., 2007), two used content analysis (Patel et al., 2022; Thomas et al., 2023) and for three studies the analysis used was unclear (Davies, 2019; Maddrell et al., 2022; Mammen 1995, n.d.). 18 papers included theoretical underpinnings (Chaudhry, 2014; Christou et al., 2023; Davies, 2019; Ekanayake et al., 2013; Hussein & Oyebode, 2009; Khan et al., 2022; Kim et al., 2017; Paudel et al., 2018; Suhail et al., 2011; Thomas et al., 2023; Gupta, 2011; Gopichandran., 2018; Inman et al., 2007; Maddrell et al., 2022; Roberts et al., 2012; Zakar et al., 2018; Warrier et al., 2019; Asim et al., 2022;), whereas for eight papers it was not clear what the theoretical underpinnings or framework used was (Patel et al., 2022; Mammen.,
1995; Hamid & Jahangir., 2020; Ghosh & BK., 2020; Garcia et al., 2020; Das et al., 2021; Batool & Azam., 2016; Ahmed et al., 2020).

2.5 Quality Appraisal

A significant aspect of a SLR is to assess the quality of included studies (Shaw, 2021). By appraising the research quality, we can understand if the studies address their aims, evaluate the credibility of findings, and understand if their method, process and context are appropriate (Hannes, 2011). There are a variety of different quality appraisal tools that can be used for qualitative research (Hannes et al., 2010). For this SLR, the Critical Appraisal Skills Programme (CASP, 2018) checklist was used, which is recommended in the Cochrane Handbook (Cochrane, 2023) and the World Health Organisation (WHO, 2014). All papers were screened by the researcher and 27% of papers by a peer to check consistency in ratings.

2.5.1 Quality of the studies

All 26 studies were appropriate to the topic of understanding bereavement experiences in the SA population. Most of the studies fell in the moderate to high-quality rating. Twenty-four met a high rating on the first five questions on the checklist which covers: clear aims, method, design, recruitment, and data collection. It was difficult to understand the recruitment process in one study (Chaudhry, 2014) and aims, method, design, and analysis were difficult to understand in one study (Mammen, 1995). All papers presented a clear data collection method.

Out of the 26 papers, 15 studies made no reference to reflexivity and the researcher-participant relationship, and although three studies stated that they had considered the participant-researcher relationship, none explained their process of reflexivity. When exploring this topic, it is important to consider the potential bias and influence researchers may have in relation to the study, particularly as the majority of people would have experienced a bereavement at some time in their life. It could be possible that the three studies that mentioned looking at the relationship may have thought about their bias and participant-researcher relationship; but due to limited word count in journal publications, may not have been able to expand on their process of reflection.

The majority of papers had ethical considerations, which included examples of informed consent and confidentiality. Two papers were rated a 'no' for ethical considerations (Chaudhry, 2014; Ghosh &

BK, 2022) and 5 papers were rated 'can't tell' (Batool & Azam, 2016; Davies, 2019; Gupta, 2011; Maddrell et al., 2022; Mammen, 1995, n.d.).

Of the 26 papers, 22 showed a good analysis of results, two papers scored 'no' (Ghosh & BK, 2022; Mammen, 1995) and two papers were rated 'can't tell'(Chaudhry, 2014; Maddrell et al., 2022). In these two papers, the results were presented but the analysis of how they came to the results was

missed. This questions the credibility of replicating the analysis with the data presented from participants.

Overall, all papers scored moderate to high, as they met the criteria on the CASP tool required. Limited word counts are common for papers which are published, which may suggest why processes can be missed when published, for example, ethical considerations, reflexivity, and the process of analysis.

Conducting the quality appraisal process made me reflect on the role being an insider researcher and the importance of reflexivity and questioning findings where there may be no reflection. It made me think of the bias that may not be monitored and how this can influence how the data is then analysed. I also reflected on the importance of addressing elements of CASP in writing up the findings of a study to make sure it is as robust as possible and replicable.

Below outlines the quality appraisal in Table 5.

Table 5

Quality appraisal for included studies

Author(s)	Clear Aims	Method	Design	Recruitment	Data collection	Relationships	Ethics	Data analysis	Findings	Value
~~Ahmed et al. (2020)~~	~~Yes~~	~~Yes~~	~~Yes~~	~~Yes~~	~~Yes~~	~~Yes~~	~~No~~	~~Yes~~	~~Yes~~	~~Very valuable for healthcare services to consider how they might reduce or prevent perinatal mortality in Pakistan~~
Asim et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very valuable as it identifies the psychosocial support this population needs and highlighted the stigma present of stillbirth.
Batool & Azam (2016)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable – Shows differences and similarities in how miscarriage experiences can be with Western culture. Highlights the need for psychosocial support for those who do not have a close supportive system. Adds to underresearched evidence base.

Chaudhry (2014)	Yes	Yes	Yes	Cant' tell	Yes	No	No	Can't tell	Yes	Focuses on women's grief and has tried to make sense of the trauma which
										continues with woman who live with the memories of the armed conflict in Karachi.
Christou et al. (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Very valuable - highlighted multiple causes of stillbirths from biomedical to supernatural factors that exist in Afghanistan.

Das et al. (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable - gives insight into lasting psychosomatic, social and economic impact on parents who have experienced stillbirth and child death which is usually ignored in India. It also highlighted the importance of bereavement support to reduce impact.
Davies (2019)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable – it gives insight to how death and bereavement may be reframed through children's biographies.
Ekanayake (2013)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Valuable – gives insight into factors

										that was important for coping with grief and loss after a natural disaster such as extended supportive networks, religious faith and practices and cultural traditions.
Garcia et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Valuable - shows there are similarities in bereavement experiences of mothers from a Pakistani, Bangladeshi and white British background. However, there is some cultural and religious differences noted for Pakistani and Bangladeshi mothers.
Ghosh & BK (2022)	Yes	Yes	Yes	Yes	Yes	No	No	no	Yes	Shows changes that occurred in covid-19 on funeral practices with deceased.

Gopichandran et al. (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Very valuable - provides insight to psycho-social impact of stillbirth in a low resource urban setting in India.
										Highlights experiences, emotions, psychological problems and coping mechanisms. Experiences with healthcare providers is also highlighted which can help give insight in how change could be implemented.

Gupta (2011)	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable – Three generations of attitudes and beliefs of Asian Indian American individuals is looked at which shows the variation of practices and beliefs that help individuals from this background provide end of life care and deal with loss of a loved one.
Hamid & Jahangir (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable - Impact of sudden event such as covid-19 impacting the way we die, the way we mourn and how we handle the dead.

Hussein & Oyebode (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable - Highlights how religious beliefs can impact the response to bereavement and on how continuing bonds with deceased may be different.
Inman et al. (2007)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Valuable - Shows the importance of needing to prepare for the loss psychologically and practically for an individual and how significant cultural specific bereavement support can be when coping with unexpected loss.

Khan et al. (2022)	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Valuable - Highlights how context can impact grieving such as not being able to say goodbye, not being able to see the deceased body, and not being able to witness rituals that may impact the mourning process.
Kim et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable - Explores widows experiences of bereavement from Nepal and shows the negative psychological reactions in responses to bereavement and suicidal ideation being common.
Maddrell et al. (2022)	Yes	Yes	Yes	yes	yes	Can’t tell	Can’t tell	Can’t tell	yes	Doesn't show their analysis for themes or ethical considerations of reflexivity however

																does have importance in showing migrant and minority memories, funerals and everyday remembrance to be an important part of rich 'ecologies' of memory and identity in England and Wales. It also shows memory is filtered and is shaped by what is forgotten as well as what is remembered.
Mammen et al. (1995)	Can't tell	Can't tell	Can't tell	Yes	Yes	No	Can't tell	No	Yes	It highlighted the psychological distress						experienced with perinatal loss and shows there are similar responses described in Western literature but not high quality.

Patel et al. (2022)	Yes	Yes	Yes	yes	yes	No	yes	Yes	yes	Valuable insight into experiences of bereaved family members of hospitalised patients. It shows how communication is an important factor as well as funeral rites, restriction of this led to emotional crisis for individuals.
Paudel et al. (2018)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable - insight into how religio-cultural context surrounding perinatal mortality in two remote villages in Nepal. Understanding of how individual and collective experiences are viewed as valid sources of knowledge in the social constructionist view, past woman and older family members are individuals who

										construct the knowledge for younger women.
Roberts et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable shows perinatal grief is a important issues for these woman and shows there are different factors that will help and not help a women's ability to cope in addressing grief. Through understanding these factors, we can offer helpful interventions.
Suhail et al. (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable shows how important religion and culture can play a role for bereavement process and continuing bond with the deceased. It also shows how time since death, personal factors such as gender and age also had an influence.
Thomas et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very valuable – highlights the experience of loss for individuals in Northern Sri Lanka
										from conflict affected groups.

Warrier et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable – shows how social worker plays an important role in supporting family needs from early stages of illness, through critical transitions and in advanced stages. Emotional support is particularly important when families are faced with uncertainty associated with neurological illness, timely support is beneficial.

Zakar et al. (2018)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Gives insight into how important early screening is to prevent stillbirths. Need for explaining scientific evidence to mothers and families to raise awareness of risk factors to stillbirth. Shows the cultural narratives that are still present in relation to stillbirth and stigma towards women.

2.6 Methodology for Synthesis

After critically appraising the studies, synthesis was then conducted to analyse the results. For this SLR, Thematic Synthesis (Thomas & Harden, 2008) was chosen as an appropriate method to explore the 26 studies analysing the differences and similarities between data sets. Combining 26 data sets, allowed an overall understanding of the experiences of bereavement in the SA population and highlighted common themes and patterns.

To conduct the thematic synthesis, NVIVO (version 14) software was used. After finalising the 26 papers according to inclusion and exclusion criteria, I became familiar with the data. The steps outlined by Thomas and Harden (2008) were followed (see Table 6). Themes were discussed with my supervisor and peer to ensure they aligned with the SLR question and to reduce bias.

Table 6

Steps for Thematic Synthesis

1) Code text line-by-line
2) Develop descriptive themes
3) Generate analytic themes

Conducting the synthesis made me reflect on language and how it is perceived within Western research, as well as my own biases and assumptions about the ways the SA Community cope with bereavement. I reflected on sometimes finding practices unhelpful when I have experienced a bereavement myself and noticing myself at times feeling angry about the findings of the studies. I acknowledged that although this might be my experience, others have found it helpful to be able to process loss. It highlighted to me how important it is to monitor our own biases and assumptions as

insider researchers. To help monitor my biases I decided to write a reflective diary to notice my feelings towards the research and to help reduce the influence on interpretation of results.

2.7 Synthesis of findings

The synthesis revealed six main themes that were important to consider when experiencing a bereavement from a SA background and 19 sub-themes (Table 7).

Table 7

Table of themes from the Meta-Synthesis

Main theme	**Sub theme**
Theme 1: Processing the loss	1. Sudden loss 2. Emotions 3. Memories and triggers 4. Blame 5. Avoidance
Theme 2: Religion and spirituality	1. Beliefs 2. Prayers and rituals
Theme 3: Connection with deceased	1. Eternal connection 2. Acts of kindness or remembrance
Theme 4: Cultural impact /nuances on a loss	1. Judgment 2. Expectations
Theme 5: Social support	

Theme 6: Post bereavement changes

Theme 1: Processing the loss.

In 22 papers, participants spoke about different factors that affected the processing of the loss when experiencing a bereavement. These are outlined into subthemes, which were: sudden loss, emotions, memories and triggers, blame, and avoidance.

Sub-theme 1: Sudden loss

In 14 studies, participants reported sudden loss having an impact on their experience of bereavement, in particular, "difficulty in accepting it" (Patel et al., 2022). This theme was particularly apparent in papers that had context of miscarriages and stillbirths, COVID-19, war and end of life. The uncertainty of a loss of a pregnancy caused a participant to feel as if "life was coming to a halt"(Batool & Azam, 2016). Participants spoke about it being "most painful when no family member was present" (Hamid & Jahangir, 2022) at the time of death. The unexpected death led to individuals feeling they were not able to process their 'grief properly' (Hamid & Jahangir, 2022), if they were able to be present, they explained this would have made them feel at "peace" (Patel et al., 2022).

Sub-theme 2: Emotions

In 18 studies, participants mentioned different emotions being experienced through processing their bereavement. Some participants mentioned feelings of "guilt" if there was an inability to be there for the deceased (Hussein & Oyebode, 2009), feeling "hopeless", experiencing "crying spells" and "loss of interest in other activities" (Mammen, 1995). There was also an experience of the "mind becoming numb… not understanding what to do" and other initial emotional reactions such as

“shock, intense fear, a desire to end one’s life and anxiety” (Suhail et al., 2011).

Sub-theme 3: Memories and triggers

In 13 studies, memories and triggers were sub themes which impacted on processing loss. Particular items were shown to be important to remember someone they had lost: a participant mentioned her grandads “harmonium reminding me [her] of him” (Davies, 2019). For another individual it was “somebody else’s child in my [her] lap, comforts me [her]” (Roberts et al., 2012). One participant explained “when I have extreme pain in lower abdomen during menstrual cycles, it refreshes the memory of forceps being used to make my body free of my baby…and it refreshes the loss of my baby” (Batool & Azam, 2016). This would suggest that grief can become an embodied feeling which can be a trigger.

Sub-theme 4: Blame

In 14 studies, participants mentioned blame being a factor through the grieving process. Blame was shown to self, others, and the health care system. Participants justified their loss as being due to “fate” (Bhagya) and “being unlucky” and because of their Karma (Paudel et al., 2018). Blame was felt from family members, studies mentioned the partner thinking the loss was the wife's fault if there was a stillbirth or miscarriage (Asim et al., 2022) because they “could not hold the baby” (Batool & Azam, 2016) or if they went to the hospital and they felt that the wife should have not attended (Das et al., 2021). Blame towards others was noted from the participants, such as “mother-in-law gave inappropriate food” (Zakar et al., 2018). Participants also blamed context: one participant expressed how “COVID-19 shattered families and killed numerous people”. Blame was also placed on health care providers: participants mentioned medical staff doing “something wrong with my [their] baby (Batool & Azam, 2016) and being negligent with care (Christou et al., 2023; Gopichandran et al., 2018; Zakar et al., 2018).

Sub-theme 5: Avoidance

In 12 studies, participants explained avoidance as a way of processing their loss. One participant mentioned she would “keep busy the whole day in household chores and working in fields...to not think about my [her] losses and get sad” (Asim et al., 2022). It felt important for participants to “leave the situation” as their “sadness increased”, so instead they would decide to “do some other work” (Thomas et al., 2023).

Theme 2: Religion and spirituality.

Twenty-three papers spoke about how individuals used religion and spirituality as a way of coping with bereavement. Participants spoke about beliefs, rituals, and prayers in relation to religion and spirituality as a way of coping.

Sub-theme 1: Beliefs

Fifteen studies spoke about beliefs influencing the experience of a bereavement. Participants commonly mentioned beliefs about death being due to God’s will (Ahmed et al., 2020; Asim et al., 2022; Batool & Azam, 2016; Christou et al., 2023; Ekanayake et al., 2013; Hussein & Oyebode, 2009; Paudel et al., 2018; Roberts et al., 2012; Suhail et al., 2011; Zakar et al., 2018). For example, a participant mentioned that “each second of our life is predetermined and these cases (stillbirth) are a test by Allah to check our faith and patience” (Zakar et al., 2018). This highlighted the significant meaning of belief in God with accepting death, it was also explained that perhaps death is in “our destiny” (Christou et al., 2023). Alongside, there were beliefs of losses being due to being “possessed by an evil spirit (Jin)” (Asim et al., 2022; Christou et al., 2023; Das et al., 2021; Hussein & Oyebode, 2009; Zakar et al., 2018) or “witchcraft (Kala jadu)” (Das et al., 2021). A participant explained this could be because of “not going to the holy shrine” (Asim et al., 2022) or contacting a faith healer

Sub-
(Paudel et al., 2018).

theme 2: Prayers and rituals

19 studies spoke about prayers and rituals as a way of coping with a bereavement. Participants mentioned “praying for hours and reading the Koran”, (Chaudhry, 2014), “reading Namaz (prayer)” (Das et al., 2021) or “going to the temple to cope with sadness” (Gopichandran et al., 2018), to help divert the mind. Specific rituals also felt important: a participant explained “when nurse informed me about my mother death, I quickly rushed to the hospital to perform few rituals… took a few tulsi (basil) leaves, sandalwood paste and Ganga jal (holy water from the Ganges), I also recited the Bhagavad Gita…” (Ghosh & BK, 2022). This suggests the importance of being able to execute rituals after a loved one has passed away to process grief.

Theme 3: Connection with the deceased.

8 papers spoke about eternal connection with the deceased and doing acts of kindness or remembrance to stay in connection.

Sub-theme 1: Eternal connection.

Participants spoke about maintaining a connection with the deceased after parting. A participant mentioned “I do feel we have an eternal connection and that we are all put together for a reason …there is some deeper meaning to this madness that we call family, I really believe that there is a reason and an eternal connection there” (Hussein & Oyebode, 2009). Some of those who believed there was an eternal connection mentioned seeing the deceased in dreams (Christou et al., 2023; Khan et al., 2022; Kim et al., 2017; Suhail et al., 2011).

Sub-theme 2: Acts of kindness and remembrance.

Sub-

Some papers mentioned remembering their loved one through organising an event they would have mentioned they would have wanted to do such as a “football tournament” or “distributing sweets to children” (Hussein & Oyebode, 2009). It was also mentioned that families would undertake acts which remembered the loved ones passing and to feel connected to their spirit, they would

“distribute the Bhagavad Gita, feed the priests, [and] made donations (Patel et al., 2022).

Theme 4: Cultural impact on a loss.

18 papers mentioned how judgment from community and family and cultural expectations had an impact on experiencing their bereavement.

Sub-theme 1: Judgment

16 papers mentioned different types of judgment towards the mother for a stillbirth and towards their way of grieving. Relatives blamed the mother for the stillbirth or miscarriage (Batool & Azam, 2016) and the mother was viewed as the “child-killer” (Asim et al., 2022; Zakar et al., 2018) or a “murderer” (Gopichandran et al., 2018). They were also viewed as a “bad daughter-in-law” or “bad wife” (Roberts et al., 2012). Participants mentioned not being able to go to events because of their presence being viewed as an “annoyance for expecting mothers”. Elderly women would also stop mothers who lost a child going to events: a participant said the elderly explained it was “to keep distance from young girls after miscarriage to save them projection” (Batool & Azam, 2016). It was mentioned by a participant that “with the Asian community it’s something to look down on” if you were grieving (Garcia et al., 2020). These judgements highlight the stigma present within the Asian community and also shows the difficult situation one can be in when experiencing a loss.

Sub-theme 2: Expectations

Participants reported different expectations for the grieving process. It was mentioned by a participant that “in India, Hindu family members are expected to cry and wail loudly as it is considered healthy. A lack of loud wailing by the widow and other family members of the deceased is considered pathological” (Gupta, 2011). This highlights that at times participants can feel pressure of having to grieve in a particular way due to the community expectation. One participant explained at

the time of their bereavement, being “forced to make tea and food for ourselves and guests, no time to mourn or share my feelings with anyone” (Hamid & Jahangir, 2022). Commonly women were expected to continue to work after a loss (Christou et al., 2023; Kim et al., 2017). These findings provide an insight to how hard it may be to grieve when cultural expectations are placed on individuals.

Theme 5: Social support

23 papers regarded social support as an important component that would impact how a bereavement is experienced. Different aspects of social support were highlighted such as isolation and silence of loss, privacy, response from family or community and accessing support.

Some studies showed that the response from family and community felt helpful for some participants in processing a bereavement. One participant explained they were “able to come to terms with the situation, as all were together, and everyone shared their experiences” (Ekanayake et al., 2013). On the other hand, isolation and silence were noted to make the experience of the grieving difficult. Participants mentioned that the environment was important and the ability to have support to grieve, one participant noted the experience “feeling more complicated when you are left to grieve alone” (Hamid & Jahangir, 2022). Participants also felt that sometimes family did not want to speak about the relative that had passed away on their “own accord”, usually it would be the person who lost the relative that spoke about the person first, which made it difficult (Hussein & Oyebode, 2009). Some participants preferred to have privacy at that time of losing a loved one, they would mention their grief as their grief (Inman et al., 2007) and others would not “know the loss the way we [they] know it” (Hussein & Oyebode, 2009). It was also noted that participants viewed seeking support such as counselling as “not a South Asian thing” (Inman et al., 2007). There appeared to be a pressure for participants to pretend “to be strong” and “deny being upset”, especially the male participants (Warrier et al., 2019). Participants did mention it being important

“to have somebody you can trust and can talk to” as “you cannot talk to everyone” (Maddrell et al., 2022).

Theme 6: Post bereavement changes

Twenty papers mentioned changes within a person after experiencing a bereavement. Changes that were noticed were: change in identity, change in wellbeing, relationship changes, and responsibility that they had to hold post-bereavement.

After the death of a loved one, “some participants reported becoming more sensitive and empathic” (Suhail et al., 2011) and for some it had changed their religious practice becoming more “regular in prayers” (Batool & Azam, 2016). For some families, financial responsibility changed after experiencing the loss of a loved one, for some this person would have been the main income earner. A participant explained “our elder brother started working in my uncle’s hotel after my father’s death and he earns for the family” (Ekanayake et al., 2013). This highlights the struggle of income for this family. Another participant explained that “worries will be there” with the financial situation changing (Kim et al., 2017). Relationship changes are also experienced after a loss, participants who lost their husband, explained changes with their mother-in-law, experiencing “negative remarks” and participants who experienced stillbirth or miscarriage, changes in relationship to partner and relation no longer “warm” (Asim et al., 2022). Due to grief, participants noticed changes in their functioning such as a “decrease in memory power” , not wanting to “eat or work” (Kim et al., 2017) or being able to “cook properly” (Roberts et al., 2012).

2.8 Summary and Critical Appraisal of SLR

The aim of the SLR was to explore bereavement experiences of those who identify as SA and the support available. Overall, the 26 papers had many similarities in how bereavement was experienced

amongst this demographic, despite the different contexts of bereavement. All papers spoke to how an individual may experience a loss or make meaning and how this may have an impact on wellbeing. Important factors were highlighted such as religion and spirituality, cultural expectations, the importance of connection with deceased, helpful social support, and the post changes a bereavement experience can have on an individual.

Inequalities are suggested to be present between SA men and women, which has an impact on depression rates; in particular, depression rates have shown to be higher for younger married women and older adult women (Gask et al., 2011; Karasz et al., 2020, Papp, 2011). It was common across the papers, that there was an impact of cultural expectations and judgment on participants wellbeing who had lost a loved one (Zakar et al., 2018). Within the UK and U.S, pressure and parental expectations have led young SA individuals to experience an increase in stress (Bhattacharya & Schoppelrey, 2004; Papp, 2011) and older women are also found to face a disproportionate amount of psychosocial stress in the community (Lai & Surood., 2008; Tummala-Narra et al., 2013; Diwan & Jonnalagadda, 2002)

Across the 26 papers, reference was made to the impact on a person's wellbeing, particularly their functioning. Participants sometimes explained mental health struggles through physical symptoms, as commonly this population will not understand their symptoms through the lens of mental health (Nazroo, 1998; Nazroo, 2002).

Those who identified as being from SA origins, talked about religion being a central part of their culture. They may turn more to prayer and counsel from religious leaders such as faith healers as a way of processing and coping with distress (Ali et al., 2005; Sheikh & Furnham, 2000). However, it may also stop those who require professional help, from reaching out (Sheikh & Furnham, 2000). Many of the participants across the 26 studies would seek counsel from faith healers and counsellors from their religious background rather than reaching out to mental health or professional services.

There also appeared to be a stigma attached to seeking out support as it was not considered the cultural norm (Inman et al., 2007).

Social support was considered helpful for individuals after experiencing a loss. Many SA communities are collectivist, which values family cohesion, solidarity, cooperation, interdependence and group priorities over a more individualistic approach. This is different to the Western perspective where individualism is more prominent with individuals showing autonomy, independence, and selfachievement being more valued (Chadda & Deb, 2013; Karasz et al, 2019, Skillman, 1999). Participants who did not experience helpful social support, noticed a negative impact on their wellbeing.

The papers investigated different SA regions, but common themes were identified across the studies. It is important to highlight that limited studies were conducted in the UK and America, and the majority were from South Asia. Westernised countries have many different backgrounds in their population. It is important to consider how the SA experiences differ in different regions to ensure effective support can be provided taking into account acculturation and migration.

2.8.1 Strengths and limitations

There appears to be no other SLR exploring SA bereavement experiences therefore, this would be the first SLR to explore this topic which is a strength. The SLR used three different databases to search for papers and applied a snowballing technique to the reference lists to ensure the search was comprehensive. The CASP quality appraisal tool allowed a comprehensive systematic appraisal of the papers, ensuring appropriate papers were used in the review. 18 papers showed the use of theoretical underpinnings, which is a strength of this SLR as it was grounded in theory. Although all studies were valuable, it was important to consider findings in relation to the weaknesses identified

within the critical appraisal. Reflexivity was used throughout this process which further enhanced objectivity, this was particularly important as I identify from a SA background.

It is important to highlight that further searches could have been undertaken to identify grey literature using databases such as CINAHL and COCHRANE. These searches were not undertaken due to time constraints; however, a search on the Kings Fund database was done to include Grey literature.

The research studies identified were undertaken in different contexts, strengthening the understanding of how participants experience bereavement. However, it should be noted that there were more dominant narratives in a particular context, for example, stillbirths and miscarriages, which may not provide an accurate reflection, and the results may not be generalisable to other contexts of a bereavement. The relationships to those who passed away from these studies were predominately baby or child; it is important to recognise that the experiences to other relations could be different (e.g. losing a sibling, parent, friend, other family member). Majority of the losses in these studies were also sudden rather than expected; the differences in experience may not have been captured by the systemic literature review.

Studies were included from a range of regions, enhancing the variation of views but highlighting the limited data available from the UK and America. This identifies the need for Western countries to do more research on this population so they can understand how to better support individuals from SA communities who are going through a bereavement experience. The studies included were all published in English and found in journals by searching databases commonly used in the UK; this could be a limitation as studies may have been missed, which provide a SA perspective as studies may not have been identified from journals that are published in SA Countries. Studies may have been missed that had been written in other languages, and published in other countries, which could have contributed to the overall findings, thereby enriching the review.

The age range of participants was from 15 -69 years old: this could be a further limitation as older adults and younger children may experience bereavement differently. Some studies did refer to children's experiences of bereavement although the age range was not mentioned (Davies, 2019). Some studies also mentioned older woman (Roberts et al., 2012; Zakar et al., 2018), and some studies did not report age due to confidentiality, therefore findings should be interpreted carefully.

Some studies investigated rural towns which would have represented a low socioeconomic demographic. It was evident from some of the studies, that there was a lack of education on preventative measures of experiencing a bereavement such as a stillbirth. This may differ from other locations where individuals have a different socioeconomic status.

2.8.2 Clinical Implications and recommendations

This SLR has outlined different factors that impact the experience of bereavement for an individual from a SA background and the need for more research to be conducted in different regions to help understand the experiences of this population.

It is recommended that researchers conduct research on populations such as ethnic groups as they are underrepresented in research (NIHR, 2021). This could help advocate for ethnic groups and encourage research to become diverse and inclusive (NIHR, 2021). To be able to understand this population experiences of bereavement further, research should be conducted in a Western context, to explore perceptions of bereavement for those living in the UK. Support looks different in every country and for UK to be able to provide meaningful support, it is necessary to understand what support looks like for this specific ethnic group of individuals to ensure that adequate support is provided to help bridge the gap of inequalities. Within this ethnic group it is also recommended that research is conducted with the varied sub groups that come under the SA umbrella term. By understanding the cultural nuances in subgroups, services can become more culturally competent and consider approaches which are mindful of cultural adaptations (Khan, 2021).

This review highlighted that even though there is a perception that SA individuals are collectivists, this is not always the case as some from this population have adopted individualistic values. This is important to consider, that our own biases and assumptions can influence individuals, thereby services, who may perceive the population as a whole (community) and not acknowledge individual differences. For example, not all individuals found it helpful to get support from family as it resulted in a detrimental impact on their wellbeing. Therefore, it is important to consider and value individual differences within this population to be able to provide adequate support.

This review shows the importance of understanding religious beliefs and different cultural nuances, it is important for services to understand what these are for individuals from different cultural contexts and how they make meaning from these factors in relation to bereavements. Models which are commonly applied to help understand the grieving process, such as Kubler-ross (1969), do not acknowledge religion and beliefs. Clinicians should attempt to incorporate these aspects within their formulation to be able to provide holistic interventions.

2.9 Conclusion

The SLR set out to understand what the current experiences of bereavement for SA individuals are by exploring existing qualitative research and synthesising data. This SLR has identified 26 studies and used thematic synthesis to identify and explore common themes and differences relating to the current experiences of bereavement from individuals who identify from a SA background. To provide adequate support for the SA population, it is necessary to understand the differences in experiences of subgroups and understand how support can provide meaningful intervention and promote accessibility of services. The next chapter (Chapter 3) explains how research was conducted to explore the experiences of bereavement in a Gujarati community (a sub-group within the SA population) living in the UK.

Chapter 3: Methodology

3.0 Chapter overview

This chapter explains the method that was used to explore the research questions. The research design that has been selected is discussed, as well as the reasoning for using Thematic analysis (TA) and the epistemological choices. The process of how recruitment and data collection occurred is explained as well as a presentation of the participant sample. Ideas from professional consultants who have been involved in developing and advising on this research are included. Additionally, the chapter will include how ethical issues were thought about in a meaningful way, as well as presenting a quality appraisal of the study.

3.1 Design

3.1.1 Qualitative methodology

Research methods depend on the study's aims. Quantitative methods, dominant before the 1980s, use numerical data to allow comparisons (Pistrang & Barker, 2012). Qualitative methods, emerging in the 1980s and 1990s, focus on understanding phenomena through participants' experiences, acknowledging their unique perspectives (Castleberry & Nolen, 2018). Using only numerical data would not capture cultural nuances and authentic experiences. A qualitative approach focuses on description, which allows the researcher to understand an experience and its complexity, within a natural setting, from a holistic perspective (Creswell & Tashakkori, 2007) and data is found from the descriptions presented and provide insights that go beyond using numbers (Castleberry & Nolen, 2018). The method also appreciates the process of interpretations to be collaboratively coconstructed with participants (Taylor & Ussher, 2001). As this research project is exploratory, and aims to understand an individual’s experience, a qualitative method was chosen to allow for indepth analysis (Barker, Pistrang & Elliot, 2002).

3.1.2 The rationale for a qualitative design

The systematic review of exploring SA bereavement experiences revealed the importance of religious beliefs and cultural nuances as being factors that influence the experience of bereavement for this population. The impact of bereavement on well-being and relationships was also identified after experiencing a loss and the differences in support, both that helpful and unhelpful, that was provided. There were limited studies from the UK included, and no research on the sub-group of the Gujarati community on understanding their experiences of bereavement. As the aim of the research was to explore the different experiences of bereavement from the Gujarati population, a qualitative design was considered the most appropriate.

The critical realist (CR) framework that was adopted worked in tandem with the qualitative design methodology as it allows for exploration of differences of views on a topic. A significant aspect of critical realism is the ability to think about reality through various lenses and to be able to help provide an interpretation which may not be the same as an individual lens (Fletcher, 2017).

I acknowledge that although I am from the same background as the participants in the study, I have limited knowledge about how experiences of bereavement manifest for this population and that my experience may be subjective. To obtain authentic views from individuals' experiences, I offered to meet participants face-to-face, in person or virtually via Zoom. This provided an opportunity for participants to be able to have a choice about how they wanted to present their authentic self within the research and share their experiences. I also offered the opportunity for an interpreter to be present for anyone who wished to be interviewed in Gujarati. However, all participants chose a preference to speak in English. I was aware that when speaking a different language, the nuances can sometimes be missed as an expression can be lost in translation. Therefore, participants had the choice of language they used, so as not to restrict the meaningful experiences they shared. I was aware of individuals from ethnic groups not being able to have many opportunities to share their

experiences and thus by adopting a qualitative methodology, I felt that it would be able to give this population a voice.

3.1.3 Consideration of alternative methodologies

In considering methodology for this research, Interpretative Phenomenological Analysis (IPA) was initially considered due to its focus on in-depth understanding of participants' experiences, typically with smaller samples (Smith & Osborn, 2003). However, given the limited research on Gujarati individuals' bereavement, Thematic Analysis (TA) was considered more suitable for its applicability to larger samples and its ability to identify patterns across experiences. Narrative analysis, which explores how individuals create meaning through storytelling, was also considered but TA was chosen for its focus on shared patterns (Riessman, 2008).

3.2 Reflexive thematic analysis (TA)

TA originates from content analysis (Joffe, 2011), which has been used since the 19th century within different disciplines (Downe-Wamboldt, 1992). TA became widely used in the 1990s and at times was not identified as TA but explained using different terminology (Braun & Clarke, 2021).

TA is surrounded by assumptions, values and practices, which together build up the method and is considered a process that applies a method to make sense of data (Braun & Clarke, 2021). TA focuses on understanding meaning across repeated patterns through the data (Braun & Clarke, 2006), therefore it supported the research aim which was to understand collective meanings in the experience of bereavement for the Gujarati population. To be able to conduct reflexive TA, a researcher needs to have qualitative sensibility which includes capturing values, and assumptions in line with their research question as well as understanding the assumptions of reflexive TA, which has developed as there is now a focus on research being fully qualitative which is known as the Big Q (Braun & Clarke, 2021). Guidelines outlined for TA by Braun & Clarke (2021) explain that to conduct reflexive TA, there is no need for set rules or a process to be followed, step by step. It is acknowledged that by following phases or a series of steps of reflexive TA, a good analysis is not

guaranteed, and similarly doing things in a different pattern will not compromise the analysis (Braun & Clarke, 2021).

Two levels are identified when analysing themes: semantic (explicitly expressed meaning which is close to the language of the participant) and latent (interpretative, focusing on deeper or conceptual level of meaning, sometimes abstract from obvious content of data) levels (Braun & Clarke, 2021). Both levels of coding are on a continuum and coding can sit at many different points or at one point (Braun & Clarke, 2021) which enables a fuller and more comprehensive analysis to be undertaken.

I chose Reflexive Thematic analysis (TA) as a process to analyse data for this research because of the theoretical flexibility, suitability to large data sets, and the framework it provides. It allowed me to be able to explore, recognise and analyse patterns across the data set and make meaning fluidly, which are steps outlined by Braun & Clarke (2006). In this project, the process of analysis, started with the semantic level (descriptive) leading to the latent level (interpretative). TA can take an inductive approach (themes drawn from the data) or a deductive approach where pre-existing theories and literature help make sense of data. As this topic has limited research, I chose to use both inductive and deductive approaches, to allow the analysis to be more fluid and reduce bias. To help monitor bias, I engaged in bracketing and the use of reflective diaries to aid transparency with my influence of identity and assumptions on the analysis of data as suggested by Creswell & Miller (2000).

It is acknowledged that when using the reflexive TA approach there is an element of subjectivity between the research and the researcher (Braun & Clarke, 2021). There are multiple truths and meanings that are revealed through interactions between the researcher and participants involved in the research study which are socially constructed (Braun & Clarke, 2021). This is in line with a critical realist epistemology which suggests there are multiple truths rather than one.

3.2.1 Strengths and weakness of thematic analysis

Strengths and weaknesses of the TA approach are outlined below (Table 8):

Table 8

Strengths and Weaknesses of TA

Strengths	**Weaknesses**
Accessible approach	Some see it as not a rigorous method (Clarke & Braun, 2013).
Thematic analysis is an accessible approach. The method is simple to learn and apply and does not require the use of theory to help process of analysis because it inductive, which means it is	Fluidity can also be seen as a limitation as it can be a challenge for researchers to identify which epistemological stance or theoretical understand the underpinnings they should use and which data they should focus on (Braun & Clarke, 2006). can be purely datadriven (King, 2004; Braun & Clarke, 2006; Nowell et al., 2017; Kiger & Varpio, 2020).
Can be used with a wide range of data sets and encourages the researcher to highlight the key points from the data (Kiger & Varpio, 2020)	Potential researcher bias exists as the researcher must play a close role in identifying and interpreting data (Nowell et al., 2017).
Flexibility to be applied to different research questions: from understanding people's experiences and broader constructs in social contexts (Clarke & Braun, 2013).	
TA can examine the different types of data and documents, analysing large amounts of data (Clarke & Braun, 2013).	
The choice of the epistemological framework can be flexible, (Clarke & Braun, 2013).	
The choice of how to analyse data from an inductive (data-driven) or deductive (theorydriven) approach (Clarke & Braun, 2013).	

Critical realism is methodologically aligned with TA as it also works to unravel the surface of reality which is the same as looking at underlying ideologies which inform the semantic content of data (Braun & Clarke, 2008).

3.3 Data collection

3.3.1 Semi structured interviews

Semi structured interviews were chosen because they provide a structure for the researcher to follow whilst also allowing the researcher some flexibility to ask open ended questions that are unique to the topic of area of interest and further explore participant responses (Gillham, 2000). To ensure the researcher covers all areas of the topic a list of questions help guide the interviewer

(Runeson & Host, 2009). An interview guide is developed which covers the main topics of the study (Taylor, 2005), this allows for structure in the interview and ensures that data collected from each participant is comparable to the questions asked (Naz et al., 2022). Semi-structured interviews allow for ideas to be exchanged between the interviewer and interviewee, allowing the interviewer to change direction or ask the participant for more details about a response (Galletta, 2013). It is advantageous to use semi-structured interviews as they allow the researcher to explore the opinions of the participants which then helps to develop a deeper understanding of their answers, which is particularly helpful when dealing with sensitive topics (Naz et al., 2022). As a result, it felt appropriate to select semi-structured interviews for this research project (Naz et al., 2022).

3.3.2 Creating and co-creating the interview schedule

To help understand various experiences around bereavement from a Gujarati perspective an interview schedule was developed (Appendix 1). It was designed to be flexible rather than rigid, it allowed participants to be able to share their views or ideas around what felt applicable to the topic questions (Whiting, 2008; Willig, 2008). To help devise the interview schedule the five-stage approach, outlined by Kallio et al's (2016), was adopted, this can be seen in Table 9.

Table 9

Development of interview schedule

First stage	The first stage involved finding an appropriate method for investigating the research and whether semi-structured interviews were the right approach by looking at the prerequisites. I looked at methods that were available to use to investigate the research question. It appeared that the semi-structured approach was the most suitable to my research question because it is flexible in its structure and allows the ability to explore a topic that addresses sensitive and emotive content (Willig, 2008).
Second stage	The second stage involved looking at previous knowledge within the topic and using this to help identify what was already known within that area of research and what needed to be discovered. I looked at existing literature reviews and systematic reviews on topics in relation to bereavement experiences and started to make a list of what is already known about bereavement experiences and what is still to be known.
Third stage	The third stage required formulating questions and developing potential questions to retrieve the required data. This led me to the next stage of listing potential questions related to the overall research question.

Fourth stage	The fourth stage facilitated the piloting of the interview guide to identify improvements for its development and make any necessary adjustments following the testing of questions with the research team and external experts (consultants) who were experts in working with parents who had experienced a bereavement.
Fifth stage	Based on the feedback received, the questions were adjusted to develop a coherent guide for the interview schedule. During the final stage, a clear and logical interview guide for data collection was developed that addressed the aims of the study.

3.3.3 Professional consultation

Professional consultations occurred with two members of SLOW (Surviving the loss of your world), both have been involved with the service for many years and have an interest in providing the best support for individuals who have experienced a bereavement. Within the first consultation the aims of the research, the design of the questions to be included and ways to recruit for the study were discussed. The consultants offered a valuable opportunity to reflect with them on my identity and position to this topic and to consider how they may engage with this research. During the second meeting the interview schedule was reviewed, and the wording of the questions were explored. The use of different terminology and ideas about context and its impact on bereavement experiences was reflected upon. The consultants also gave advice on how the research could be disseminated. The third meeting explored the themes and reflected of the name given to each theme. We reflected on how understanding bereavement can change with age and acknowledged that culture can have an impact. There were discussions over models of theory, such as Continuing Bonds Theory (CB; Klass et al, 1996), and growing around grief (Tonkin, 1996). CB theory related in term of individuals having possessions of loved ones around them and using photos as a way to cope. Growing around grief

also resonated with us as we reflected on how much this population has the space to be able to grow around grief with the customs and rituals which can sometimes be imposed.

3.3.4 Piloting the interview schedule

The interview schedule was piloted with a peer from a Gujarati background. The peer provided valuable insights on questions which were developed, these were then taken back to the research team and reviewed in relation to the draft of the interview schedule. After completing the draft, the schedule was shown to the research team, the consultants and peer for any initial reactions and further feedback. The consultants suggested it was important to consider the amount of time required if an interpreter was used due to the sensitive nature of the topic being discussed. After the changes were made the schedule was then finalised with the research team.

3.4 Participation criteria

To ensure bereavement experiences were collected specifically from the Gujarati community in the UK, participants who were over 18 years old, lived in the UK, self-identified from a Gujarati background and had experienced a bereavement were included. Inclusion and exclusion criteria are outlined in Table 10.

Table 10

Participant Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
Self-identifies from a Gujarati background	Under 18 years old
18 years old or above	Not experienced a bereavement
Based in the UK	Not from a Gujarati background
Has experienced a bereavement at any point in their life	Being unable to share experiences in significant detail with me (e.g. not being able to speak about the loss of a loved one).
Able to share experiences in significant detail with me (e.g. being able to speak about the loss of a loved one).	

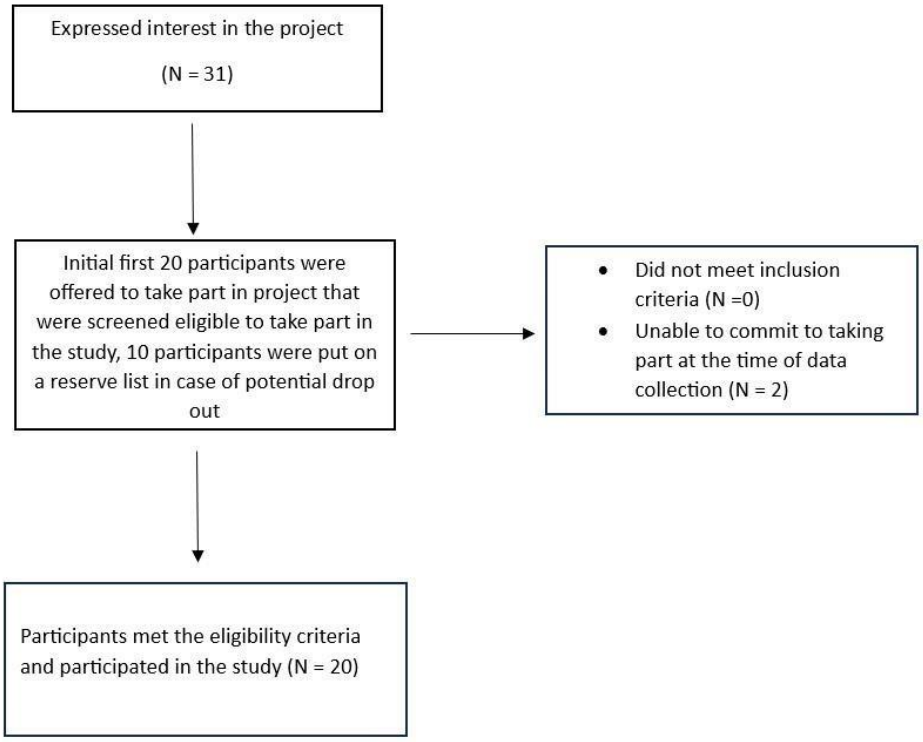
3.4.1 Recruitment

Purposive sampling was selected as an appropriate method as the participants were required to have particular characteristics as suggested by Obilor (2023). The recruitment process occurred between September 2023 and November 2023. A poster (see Appendix 2) was created to advertise the study and was circulated through community forums on WhatsApp and Facebook and. This was followed by a snowballing approach. Participants were offered the opportunity to share details of the study with peers and family who would meet the inclusion criteria and would be interested to take part. Thirty-one people expressed an interest in taking part, however due to time restrictions only the first 20 participants, that met the inclusion criteria, were invited to take part. A reserve list was made in case any participants were unable to commit. Two participants from the initial 20 selected were unable to then take part due to other commitments, thus two participants were selected from the reserve list in the order they had emailed interest. This process is outlined in Figure 2.

The number of participants that reached out to take part in this research surprised me, as I was unsure if individuals would come forward given the stigma that I feet is still present of talking about mental health. I was also aware of the cultural attitude of "getting on with it" and wondering how this play a role in individuals' willingness to participate in this research. Participants spoke to me about wanting to talk about their experiences and acknowledging this was an important area to explore for support to be able to be offered in the community, after witnessing others face difficulties post-bereavement. It highlighted to me how crucial it was to do this research with this population, as it allowed individuals to have a voice in sharing their experiences.

Figure 2

Recruitment process



3.4.2 Participant Demographics

In total, there were 20 participants in the sample; they were aged between 22 – 65 years old (mean age = 38.6); twelve participants identified as female and eight identified as male. All participants selfidentified as Indian and Gujarati. Participants came from different geographical locations in the UK (London, Hertfordshire, Manchester, Leicester, Hampshire, Bradford). Out of the 20 participants, 17 were employed, one self- employed, one retired and one unemployed. 18 participants had attended university and obtained a degree and two participants obtained college qualifications. All participants identified as Hindu. However, one participant did indicate a preference for being called spiritual rather than Hindu. All participants had experienced more than one bereavement, and only four out of the twenty participants had previously received support for their bereavement. All

participants except one shared that they had a Gujarati community around them.-All individuals reported to speak English and Gujarati and some participants also spoke Hindi. 10 participants were married, two participants were in a relationship, one participant was a widow, and seven participants were single (see Table 11). To protect anonymity of these participants geographical location and age is not included in the table.

Within the sample, twelve participants had experienced the death of a parent, one participant experienced the death of a sibling, three participants experienced the death of a grandparent, two participants experienced the death of an uncle, one participant had experienced the death of a cousin, and one experienced a death of a mother-in-law.

In terms of the duration of a loved one's loss, two participants had experienced their losses within the last year, six participants within the last five years, four participants within the last five to ten years, and eight of the participants' losses occurred over ten years ago.

The majority of participants' cause of loss was from long-term health conditions, and some participants experienced sudden loss through relatives having pneumonia, asthma or heart attack.

Table 11

Participant demographics

Participant	Gender	Gujarati community	Is the community helpful/ unhelpful in the area / not sure	Work status	Education	Religious	Received support	Relationship status	Bereavement (s) experienced
Anu	Female	Yes	Unhelpful	Part-time employed	University	Hindu	No	Widow	3
Raj	Male	Yes	Not sure	Part-time employed	University	Hindu	No	Married	5
Anish	Male	Yes	Helpful	Unemployed	University	Hindu	No	In a relationship	5
Vivek	Male	Yes	Not sure	Part-time employed	University	Hindu	No	Single	3
Rohan	Male	Yes	Yes	Full time employed	University	Hindu	No	In a relationship	2
Shreya	Female	No	Unhelpful	Full time employed	University	Hindu	No	Single	3
Roshni	Female	Yes	Not sure	Full time employed	College	Hindu	Yes	Married	3
Heena	Female	Yes	Helpful	Full time employed	University	Hindu	Yes	Single	8
Hiren	Male	Yes	Helpful	Retired	College	Hindu	No	Married	4
Chandni	Female	Yes	Unhelpful	Part-time employed	University	Hindu	Yes	Married	6
Viran	Male	Yes	Unhelpful	Full time	University	Hindu	No	Married	6
Alisha	Female	Yes	Helpful	Full time	University	Hindu	No	Married	3
Aarti	Female	Yes	Unhelpful	Full time	University	Hindu	No	Single	4
Jay	Male	Yes	Unhelpful	Full time	University	Hindu	Yes	Married	4
Nitin	Male	Yes	Unhelpful	Full time	University	Hindu	No	Married	4
Kavita	Female	Yes	Yes	Part-time employed	College	Spiritual	No	Married	3
Anjali	Female	Yes	No	Full time	University	Hindu	Yes	Single	3
Pooja	Female	Yes	Yes	Full time	University	Hindu	No	Singe	3

Bhavita	Female	Yes	Yes	Part-time employed	University	Hindu	No	Married	7
Vidya	Female	Yes	Not sure	Self-employed	School	Hindu	Yes	Single	5

3.5 Ethical considerations

To obtain ethical approval, a proposal was put forward about the research project to the ethics committee. To ensure the project followed strict adherence to ethical guidelines, The code of Human Research Ethics was used as a reference (British Psychological Society, 2014). The University of Hertfordshire Health and Science Engineering and Technology department granted ethical approval for this project; Protocol number: LMS/PGR/UH/05419 (Appendix 3).

3.5.1 Informed consent

Once participants had expressed interest in a project, an information sheet was sent by email to explain details about the research project (Appendix 4). Within the information sheet, the main aims of the project were explained.

Participants were given the choice to take part, and at which points they could withdraw if they decided to change their mind. The potential benefits to taking part, potential risks involved, and how data will be collected, stored and used was explained. Participants were also given opportunities to ask any questions they had after reading the information sheet before consenting to take part. An informed consent sheet (Appendix 5) was sent electronically to participants who agreed to take part and on return, they were stored securely, and password protected. Consent was re-visited at the start of the interview and the opportunity to ask any questions was encouraged. Verbal consent was also sought at beginning of interview to audio record the interview for the purpose of data analysis.

3.5.2 Confidentiality

Data was collected, stored and managed according to the requirements set out in the Data Protection Act (Data Protection Act, 2018). When informed consent was received from participants, there name was pseudo- anonymised to ensure confidentiality. The consent sheets were then stored onto the encrypted hard drive and password protected. Demographic information obtained at the beginning

of interview was also password protected and stored on the encrypted hard drive and pseudo names replaced original names. Any identifiable information that was included in transcripts was removed. A unique code was allocated to transcripts, which was only identifiable by the researcher to help identify participant data. Confidentiality was explained within the information sheet and consent form and reiterated at the beginning of the interview in case of any concerns.

3.5.3 The right to withdraw

Participants had the right to withdraw up until two weeks post-interview due to the nature of TA. It was explained that after this period the data is difficult to remove as it is merged with other data before being analysed. Participants were made aware that participation was voluntary and if they decided to withdraw before the interview or even after data had been collected within the twoweek window, then there would be no repercussions or negative impacts and they would be able to take part in future research still.

3.5.4 Risk of distress and psychological harm

It was acknowledged that there was a chance of participants experiencing psychological distress due to the sensitive topic being explored. Participants were asked at the beginning of the interview if they felt comfortable sharing their experience of bereavement in detail. They were also made aware that they could skip any questions they liked or take a moment in the interview if needed. To reduce the risks conscious steps were taken to ensure space was given by pausing and checking-in with the participant throughout the interview and validating their feelings in relation to the topic. I was also aware there was a limitation to interpreting social cues; therefore, I paused frequently to give the opportunity for participants to take their time in responding to questions as well as allowing time to process their understanding of the question being asked. The final part of the interview included a debrief which summarised what was outlined in the debrief sheet (see Appendix 6). The debrief provided an opportunity for participants to share how they were feeling post-interview and for me to check that they felt safe and ready to close the interview. I explained the mental health support

information and specific bereavement organisations which could support them if they felt they wanted further support.

3.6 Procedure

The procedure of research is outlined in Figure 3. Once ethical approval had been sought, posters were then advertised through community forums and social media to attract interest in the research study. Participants who expressed an interest were all sent the information sheet which outlined the details about the study. Participants who met the inclusion criteria were then sent an informed consent sheet. Once participants had sent the informed consent sheet back, the interview was arranged at a date and time that was suitable for both the participant and interviewer. All participants requested to do the interview online. Zoom was used as a platform to conduct interviews and an encrypted link was sent to their email with confirmation of time and date of interview. Data of informed consent and emails recorded for communication was stored on an encrypted hard drive to ensure data protection was maintained.

At the beginning of the interview process, individuals were reminded about the purpose of the study and right to withdraw. Consent was obtained to record the interview for the purpose of data analysis. Confidentiality was outlined and participants were informed they could choose to skip questions if they wished or take a break at any point in time. Demographic questions were also covered at the beginning of the interview. The interviews followed an interview schedule which was developed to guide the questions for exploring the topic. There were also prompts used if participants found it difficult to answer a question and a flexible approach was adopted allowing the researcher to ask additional questions about their responses. Interviews lasted between 60 – 90 minutes. Due to English not being the first language for some participants additional time was provided. Generally, it is more difficult to spot social and visual cues when conducting interviews remotely (Carr & Worth, 2001), thus extra time allowed for opportunity to check in with the participant throughout the interview to see how they were feeling and allow time for expression of thoughts. Participants were

happy to access the interview via the Zoom platform and were confident in using the software due to it being the common platform used in the global pandemic for working and socialising.

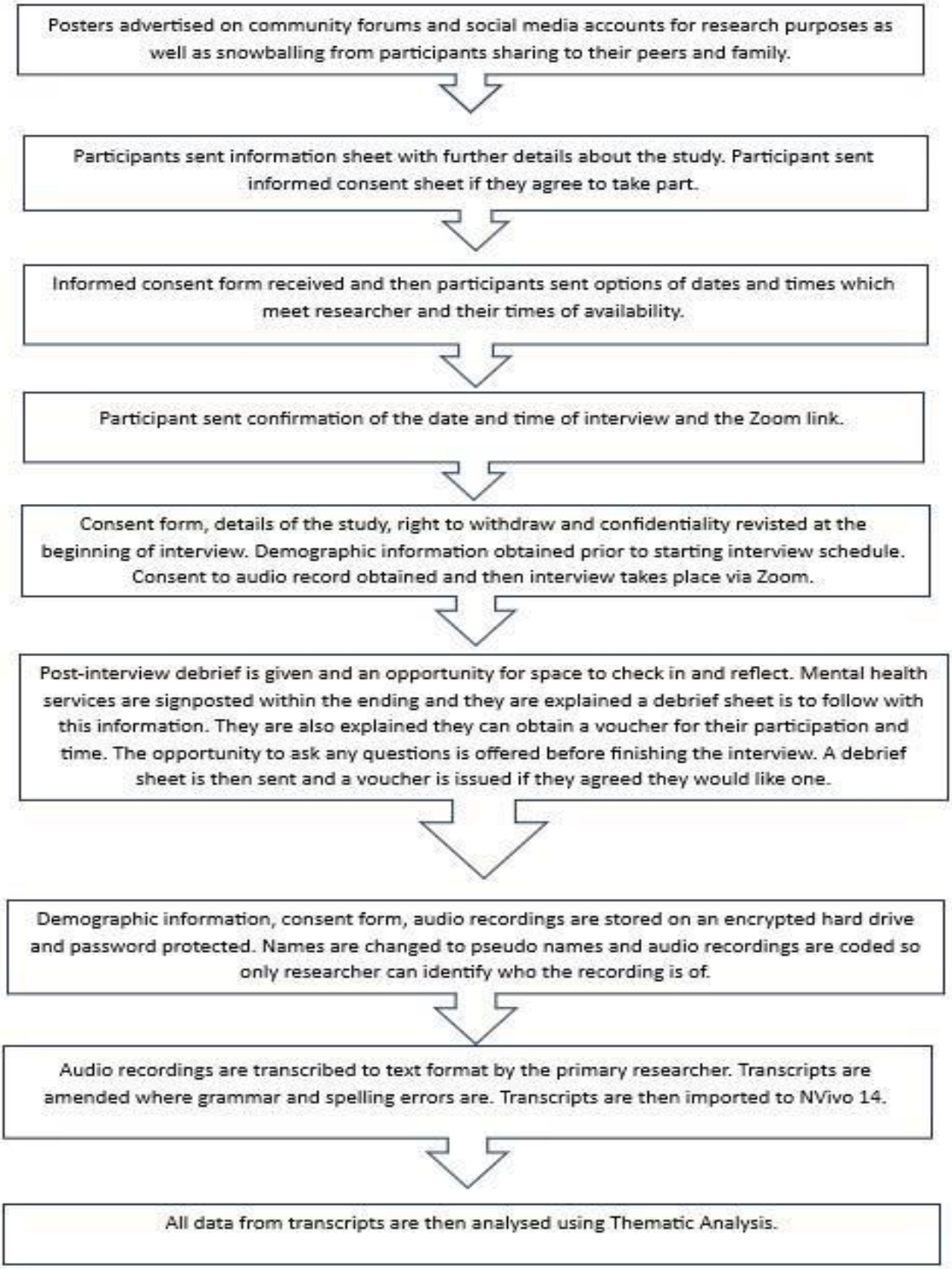
After the interview, participants were provided with an opportunity to check in with the researcher to see how they were feeling before the interview was ended. Participants were also provided with a debrief sheet which included contact numbers for support services which they could use if they felt they required further support. Participants were also offered a £15 gift voucher as a thank-you for taking part.

I noticed myself after some interviews having strong feelings towards some participants individual experiences. I was aware of how my biases could impact the way I interpreted results so as an attempt to reduce this, I wrote a reflection after each interview (Appendix 16).

Audio files were then transcribed by the primary researcher in December 2023. All 20 transcripts were listened to and transcribed manually. Once all transcripts were transcribed, the audio files were deleted from Zoom. Transcripts were written using pseudo names and confidential information was removed. All transcripts were then imported into NVivo 14 (QSR, 2023) and then analysed using a TA approach.

Figure 3

Procedure of recruitment



3.7 Data analysis

TA was chosen to be the appropriate analysis. Braun and Clarke (2006) outline six phases to follow when completing TA. The six phases are detailed below in Table 12.

Table 12

Phases of TA

Phase 1: Data Familiarisation	To become familiar with the data, I transcribed the twenty interviews myself; I intentionally spent time doing this to help immerse myself in the data and become familiar with it, as Braun & Clarke (2006) suggested. Initially, I listened to each interview once, then again whilst transcribing. I then read through the transcript in a more 'active way' (Braun & Clarke, 2006); this process involved noting initial thoughts that came to mind, particularly when noticing patterns or potential codes. This is where I started to "engage analytically" (Braun & Clarke, 2021, p. 133).
Phase 2: Coding the data	After familiarising myself with the data, I then coded each transcript, moving to more of a 'systematic' process (Braun & Clarke, 2021). NVivo 14 was used to code all the transcripts, this was done line-byline (Appendix 7). The dialogue was coded if it was felt that it could answers the research question and aims. I chose to be led by the data at this stage which is known as taking an 'inductive stance' as opposed to being led by prior knowledge or literature (Braun & Clarke, 2006). Both latent (explicit) and semantic (interpretative) codes were drawn out from the data, this ensured I was coding broadly and was able to provide context to understand the data (Bryman, 1998) and capture potential nuances from different participants (Braun & Clarke, 2021). This process resulted in 110 initial codes being identified from the 20 interviews (Appendix 7). To aid reflexivity throughout the coding process, I shared subsections of anonymised transcripts to my colleague and their feedback allowed me to reflect on the biases and assumptions that may have been present when I was coding initially. It also allowed me to reflect on the language being used. Appendix 14 provides an excerpt from a conversation I had with my colleague which details my thought process.

Phase 3: Initial theme generation	To help me think of the broader patterns on shared meaning between the codes (Braun & Clarke, 2021), I created a mind map and started to write out the specific codes that I felt would cluster together to make a theme (Appendix 8). Some codes were able to be grouped together to make an overarching theme, which included sub-themes; however, some codes identified were not relevant and were discarded (Appendix 9, Appendix 10).
Phase 4: Developing and reviewing themes.	To be able to move through the process of developing and reviewing themes, several steps were taken. Initially, I looked at the original codes, which were derived from the transcripts and the themes identified from the original transcripts; this was to see if the themes were capturing the story and its nuances and to make sure they were addressing the research question (Braun & Clarke, 2021). I also created a table outlining the main quotes concerning each theme to help me monitor my analysis and identify potential 'drift' and made sure each theme captured the various meanings and concepts participants presented which helped me identify if any important meanings had been missed (Braun & Clarke, 2021). Critical conversations discussing the themes and subthemes identified were had with peers, the research team and the consultants. These conversations allowed me to think of how to organise concepts, understand the connectedness between the themes and try to accurately label the theme to capture meaning.
Phase 5: Refining, defining and naming themes.	Creating a table with the main quotes allowed me to think about naming themes and refining them (Appendix 10). Reflecting on the quotes was helpful as it helped me to see whether they supported the themes and subthemes. This process, together with feedback from the research team and the consultants, helped to refine the naming of the themes and subthemes enabling relevant quotes to be captured (Appendix 11). This phase then led to the final analysis which is represented on a thematic map (Appendix 12). Chapter 4 discusses the analysis.
Phase 6: Writing up reflexive TA	After conducting the TA rich descriptions from each theme were written up

3.8 Quality, validity, and self-reflexivity

This next section will focus on the quality appraisal of the research project, and I will also explain my position in relation to the research topic.

3.8.1 Quality assessment of the current research project

CASP (2018) as applied to my SLR review, was also used to appraise my research project to check that it met the criteria (Table 13).

Table 13

Quality assessment of current research using (CASP 2018) criteria

Criteria for Quality (Y=Yes N =No and ? = Cannot tell	**Criteria**	**Evidence for meeting the CASP criteria**
1. Is there a clear statement of the aims of the research?	Y	The objective of the study was to explore the bereavement experiences of individuals who identify from a Gujarati background. Aims and research questions has been highlighted in Chapter 1.
2. Is a qualitative methodology appropriate?	Y	A qualitative methodology was appropriate for exploring the research question as it was explorative to accounts of experience. The methodology for collecting data was appropriate and allowed flexibility which enabled indepth data and nuanced perspectives to be gathered.
3. Was the research design of the research?	Y	Findings from SLR showed there was a lack of research with this population on bereavement experience and limited research in the UK. Qualitative methodology was appropriate to address the aims and the most appropriate to address the gap in research. TA was also chosen due to it's flexible approach and allowing for varied nuances to be explored about a topic. Consultants involved in the

		research also felt this was an appropriate research design as within their service there is a lack of research on those who identify from an ethnic group and their experiences of bereavement.
4. Was the recruitment strategy appropriate to the aims of the research?	Y	The project used purposive and snowball sampling to be able to reach out to this community for recruitment. Snowball was included to make sure recruitment would be achieved, it is also suggested when trusted sources refer another individual it can help increase interest and uptake to participate (Berg, 2014).
5. Was the data collected in a way that addressed the research issue?	Y	Participants were able to be interviewed face to face or via video interface. Open-ended questions were used throughout, using a semistructured interview guide. Space was given to interviews to share their experiences as they wished and to answer questions. The process of how data was collected is outlined in this chapter.
6. Has the relationship between participants been adequately considered?	Y	I recognised my position as a the researcher and inside-outsider researcher. I have reflected on my personal biases and influences I bring to the research and its process. This has been done through using reflexivity and understanding where I position myself with this research. I have used a research diary to note my reflections and observations, I have had critical conversations about my research to peers who are

			from another background, used regular supervision, and reflected with consultants who are experts in the field of working with individuals who have experienced a bereavement.
7. Have ethical issues been consideration?	Y	been thought throughout this	Ethical considerations have taken into project. Initially it was when gaining approval for this study and obtaining ethical approval. This is outlined in the ethics section of this chapter. Risk assessment was completed with the research topic being sensitive and having the potential to cause harm which considered essential responses to help mitigate this risk such as debrief, check in throughout interviews, signposting services, and acknowledging whether they felt they were able to speak about a bereavement experience in detail at the beginning of the interview. They were also able to stop the interview at any time or remove data up to post two weeks of completion.

8. Was the data analysis sufficiently rigorous?	Y	An in-depth, rigorous analysis was conducted using TA which is explained in the analysis section. The analysis involved familiarising self with data, extracting quotes, coding and then making sense of codes into themes that narrates the story of the participants' experiences about bereavement. I checked throughout this process my biases and assumptions with a peer when discussing codes. I also had critical conversations about naming of themes with the research team. Meeting with consultant was also arranged to overlook the data and the theme development.
9. Is there a clear statement of findings?	Y	The study gives a summary of research findings and how it answers the research question and aims which were set to be investigated.
10. How valuable is this research?	Y	This study is the first study to explore bereavement experiences of Gujarati population in the UK. It highlighted the difference between cultural nuances and provides insight to individuals who are not from this background of how bereavement is experienced for this demographic. The findings highlight barriers to support which gives clinical implications for clinicians to be mindful of such as lack of awareness of services, lack of cultural competency some participants have felt, and engagement from services to be on a community level. It also highlights a generational difference and how each generation may learn from

each other about perspectives in how bereavement is experienced.

An integral aspect of reflexivity is to reflect and examine our social identity, so we can understand how it interacts with the population that is being researched; it is important to consider power, privilege and visibility in the process (Jacobson & Mustafa, 2019). I have considered myself as an insider-outsider (Dwyer & Buckle, 2009) researcher: as a young Indian woman and mental health professional, I bring many assumptions and biases to this project which include my own and how I have been influence by others. I have reflected on this position as a researcher and the impact it would have had on the analysis of the findings.

I reflected on the opportunity of being able to engage with this community during the research process and being able to advocate for their views. To acknowledge which aspects of my identity, values and opinions may influence the research project, I completed the two tiers of the "Social Identities Map" (Jacobson & Mustafa, 2019), as seen in Appendix 13. This helped me to reflect on what underlying assumptions and biases I may bring to the research such as the privilege of being a trainee clinical psychologist and the level of education I have been exposed to. Excerpts are included from the reflective diary from different stages of the research where this was reflected (Appendix 14). Peers, consultants, and the research team allowed me the space to consider my position in relation to this research from the beginning and during the writing up phases. This allowed me to be transparent with my assumptions and biases with the research team, consultants, and peers. I also acknowledged their position in relation to the population being researched and the topic.

4.0 Results

4.1 Overview

In this chapter, the findings are presented from the reflective TA. Five primary themes and 20 subthemes were identified and constructed from the data (Table 14). Verbatim extracts and quotes from the interviews were used to elaborate on the themes and subthemes.

Table 14

Overview of themes

Theme	**Sub-themes**	
Theme 1: Understanding bereavement and process	1.	What is bereavement?
	2.	Internal and external ways of processing
	3.	Age and understanding
	4.	Being prepared for a death
	5.	Western versus Eastern Practices
Theme 2: The aftermath	1.	Impact on well-being and functioning
	2.	Relational changes
Theme 3: Coping with grief	1.	Time to self or time with others
	2.	Religion and spirituality
	3.	Distraction and avoidance
	4.	Remembrance and celebrating life
Theme 4: Cultural influence on grieving	1.	The expected way to grieve
	2.	The unknown
	3.	Judgments of others
	4.	Ignorance is bliss

	5.	Traditional Roles
Theme 5: Support through a bereavement	1.	Community level engagement
	2.	Lived experience creating openness
	3.	Barriers faced by our population
	4.	Experience of having therapy

Theme 1 - Understanding bereavement and process

The first theme outlines how individuals understand and process bereavement depending on different factors. *Besvanu*, usually occurs straight after the loss has occurred and can last up to 13 days. Throughout this theme, there were different perspectives on understanding what bereavement means to this population and different ways of processing a loss which includes both internal and external ways. This theme also outlines how bereavement can be understood differently depending on age, being prepared for a loss, context, and geographical influence.

Sub theme 1 – What is bereavement?

Within this sub-theme, 11 participants spoke about bereavement feeling like a process and something you learn to live with, which comes with a mixture of emotions. Participant explained bereavement as a fluid process rather than a linear process where a person goes through particular stages to be able to process the loss of a loved one.

Vidya: "It's a process, you just don't know […] how it's going to hit. It's guilt and it's not guilt. It's all emotions, there will be days where you just sit there and think, why am I feeling so guilty... you end up remembering things, and thinking maybe I should have done this".

Here Vidya explains that grief can come up at different points after experiencing the loss of a loved one, she highlights that grief is not just experienced within a certain time frame after a loved one has

passed away. For her, grief would come up on random days when she would remember old memories and spend time reminiscing, and this would bring up a mixture of emotions such as guilt, regret and sadness. The mixture of emotions that were felt for Vidya were ongoing and confusing, showing how difficult experiences of bereavement can be, and hard to make meaning of. Similarly to Vidya, half of the participants explained that there is a difference in the range of emotions you experience post-loss depending on the person who has passed away:

Vivek: "I think it probably is a very different experience, depending on the person you lost and how close you are to the person as well".

Vivek explains how bereavement experience can vary with the relationship you have to the loss of an individual and depends upon how intimate the relationship is. This suggests that the impact of the emotions experienced is dependent on whether the relationship is close or distant as this influences how a bereavement is processed.

Half of the participants explained acceptance as being part of the process of understanding bereavement and explained teachings from Hinduism of the soul being immortal and this reasoning around death helped them to process the loss of a loved one.

Viran: "Someone dies, it's natural to be upset and cry, […] the only difference is, if your spiritual, you have this understanding that death is an inevitable part of life, so that acceptance, that death is natural, and it's going to happen, just helps you move on".

Viran alludes to the fact that it is common to be upset after experiencing a loss but with understanding of spiritual teachings you learn that death will happen to everyone and when you understand this then processing of loss will be easier and help you to move on. Kavita also similarly speaks about the soul moving on and this gives her comfort when processing loss.

Kavita: "The soul is immortal, and it doesn't die, just the body dies".

Kavita describes how teachings from Hinduism, have taught her to understand how the soul carries on with the journey and that it is the body that just dies. She explains how this concept took her time

to understand and that as she has grown older, she has made sense of understanding loss in this particular way. Kavita alluded to age being a factor that affects how we understand death and process death.

Sub-theme 2 – Internal and external ways of processing

This theme discusses how processing grief can be internal or external, one state is not suggested to be a fixed entity on how to process the loss of a loved one. Anu explains how you can go between the two:

Anu: "You can sit here and cry, cry your eyes out, you can talk to people, you can go out for a walk, go to the park and sit there and just talk to the birds of the trees".

Here Anu explains how for some individuals internally processing grief helps make meaning of the loss and perhaps crying as way to process loss. However, for others, it will be talking to someone about how they are feeling or even doing practical activities to help with thoughts related to the loss. There is also a factor of not understanding how to process loss. Chandni explains she grieved internally to try processing the loss as she did not know any other way:

"I spent, many, many hours on my own crying, I literally didn't know how to deal with it".

Here Chandni reports the only way she knew how to cope with the loss she had experienced, was to cry. She explained feeling confused about how to deal with the loss and process it, as others around her would act like nothing had happened and carry on as normal. She would cry by herself privately and keep her thoughts to herself as she did not want to appear 'weak' in front of others. This shows how the emotion of sadness may present in the form of crying when unable to speak about sadness itself around the loss. For Aarti, she explained feeling numb when she experienced a loss:

Aarti: "I was quite in touch with my emotions, but now I'm just quite numb".

Aarti highlighted there are other emotions than sadness that can be experienced when losing a loved one, such as the emotion of numbness. This demonstrates the different internal emotions

experienced when processing a loss;. There is no one specific or fixed emotion with grief that you can identify that you will experience; it will be different for each individual at different points in time.

With processing loss externally, some participants explained looking at memories to remember a loved one or speaking about them with friends and family. It felt important to keep the person alive and to continue to celebrate them.

Jay explains: "There are lots of stories about my mum that I don't know about, so the only way to do this is to get everyone together and talk about her."

Jay reports being able to process the loss of his mum through hearing stories about what she did and memorable moments for her and her family. This allows him to remember his mum through the stories and be able to engage in grieving. Vivek similarly expresses the same about hearing stories of others who have passed away near to him:

"There's this thing about telling stories about the person that's died. it really helps you kind of just fulfil yourself and love their life […] rather than being sat in the silence of their loss."

Vivek explained to help him process a loss he experienced, he preferred to speak about the loved one that passed by sharing memories he had in relation to them, rather than sitting in silence amongst other family members during *Besvanu period*. He explains feeling a sense of fulfilment when remembering stories linked to the individual and a sense of pride when remembering the good things the person did. A few participants also alluded to the preference of sharing stories and remembering memories together rather than being in silence during the mourning phase to help start processing the loss for them.

Overall, this sub-theme captures different ways of processing loss, it can be internal ways of processing or external ways of processing or even both. Individuals can go between or do either or both. There is no fixed way to process a loss. Internal processing captures the different emotional experiences one can feel and the external process highlights remembering the loved one through pictures or telling stories to help process the loss.

Sub-theme 3 – Age and understanding

All participants except one shared that as they got older, they started to understand what loss of a loved one meant and how they may grieve. The age someone dies was also considered a factor to how an individual was able to process loss and understand loss of a loved one. Some participants had the perception that if a person was older in age when they passed away. then the loss felt slightly easier to accept than if someone was younger:

Jay: This is going to sound bad, but once someone gets past a certain age, you know, 75 or 80 years old, when they pass away, I don't get upset about it. [...] they've had a great life."

Jay describes that he processes and makes meaning of a loss by the judgment of the age of the individual when they passed. He explains a level of acceptance of death when someone older in age has passed away in comparison to someone who was younger. He alludes to it being difficult to accept the loss when someone is younger because they would not have lived their life and fully achieved their wishes, whereas someone older may have experienced most of their life and met goals and wishes they had.

With age as a factor of understanding loss, Nitin explains his understanding of death changed as he grew older:

"For me as a 7-year-old, remembering back then, the process was, oh, he's gone now, but I've got all these people coming to my house. I've got my nephews, my cousins coming over, and I've got my elders coming over, and we are doing things, and as a child, you see people and you're like, yeah, he's gone, but we're having a party for the next 12 days".

Nitin explained when he was younger, he did not understand what was happening at the time of experiencing a loss in his family, he could not grasp why certain rituals or customs were being conducted at Besvanu. He understood the mourning phase to be a time for him to socialise and have fun with his cousins and nephews, rather than it being a time to process feelings of the death. He

explained that instead of feeling sad and mourning the death, the children would play games and chat whilst adults were praying.

Although, some other participants also explained when they were younger, they did not understand what loss is and what was going on during *Besvanu*, they reported finding that phase intense:

Aarti: I lost my […] my grandparents, but […] I was quite young then […] people would cry and like we just kind of get together […] and it has just always been quite intense in my head.

Aarti noticed that it was an experience of family coming together and letting out emotions for her rather than having fun with other family members. She was confused when she observed different rituals and customs being done and did not understand why they were being done. She spoke of being confused about how she was feeling about the loss, and did not know what grieving was, as it was not talked about.

In summary, this sub-theme captures different perspectives of understanding bereavement at different ages. Participants emphasise how it may be more likely for an individual to be able to process loss depending on whether the individual was older in comparison to a younger individual, and reflect on how understanding of loss can change with time. Participants explained when they were younger, it was difficult to understand customs and rituals done in *Besvanu*, which made meaning-making of loss difficult.

Sub theme 4 – Being prepared for a death

This sub-theme shows how individuals responded to processing bereavement, dependent upon whether they felt prepared for the loss of their loved one or unprepared. For over half of the participants, the bereavement felt sudden, however, for five participants they knew their loved one was going to pass away. When a death was not expected, participants explained it was difficult to be able to process the loss and make sense of the loss which had an impact on their functioning at that time:

Anu said: "Bereavement means a shock to the system […] nobody understands that…that person is not in the right frame of mind and they could be saying things that they don't mean".

Anu explains at the time her partner passed away; she was in shock as she was not expecting his loss. She found herself saying things out of context during *Besvanu* phase, which she did not mean, as she was confused. Anu mentioned things she had said were misinterpreted by family members which resulted in distant relationships with family members of the partner side. Managing practicalities at the time of an unexpected loss was also highlighted by Anjali, she explained feeling confused about what needed to be done:

"I think sometimes the most stressful thing is…it sounds awful, but if somebody dies at home, what do you do? Who do you call? […] I think is quite stressful".

Anjali explained having various questions in her head: experiencing a state of confusion in accepting the reality of loss in that moment, a state of shock leaving her feeling stressed and overwhelmed, all whilst managing the process of what she was expected to do according to cultural expectations. She gives insight into the difficult experience an individual may face, when trying to navigate processing a sudden loss and trying to meet cultural expectations of what should be done when a death has happened.

Overall, this sub-theme captures the difference in processing a loss depending upon if someone feels prepared for the loss or if it is unexpected. The latter was experienced by participants as a shock to the system, impacting of their day-to-day functioning. The practicalities individuals also manage at that time can cause stress and confusion about what must be done.

Subtheme 5 – Western versus Eastern

This theme speaks to the differences of how bereavement is seen from a Western cultural perspective versus an Eastern cultural perspective. Participants speak about the varied cultural practices of grieving, they explained from their perspective, they understood the Western view to grieving, being about celebration of life and the Gujarati perspective as having an extended period of mourning period and trying to liberate the soul from the body. The difference between collective

and individualistic approaches to the process of grieving is also spoken about concerning Western and Eastern perspectives.

All participants acknowledged the Western perspective on grieving to be different from Eastern perspective and the way bereavement is processed. Differences highlighted were the length of the process of mourning and the difference of celebrating the loss of a loved one:

Aarti explains: "They don't have such a long process…when the person passes, the family gets together for that one day, and it's more of a celebration of life, whereas with us […], we will properly grieve them, […] it's like you should be crying, the 12 days of our mourning period you can't go here, you can't drink alcohol… it's just a lot of can't".

Aarti alluded to the length of mourning period individuals from a Gujarati background follow being longer than the Western mourning period. She highlighted the feelings of restriction she had experienced in the initial days of the mourning period and the limitations of not being able to do what she felt she needed to do for herself, to process the loss she had experienced. Aarti also touches on the cultural expectation of crying during this period, without any acknowledgement of the person life being celebrated. Six other participants also spoke about the celebration of life and how it would be nice to adopt this approach:

Pooja: I really like the idea of when they have this wake or gathering because I think it's quite beautiful, it's more of a celebration, I think in our […] Hindu culture, it's very emotionally charged. You have to feel that remorse […] as opposed to celebrating someone's life".

Pooja also alluded to the cultural expectation of sitting with sadness when experiencing a bereavement and finding it difficult to follow, to help her process a loss. She indicated how she would have a preference to celebrate the loved one rather than sit in despair. Pooja explained the importance of choice to be available for individuals to choose how they want to process a loss rather than feeling that they must follow the cultural norm.

In sum, this sub-theme has highlighted the perceptions participants had on cultural perspectives on grieving and how it can impact understanding bereavement and processing the loss of a loved one. Participant explained within the Gujarati culture, individuals are encouraged to mourn for twelve days, and in the Western culture mourning was viewed to be a shorter time period. They felt that the western way of grieving encourages celebration of life rather than focusing on feelings of sadness around the loss. Some participants highlighted how they would like to adopt other cultural practices as it felt it would help them make meaning of loss but explained that individuals may refrain from this because of how it may be viewed culturally.

Theme 2 – The Aftermath

The second theme focuses on the post-impact of the participants after experiencing the loss of a loved one. Participants talked about the loss affecting their well-being, including mental health deterioration and reduced level of functioning. Financial constraints were also a challenge for a few participants, which affected the process of being able to grieve, as it was not something that was able to be prioritised. Participants also explained relationships changing between families either becoming closer or distant and for some completely cut off which left some people with more support or less support.

Sub-theme 1: Impact on well-being and functioning

Twelve participants explained noticing changes in their mental health after losing a loved one, they also explained how this impacted their functioning and wellbeing. Due to the challenges, they faced with their mental health this impacted day to day functioning and being able to process the bereavement:

Chandni: "It was hard, because you can't sleep because you're still processing, so if you can't sleep, you're tired, and not eating properly".

Chandni highlights the vicious cycle she was in after losing a loved one. She explains being caught between trying to process the loss, and then trying to get an adequate amount of sleep as well as

keeping an appetite. Juggling all of the everyday demands felt difficult for Chandni which made it difficult to process the loss. Similarly, this was felt by Shreya's dad:

Shreya: "So we're about to hit puberty […] he doesn't know what to do himself, […] he had just become redundant from his job… trying to deal with me and my sister at the same time as well, it was really hard".

Shreya highlighted the struggle for their widowed dad and the hardship this brought to their family, such as financial constraints and having to take on the maternal role of a mother. The struggle was noticed by Shreya, which affected her ability at the time to focus on grieving the loss of her mother due to wanting to help her dad with the pressure he was under.

Sub-theme 2: Relational changes

All but one participant spoke of , there were changes in relationships within the family, after the death of their loved one. Participants presented with a mixture of views on the experience of relational changes, highlighting closer or distant relationships with family or community and for some having no relationship with some family members.

14 participants reported being closer to particular family members after a loved one passed away. They highlighted that the process of grieving and mixture of emotions experienced helped them to become closer.

Aarti: "I think everyone was just kind of like in their own lives[...] didn't really feel the need to like check in on each other [...]. But after his loss, we're all very close, like we check on each other every day [...]. Again the 12 days, maybe it does help, […], it kind of forced us to be together for 12 days".

Here, Aarti explains how the loss they experienced as a family brought them together. She explains that before, the relationships were distant, and she did not know how other family members were doing in general. However, after experiencing a loss, it had brought them together. She alludes to how *Besvanu* may have helped initiate this development in their relationships.

On the other hand, many participants experienced some relationships becoming distant or nonexistent after losing a loved one. Raj highlighted his reason for distance with some family member was due to the ambiguity around understanding the reason for the loss of his mother and decisions being made for him of what he should be told at the time of the death.

"I broke a lot of relationships off, as a result of this death. Just because I didn't get the answers I wanted".

Raj highlighted when he was younger, he was not told about the reason for his mother death. This left him feeling angry towards others as he wanted an explanation to be able to make sense of the loss he had experienced and to be able to process his loss. It was assumed by family members that he was too young to understand the reason for his mother's death, so they were silent around him and did not speak of his mother. This impacted Raj's ability when younger to make relationships with friends, as he spent time feeling confused and questioning his mother's loss, he was not able to make meaning of his loss. As a result of the silence around the loss, Raj distanced himself from the family members and decided to cut contact, as he felt angry about the lack of communication around his mother's passing. This demonstrates the impact silence can have on helping an individual to process a loss they have experienced and the importance of conversation and acknowledgment of loss even if the individual is young.

Along with silence being present from family members after someone has passed away, blame was identified as a factor by Chandni which impacted her relationship with family members.

"One of my aunties said, oh, you know you did it, you were the one to blame, so from that phone call onwards, I didn't speak to her."

Chandni decided to cut off her relationship with her aunt and explained how that comment stayed with her in her younger years and impacted her mental health. It took her a long time to come to some level of acceptance of losing her cousin as being able to grieve felt difficult in the environment she was in.

Overall, this theme highlights how bereavement has impacted participants state of wellbeing and mental health. A deterioration in mental health showed to impact everyday functioning which included: getting enough sleep, eating properly, managing responsibilities and being able to financially support family. It draws attention to, how all relationships will not stay the same and how a loss can have an impact on the continued relationships within families or communities and how that can be an adjustment for the individual whilst still processing a bereavement.

Theme 3 – Coping with grief

This theme outlined the various ways of coping with grief, such as: using beliefs to help cope, using social support, having privacy, using distraction and/or avoidance, remembering that person actively and celebrating their life.

Sub-theme 1 – Time to self or time with others

During the time of *Besvanu*, many people come together to pay respects and pray for the soul of the individual who has passed away, families usually will not be by themselves during this period. Twelve participants explained they wanted privacy to be able to process the loss they had experienced rather than focusing on managing other people at the time of *Besvanu*.

Raj: "In our culture, it's almost like you're not given that space and that time. Your personal space is almost non-existent, because you've constantly got people buzzing in your ear, and it's like, no, just leave me alone. I don't want to do this and that's the difficult part".

Raj explains that it felt important to have the time for himself to be able to process the loss of his mother and to be able to be left with his feelings. He explained at that time of experiencing this loss, he felt pressure to follow customs and rituals that he was told to do by older members of the family and at that point he did not want to do any of that, he just wanted his space. He explained there was many people present, which restricted him to have his own space. Several participants mentioned that sometimes people would come for *Besvanu* and then they would not show up after to provide support:

Aarti: *"There is support that everyone comes together, for when it happens, but it's not like long-term support".*

Aarti said that initially the support was there but then after 13 days no one came to support her family. She found it difficult to adjust from having lots of support, to then suddenly no support; this made it difficult for her and her family to navigate the grieving process.

Some participants explained the immediate support post-loss during the *Besvanu* to be helpful. Some participants mentioned not knowing what to do at the time of experiencing a loss and that by family members helping sort practicalities out, they were able to focus on grieving during that period because others would take care of everything:

Heena said: "having that sort of protected time and that time of the community around you, there's good aspects, because you are surrounded by people, you're not left to it by yourself".

Heena felt the people she was surrounded by at the time off experiencing a loss were helpful during the time of grieving. She felt she was not left with her emotions and that she could talk to others about how she was feeling, and they could help with rituals and customs that needed to be done at that time. Some participants also specifically expressed that a friend felt more helpful during the grieving process over family:

Pooja explained "I felt I needed to allow them to deal with it themselves that moment in time, and I didn't want to burden them anymore".

Pooja alludes to friends being her main support network, she felt comfortable to share how she was feeling after experiencing a loss. She highlighted that not everyone will feel the family and community are supportive and for some it may be friends. Some participants would say different relationships were supportive over others and for some there was no specific relationship suggested to provide the best support. For some, speaking to family members felt difficult as they did not want to risk burdening others with their emotions, whist they were also grieving. Therefore, they turned to people who were not in their immediate relations to help reduce the risk of burden.

Overall, this theme explains how there is variation in individuals' preferences for *Besvanu*, some preferred to have family and community around, whilst some preferred to have privacy to be able to process the loss. Some participants explained the difficulty in navigating the bereavement when there was a sudden reduction in family or community members around the post mourning phase as it felt there was no support offering support. Support networks are also varied, and many prefer to speak to friends to be able to openly speak about they feel and also reduce burden on other family members so they can also grieve freely.

Sub-theme 2 – Religion and spirituality

This theme focuses on how religion and spirituality helped individuals make sense of a bereavement and use certain teachings to cope. The majority of participants mentioned following Hinduism as a religion and a few expressed preferring not to label it as Hinduism but spirituality. Fifteen participants mentioned prayer as a tool to cope with grief and the understanding from Hinduism of reincarnation and that the soul is an eternal being.

Viran: "Death is just an inevitable part of life, [...] as Hindus, death is not the end. It's the end of one life, but the beginning of a new cycle. So, I guess that kind of just gives you a bit of comfort, the ability to cope with something that is inevitable".

Viran alludes here to Hinduism teachings around the soul being eternal and the process of reincarnation. He explained that because he understands these teachings, it helped him feel comfort and allowed him to understand and process the loss of his father. He felt having the understanding made it easier for him to let his father's spirit go, and move on with his life. Other participants also mentioned that by reminding themselves of teachings around death from Hinduism, through reading religious texts such as the Bhagavad Gita, helped to provide comfort through difficult feelings they experienced when processing the loss and trying to accept the loss. Six participants felt that remembering God and chanting God's name helped them find peace through coping with a loss:

Rohan: "Just chanting a God's name, or just like praying to someone, just helps me find a little bit of inner peace, whether there is one or there isn't one".

Rohan alludes to prayer being helpful when trying to process loss and navigate the experience of bereavement. He speaks to prayer still being helpful even though he is not sure if there is a God, but believing in some almighty being, helped him to find peace through the difficult time.

This subtheme overall explains how remembering the teachings of religion, has helped individuals from the Gujarati community process bereavement and make sense of a loss. Prayer has also been a helpful tool when grieving a loss of a loved one.

Sub theme 3 Distraction and avoidance

Distraction and avoidance were noted by nine participants as a helpful way of processing a loss in the short term. Participants felt it was not the right time to focus on the loss and felt it was easier to keep busy rather than focus on what was going on around them at the time. However, it was also acknowledged that it can delay the process of grieving:

Vidya: "It was nice to be busy and be able to focus on sending my dad at peace, but then, when the quietness hit, reality also hits, it's like, right, now this is life without him. You still have reality to go back to [...]".

Vidya explained it felt easier for her to carry on functioning, when things were busier and there was certain rituals or customs to focus on, in sending the loss of loved ones' soul to peace. However, Vidya explained that later she noticed when she stopped being busy, she had not processed the loss and the reality of the loss was then present again with the same feelings. Avoidance of dealing with things was a common theme that was identified from participants:

Bhavita: "There's a really big thing in the Gujarati community, that a lot of things are brushed under the carpet".

Bhavita explained how the community deals with feelings and mentions that it is common for individuals from this population to brush things to the side, and not deal with how they are in that moment. She alluded to the restrictions felt of expressing feelings freely in relation to loss, which are set by the cultural expectations and customs during the Besvanu period.

In summary, this sub-theme explains how for some participants, distraction and avoidance was a helpful coping strategy in the short term in managing grief, particularly during *Besvanu* ,as they could focus on rituals and customs. However, participants acknowledged that it was not a long-term solution and noticed when they were not busy, the feeling of grief would appear with the same

intensity that was originally felt at the beginning. Avoidance is also mentioned to be common theme within the Gujarati population by participants when dealing with grief.

theme 4 Remembrance and Celebrating Life

Thirteen participants found remembering loved ones through talking about their memories with others was a helpful way to cope with grief, helping them to feel that the individual was not lost, and their presence was still felt. The concept of trying to celebrate their life helped make coping with grief less morbid and encouraged others to celebrate things in the moment. Seven participants have tried to adopt this approach of celebrating life:

Bhavita said: "Instead of walking out crying, we have videos of people walking out dancing because it is just about embracing life, celebrating it and not waiting for tomorrow".

Bhavita explained that her family did not want to follow the traditional approach of *Besvanu* after her father's loss. She spoke about how her father always mentioned to the family that he would want to be celebrated after he passed away. It felt important for Bhavita and her family to honour this for her father, and she explained it was helpful to remember his memories and what he had achieved in his life to help process the loss. Bhavita mentioned that although coming to terms with losing her father was hard, celebrating his life, made it easier to grieve his loss and taught them and others to live more in the moment. Some participants explained they also found through remembering the loved one and sharing memories together, it was a helpful way to process grief:

Heena: "I do like the aspect of getting together and sharing happy memories rather than getting together and watching each other cry, it's a hard time for everyone as it is, but adding that lighter touch may just make it a little bit easier".

Sharing happy memories was found to be helpful for Heena in processing the loss she experienced. She spoke to the culture creating a morbid atmosphere when following expected cultural traditions or customs which impacted the process of being able to grieve in a way that feels helpful. Heena

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explained that some people feel they need to be sad or cry, when they may not even be sure how they are feeling about the loss.

In summary, this sub-theme speaks some participants finding it helpful to adopt an approach of celebrating life to be able to help process a loss rather through the traditional known way, as it may impact them to make meaning and grieve the loss they have experienced. does not help some process the loss they have experienced. It was emphasised that sharing memories with others about loved ones that have passed was more helpful than sitting in despair.

Theme 4 – Cultural Influence on Grieving

This theme explores the different cultural nuances that have an impact on the grieving process for individuals from a Gujarati background. Seven participants explained that it felt within the culture, there is a specific way to grieve according to cultural expectations; sometimes individuals will not understand why certain customs and rituals are done but will do it out of expectation and obedience. Most participants spoke of the judgments that were made by their community and family, on how one should grieve. Participants also explained that their families preferred to avoid their feelings around loss and silence was dominantly present.

Sub-theme 1 – The expected way to grieve

All participants spoke about *Besvanu* lasting between 9-12 days and for one participant it lasted 16 days.

Participants explain certain rituals and customs that are expected to happen within this period:

Nitin: "we all process grief differently, some people take longer, some people take less, and within our culture, there is this rule of 12 days of mourning and on the 13th day you get one with your life, to a point it is good, but to a point, it is too regimented".

Nitin explains how 12 days for him felt absolute with no flexibility, he mentioned finding it difficult to meet the expectation of grieving the loss within that time frame. Several others agreed with

Nitin, that there is no specific number of days that can measure grieving and for some it might not be the right time to engage in managing grief the way the culture sets it out to be. Participants highlighted here how they would prefer flexibility with cultural expectations and traditions to be able to grieve

the way they would feel is helpful. Anish explains that some specific cultural expectations felt challenging for him:

"Two hours later we're at home moving sofas around, moving furniture out of the way, because we knew there was going to be an influx of people coming to the house. Thing need to get done, it was like project management for a funeral".

Anish explains the difficulty he experienced of being able to process the loss of his father with having to think about the cultural expectation of what needed to be done. He mentioned the bereavement process felt difficult for him as there was no time to stop and think about how he was feeling or even support his mother. He alludes to the Besvanu phase focusing more on others and the expectation by the culture and community to following through with cultural traditions during this phase. Raj highlighted how the cultural expectations did not allow him to say goodbye in his own way:

"I don't think it gives them the opportunity to just say goodbye because you would have 10 to 15 strangers singing away. I didn't care. That was my time to say my goodbye".

Raj speaks to the hurt he felt of not being able to say goodbye to his mother in the way he would have liked to. He speaks about the others choosing for him and how this impacted his ability to be able to grieve the loss of his mother, making the bereavement experience even more difficult to process. He explained that all individuals having different ways to grieve a loss and that it felt unfair for him to be placed with cultural expectations.

To summarise this sub-theme explains that for some participants the cultural expectations of grieving, in a certain number of days felt rigid and that it can take a different amount of time depending on the individual. Participants highlighted the restrictions they feel to be able to grieve freely when there is a set and known standard within the Gujarati community which is usually followed.

Sub theme 2 – The unknown

Confusion between what is cultural practice and what is religion stood out throughout all interviews. Participants mentioned that it was difficult to ask older members of the family as they themselves did not know, merely just following the custom or practice:

Anish said "There's a big line between religion and culture, but it's merged, like blurs of the two together. [...] We didn't even have an opportunity to say…we agree with this, or we find this problematic".

Anish here alludes to how cultural traditions and religious practices have become mixed within his family. He explains some family members would not agree with following certain cultural Gujarati practices but are happy to follow the religious practice. He explained that practices and customs for him have been expected to be done without the opportunity to choose if he would like to perform them or question why they are being performed. Half of the participants also shared that questioning around what is expected to be done at the time of a loss, was frowned upon:

Chandni: "I questioned, but I was told not to question".

Chandni spoke of it being difficult to question family members about why certain rituals or customs were being done. She shared that not getting any answers made the grieving process difficult to understand and impacted the way she would have liked to grieve for the loss of her cousin. She alluded to how conformity is encouraged within the community rather than questioning and/or having a different view. There were differences in the perspective of older and younger generations views on how cultural practices and customs should be done and how an individual should cope when experiencing a loss:

Aarti: "They all get together [...]do prayers, because that's the only thing that they've seen, and they believe that this is where the person is going, or this is the only way the person will find peace, whereas, with us, it is more like the questioning behind it".

Here Aarti outlined how the older generation will continue to do rituals and customs how they have been told and will not question why there are practises, whereas the younger generation would like to know why they are doing a particular practise. Aarti highlights for the older generation they are able to make meaning of the loss in this way but for the younger generation they are left with questions on the process which impacts the grieving process. Difference in perspective was also seen between generations in sharing how they are feeling:

In sum, generations differ in how they process loss and cope. Both generations have been exposed to different experiences which would impact on how they express feelings about a loss and how they may want to have support. For the older generation, it seems that it is more about doing things the way they have been done, whereas the younger generation would like to know why they are doing specific rituals or customs, and be able to continue to express their emotions and seek support if necessary.

Sub-theme 3 – Judgment of others

All participants described different cultural nuances within the Gujarati community around the loss of a loved one. Judgment from community and family members was spoken of by 17 participants. They reported feeling judged on how they appeared during the bereavement process and the type of relationship they had with the individual who passed away:

Aarti: "if you're the wife, or just immediately related, if you're not crying, there's something wrong with you, it's very much like, oh, does she not have emotion? Does she not care? But people go into shock, people deal with it differently".

Aarti here explained how she was expected to be seen crying after experiencing a loss, she also reported hearing others' comment on people who did not cry. Aarti alluded to family members commenting on individuals who did not cry and suggesting that they did not have a good relationship with the individual that had passed. Within theme one, sub theme one and two, participants explained different internal emotions experienced such as feeling numb, confused, guilty and sad,

which highlighted that there can be different emotional states for a person. Similarly, Aarti agreed with this view and shared that just because one does not cry, it does not mean they have not been impacted by the loss, individuals can grieve in different ways and at different points in time. Judgment was also noticed if you did not attend *Besvanu*, Anjali explained:

"I find that in the Asian culture, […] people go more for obligation rather than respect, it's more about, what would people think if we don't go".

Anjali explained at the time she experienced a loss, she was worried that if she did not attend *Besvanu,* she would be judged from other family members and the community. She explained that she does not agree with the cultural expectations and at the time she was grieving, she did not want to grieve in that way, however, to avoid judgment she still attended. Furthermore, 15 participants talked about judgment from family and community towards those who showed emotional and mental health difficulties:

Nitin: "It takes a very strong person to say I am not well mentally, because if that comes up, the next thing is being ostracised".

Nitin spoke to how he faced difficulties with expressing his emotions within the Gujarati community. He explained that he feared not being accepted or being considered 'weak' if he spoke about struggling psychologically. He explains how he supressed his feelings for a long period of time which resulted in his mental health deteriorating.

Overall, this theme explains how judgment from others has impacted participants experiences of bereavement and being able to process the loss they have experienced. Fear of being excluded or judged has impacted participants mental health as they have had to hide their feelings. Some participants felt that there was a pressure to perform in a particular way during *Besvanu* otherwise you were be perceived as a person who did not care about the individual who had passed away.

Subtheme 4 – Ignorance is bliss

Thirteen participants spoke about the silence they felt from family members and community, around the loss they had experienced. For many, this was a difficult experience, as they would have preferred to have spoken about the person who they lost as they felt it would have helped to process their grief:

Chandni: "They didn't want to process it, because they wanted to pretend as nothing had occurred, and that there's no problem".

Chandni spoke to a common theme amongst all participants in the interviews, which was about just *'getting on with it'*. She shared that it was the norm in her family to be silent in relation to feelings that was felt and there was a lack of support with each other through the difficult times of grieving her cousin. Chandni explained because the processing of the loss felt so difficult for the family, it was easier for everyone to pretend that nothing had happened and to continue with their day-to-day routine. 14 participants spoke about the difference in the older generation's views to the younger generation's views speaking about their feelings:

Pooja: "It doesn't come natural to them, to talk about their problems [...] they don't want to expose themselves too much".

Here Pooja explained that she has observed that the older generation struggle to show vulnerability, as growing up they did not speak about their feelings, they just 'got on with it', so for them it is natural to not speak about how they feel as that is not their norm. and thus not seek support. However, the younger generation has perhaps been able to experience feeling safe and the opportunity to talk about their feelings, making this easier for them.

In contrast to Chandni, Pooja also explained that she was silent to protect her siblings:

"I think I didn't express myself with my siblings, because I naturally thought I'm the stronger one".

Here Pooja alluded to masking and ignoring her feelings to be the strong person in the family. She felt as the eldest sibling she needed to be careful on how she expressed how she was feeling, as she was worried about how the others would react and cope. Pooja explained with her being an older sibling, she has always had the responsibility of looking after the family and being the 'strong' person. She felt if she showed her sadness, then others would have found it harder to process the loss, and she would have failed to have meet the expectation of being the responsible sibling that family members and community expect of her. Pooja felt that if she expressed her emotions, it would have hindered other family members ability to be able to process the bereavement: she prioritised others' emotional wellbeing over her processing of the loss.

In sum, this sub-theme explains that it is common for individuals to get on with their day-to-day routine and try to suppress their feelings. Within the community individuals can act as if nothing has happened and decide to not give attention and time to processing the loss. However, it could also be a protective measure to support others' health and wellbeing due to responsibility that is placed on a family member to support the family and be 'strong'. Generational differences are also observed by participants within their families on their ability to share emotions.

Subtheme 5 – Traditional roles

Expectations from the Gujarati culture showed in traditional roles, which showed to have an impact on how an individual would experience a bereavement. Seventeen participants explained traditional roles being a factor in how bereavement is experienced and how gender also played a role within this.

Participants spoke about males not expressing their feelings and how that impacted others in the family to process their grief:

Alisha: "Because my dad is male [...], they don't discuss about emotions and feelings. It was almost impossible to talk to him about it, but me and my mum could have a short conversation".

Alisha explained here how her dad would not talk about her brother's loss and at times she found this difficult to be able to process her loss. She was aware she had also seen this with other male family members at the time of the mourning period. Alisha explains how her mother would engage in speaking about her brother, but her dad did not want to speak about it. Alisha alludes here to how males may supress their feelings in comparison to woman. A few participants also explained a difference between younger and older sibling:

Anjali: "if you're living with a joint family, and let's say you're the eldest, then it is the unsaid thing, that the eldest looks after everything [...] It's almost like an unspoken rule. Whereas if you [...] the youngest sibling, then you might not have that much of a pressure, or if you live in separate households".

As alluded to before in sub-theme four, the eldest sibling can experience pressure to be 'strong' for others and therefore not openly share their feelings with other family members. Similarly, Anjali explained the other pressures the eldest sibling may have such as looking after the rest of the family and having to carry on with day-to-day routine tasks to keep the family functioning. Other participants also mentioned gender playing a role: Anish spoke about the difficulties of meeting the expectations that were placed upon him as the eldest son, whilst also trying to process his grief:

"Everyone kept saying to me, because I'm the only son, you need to look after everyone. You're the man of the family and like I didn't agree with it".

Here Anish shared that he was expected by his family and community to look after everyone, even if he necessarily did not agree, and found the expectations placed on him as the older son as unfair. He found himself comparing himself to his siblings as they did not have pressure to do certain rituals or customs or carry out responsibilities. Anish explained he did not have an opportunity to share how

he was feeling or grieve during *Besvanu* because of the responsibilities he had to undertake, this made processing the loss of his dad difficult.

Overall, this sub-theme explains the differences seen between males and females and how they may openly grieve or express their emotions. There are also differences of views on how one should grieve depending on whether one is from the younger generation or the older generation and following the cultural expectations that have always been done.

Theme 5 – Support through a bereavement

This theme highlights how participants felt services could engage with the Gujarati population to offer support post-death. It outlines the barriers that are faced by the population to accessing support, as well as participants' experiences of services that have been helpful. Knowledge and awareness were shared as important factors to helping to provide adequate support for this community.

Sub-theme 1 – Community-level engagement

All participants spoke to the importance of services engaging at a community level and helping to increase accessibility for support rather than promoting services through another service (e.g through the doctors). They felt it was important for the person who offered support, to be competent in the languages which are spoken commonly in the Gujarati community, which are Gujarati and Hindi:

Viran: "Having talks, possibly in Gujarati, Hindi, and in temples on mental health and wellbeing would be helpful, because I think my parent's generation would possibly attend if it was at the temple".

Viran speaks to accessibility being created through using a common language, he explains how with different generations, there are different communication needs, as English is not everyone's first language. He explained providing support in the temple would provide more accessibility as

members of the Gujarati community commonly attend temple and find it a comfortable space. He explains individuals are less likely to go to the doctors but will go to temple to worship. It was noted by Nitin that commonly there will talks in temple around physical health awareness rather than mental health:

Nitin: "We've seen people going to temples talking about breast cancer, prostate cancer and blood donations…but what about mental health?".

Here Nitin explained how he has observed physical health awareness being promoted in temples but has not seen talks being promoted on mental health. He explained within the community, physical health difficulties is often more visible than mental health difficulties, and that because of the stigma related to mental health it is avoided being spoken about. He mentioned that it has been helpful to see talks being promoted to build awareness of physical health problems, but there is a need to emphasise the importance of mental health to reduce stigma around this taboo topic.

This sub-theme captures participants preference for services to promote support through familiar places such as the temple, to create accessibility for the community. Participants emphasise important factors for accessibility, such as using a common language, so all generations are able to be educated on what support is available. There is also a need to address topics which are associated with stigma or taboo.

Sub theme 2 - Lived experience creating openness

Nearly half of the participants explained it being helpful to speak to someone who had also gone through a bereavement, this was helpful to process their loss. Participants felt that if an individual had not gone through a loss, then they would not be able to understand their experience :

Anish: "Unless people had experienced what I was experiencing on a day-to-day basis, it was hard for me to explain exactly what was going on, and I think it was a little bit frustrating sometimes when people just like, oh, it'll be fine, or it can't be that bad, or it's just a few days".

Anish explained the importance of being able to speak to someone who has lived experience of a bereavement, to be able to help someone through the grieving process. He found it difficult to have conversation with individuals who were not able to understand how he was feeling as he felt his emotions were dismissed. A handful of participants also highlighted they felt they would be more open about feelings experienced around a loss, if they were able to speak to another person who had gone through a similar experience, than if they had not.

In summary, this sub-theme highlights that participants felt lived experience was factor which influenced whether they felt they could share how they felt to another individual. Participant felt they would be able to share their emotions freely than worry about being dismissed, which would help them to process the loss and make sense of the bereavement.

Sub theme 3 – Barriers faced by our population

Various barriers were highlighted by participants which affected the accessibility of being able to access services for support. As explained in theme four, judgment by community and family was noticed by participants to affect their ability to grieve freely when a bereavement had occurred, similarly judgement was also noticed if participant tried to seek support. Fifteen participants explained judgment influenced their decision to come forward and seek support because of how they may be perceived by the community:

Heena: "I didn't want anyone to know that I was having treatment and therapy. So…at the period of accessing those services, and when life really folded in on itself, that is, when the shame, the stigma, everything happened, I pulled away".

Heena explained that she was not able to outwardly let people know that she was having therapy and did not want people to find out because she was worried about what people would think of her and her family. She was worried about the shame it would bring to her parents and the comments family or community members may make of her accessing support, thus as a result it made her pull

away from trying to engage with support. Three participants explained privacy of having therapy sessions being an issue:

Roshni: "I could never have those conversations confidentially, [...] they would always cancel them [...] you'd never get those sessions back or reschedule them".

Roshni explained that services did not understand the obstacles of having sessions at home and how this can then affect engagement for sessions. She acknowledged she needed support at the time, but because she felt restricted, she was unable to speak about how she was feeling within her house. This made therapy difficult to continue, as situations at home were part of the difficulties she was experiencing with trying to process the loss she had experienced. Roshni shared that she felt it was unfair that the service discharged her, after missing two appointments, without understand the difficult context she was in. Financial constraints were also named by Anjali to be a barrier in accessing support:

"Unless you're rich and you can afford a therapist, you're not going to get a therapist".

Anjali explained how finances affect an individuals' position on being able to access therapy and that not being fair. She mentioned being on the waiting list for therapy and waiting for a long time before she received supports, as she did not have enough money to go private . She explained with having to wait long for support her mental health deteriorated further. A few participants also named there was a lack of knowledge that services did exist to support individuals that were experiencing a bereavement:

Pooja: "Had there been like groups that she could attend, my bad, if there was, we didn't make use of it [...] But then, clearly, it wasn't advertised well enough, to let us know that such services are available, and I think that would have been really helpful for her recovery".

Pooja explained that she saw her mother going through a deterioration in her mental health. She noticed a decline in her mother functioning and that she did not want to activities which were part

of her everyday routine. Pooja mentioned she did not know about any services that could offer support. Pooja expressed wishing she had known because she could have got support for her mother rather than having to support her by herself. She shared it was difficult to be a carer and also grieve the loss of her father at the same time. Similarly to Pooja, the majority of participants explained they were not aware of services that offer support post bereavement and explained it was only from this research they had realised it was available. Vivek explained that he felt the support was not visible:

Vivek: "[...]they're not like put out there for us to see. [...]. Although we have family systems [...] and communities to support us, I don't think the external help is shown or in our networks".

Vivek explains the lack of advertisement of services available to help with processing a bereavement to the community. He explains how services do not think about promoting the help because perhaps it is assumed that this community will be supported by their support system or family systems, however not all individuals have this privilege of support system and may require external support to be able to get help.

In sum, this subtheme highlighted that services are not promoted well to this population and there is a need to increase advertisement so individuals who may not have adequate support systems can have the option to access support through a bereavement they may experience. It also sheds light on the assumption services may make about this community around their support networks, and not understanding individual differences within the community that may make it harder for an individual to process loss.

Generational trauma was also considered to be a barrier. Vivek explained how the older generation were less likely to access to services because of their experiences of migration:

"It's the fact that a lot of older generations feel like they are being tricked in some sort of way, or don't feel like they're being given the right treatment, so they don't want to share or be involved with the service".

Vivek here alluded to the Windrush generation and explained that the older generation does not trust the system, therefore they do not think services can support them. He explained that his grandad had shared with him, that he had felt the system was a lie, as they were not given what they were promised when migrating:, this was why he would not choose to access services even if he needed support. Vivek explained that this this damage still requires repair, and for that to happen it would be helpful for services to engage at community-level to build rapport and trust with the community that they have lost.

Individual differences amongst the family and community were also a barrier dependent upon personality. Alisha spoke to expression of feelings being easy for some individuals but harder for others, she refers to seeing this difference across the generations:

"getting therapy and things like that, it's still a little bit frowned upon, some people would comment on it. But obviously now, with the newer generations, it's not so much".

As explained in Theme 4 and Theme 5, sub-theme one, judgment is noticed by family and community in the way participants may grieve or express mental health difficulties, resulting in stigma to access support services. With this judgment being present within the community, Alisha explained that she has noticed that the older generation can find it difficult to explain how they are feeling. She shared that with newer generation (0-40 years old), judgment is taking less importance and they prefer to speak about how they are feeling.

Overall, this sub-theme explains various barriers the Gujarati population faces in accessing services which limit the ability of them being able to get support. Participants emphasise the impact judgment by family members and community can have on whether an chooses to access and engage in support. Anjali explained how accessing therapy felt dependent upon privilege and waiting for a long period of time on the waiting list for public health support can cause further deterioration with mental health and wellbeing. Participants felt services need to be flexible with their discharge policies and take into context an individual's barriers to accessing therapy. The importance of

building trust with the Gujarati community was also identified as a crucial element to encourage accessibility. Participants shared that education would be helpful to both the younger and older generations to understand differences in perspectives.

Sub-theme 4 - Experience of having therapy

Five participants explained they had received therapy: they found speaking to a therapist helpful in understanding their grief and processing the death of a loved one:

Jay explained "Sometimes it's good to talk to a stranger who doesn't know you [...] I get counselling, on average once a month at the moment, it's good, just to talk to someone who isn't going to judge you, […] they might give you some coping mechanisms of what to do. It's okay to cry, get emotional".

Jay mentioned therapy for him was a helpful experience to speak about his grief in processing the loss of his mother. He found he was able to be more open about his feelings and express himself to a stranger who was not from the same cultural background as him, and that person would not be able to identify him. Jay felt less judged when he had therapy to explore how bereavement had impacted him. He also highlighted how therapy for him had taught him skills to be able to cope with the loss and make meaning of it. He shared that through speaking about how he was feeling, allowed him reduce the emotional load that he had been carrying for some years since the loss of his mother. In contrast, Roshni explains that it would be helpful for a therapist to be from the same background and understand cultural nuances that impact on bereavement experience:

Roshni explained "I went through the NHS, and I specifically requested Cognitive Behavioural Therapy (CBT), and [...]an Asian female, because it's the only way someone was going to understand me, and she was great".

Roshni shared that for her, it was important to be able to see a therapist from the same cultural background, as she felt they would understand the cultural nuances that occur when an individual

passes away. She alluded to it being important that the therapist understood the different customs and rituals which are expected within the culture as she felt they would be able to understand how her wellbeing was impacted. Many participants also explained that they would find it easier to speak to a therapist if they understood their cultural background, as they would not need to explain what the cultural customs is and can focus on speaking about their experience. For Roshni it was also important to also see a female therapist, as she felt they would understand the impact of expectations on gender roles at time of a bereavement.

Overall, this subtheme explains that participants found it useful to speak to a stranger about their experience of bereavement. Majority of participants had a preference for a therapist from the cultural background and a few explained preferences for someone who was not from the same background, as they felt there would be less judgement and reduced likelihood of the therapist knowing them.

4.2 Summary of results

In conclusion, bereavement experiences varied among participants, influenced by religious beliefs, cultural and generational differences. They used diverse coping strategies and support systems and offered suggestions for future support. Holding in mind the CR epistemology, this highlights how experiences of bereavement can be varied and that not all individuals will experience bereavement in the same way.

With relationships the needs, responsibilities and hopes associated can vary and different social implications and personal meanings can be attached to each type of death (Osterweis et al., 1984) impacting the experience of a bereavement. Within the study, over half of the sample had experienced the loss of a parent, which may be a different bereavement experience to other relations lost such as an aunt or cousin. Research suggests that when an adult loses a parent they experience a developmental push, which pushes them into the next stage of life as they suddenly

feel the weight of responsibility of being in the oldest generation of the family (Osterweis et al., 1984). Those that had lost a parent expressed the difficulty of being able to grieve their loss at a young age, because of having to take on responsibility at a young age of the parent and help their younger sibling or other parent which impacted their wellbeing.

From the findings of the study and SLR, there were similarities in experience of bereavement although the relationship of death differed (SLR with focus on stillbirth experience and study on focus of loss of parent). Similarities that were across both the review and study were cultural expectations and influence of culture when a bereavement occurs, ways of coping with grief such as religion and spirituality and post bereavement changes such as relationships with extended family.

Many participants had experienced a loss over ten years in this sample and reported to still be grieving the loss and finding the process difficult, which shows how grieving is an ongoing process and may not necessarily have an end point.

As I conducted the analysis, I became increasingly frustrated seeing how cultural expectations restrict individuals' ability to grieve freely. I felt sad that cultural expectations were placed so highly over individuals' emotions. I was aware that my emotions could impact the way I analysed the data. To help reduce bias, I wrote a reflection on my feelings after each interview and took breaks when trying to immerse myself in the data to maintain an objective stance. I also checked themes and quotes with a peer, a consultant and supervisors to monitor my biases.

Discussion

5.0 Chapter overview

In this chapter, a summary of the key findings of the project is explained, addressing the research aims and objectives. The results are explained in relation to existing literature and are situated within a theoretical context. I highlight the limitations and strengths of the study, as well as clinical implications, suggestions for future research and my reflections on the project.

5.1 Reviewing the research questions

This research project explored the experiences of bereavement for individuals who are from a SA background. The main research question was: 'What are the experiences of bereavement for those who identify from a Gujarati background?'.

5.1.1 Aims and objectives of the project were to understand:

1) How do individuals from a Gujarati background make sense of their bereavement and grief?
2) How has bereavement affected their mental health?
3) How do individuals from this community obtain support and how can this community be supported?

5.2 Understanding bereavement and grief

For many Hindus, death is understood as a transition to another life, and the goal is to attain Moksha (liberation) from the cycle of rebirth (Firth, 1997). A few participants explained that they made sense of their loss by reminding themselves of the soul being eternal and moving on, which provided them comfort. However, for some participants it was not the teachings that provided comfort, it was acknowledging that grieving takes time and acceptance does not happen straight away.

Practices that are conducted when someone passes away are based on family, caste and local traditions; usually, at times of a loss, bereaved family members will turn to older members who give guidance and advice on how to perform practices (Firth, 1997). Participants in this study reported doing different practices during the Besvanu such as, reading the Bhagavad Gita (Holy book), using rituals or prayer, singing hymns, celebrating the loss of a loved one and spending the days talking about memories of loved one and reminiscing them. Younger participants explained finding it difficult to understand why older members conducted certain practices and customs even when they did not understand why. With the lack of understanding of why certain customs and practices are

done, participants explained how this has impacted their understanding of bereavement creating the sense of things feeling unknown.

Literature highlights that prayer has shown to be a way of coping with loss (Chaudhry, 2014; Das et al., 2021; Gopichandran et al., 2018) and to help make meaning of loss, hence the emphasis from some individuals in making sure rituals are conducted (Ghosh & BK, 2022). Some participants felt prayer and hymns during *Besvanu* helped them to find solace. A few participants explained finding peace through customs and rituals being conducted as it meant to them that their loved ones' souls had moved on. Conversely, some participants felt it was more helpful for them to use distraction and avoidance or speak to a friend for support.

5.3 Models of bereavement and applicability

The Kubler-Ross (1969) model links to experiences of participants reporting their emotional responses at different stages, for example, experiencing a range of emotions, such as guilt, anxiety, numbness, and sadness through the Besvanu period and post-Besvanu. All participants acknowledged acceptance as a difficult stage to reach and that it is an ongoing process. Some participants explained that emotions such as anger and sadness felt intense during the Besvanu period, when having to conduct customs or rituals according to cultural expectations. Others felt they were not able to express their emotions, as they feared being judged by family or community. Some participants explained the silence around the loss by family made it difficult to express how they felt but they did acknowledge internally experiencing emotions of sadness, anger, and numbness.

Some participants felt through reminding themselves of Hinduism teachings, conducting rituals and prayers during the *Besvanu,* it helped them to accept the loss, as they felt the soul was reaching peace. However, for others it was through celebrating the individual and reminiscing them, that they were then able to start processing the loss in order to accept the loss. This demonstrates that similar

emotions are experienced that are outlined by the model, during Besvanu and post Besvanu period, however the model is limited in taking into account the cultural nuances within the Gujarati population which can impact emotional states of grieving.

For many participants, their experiences fitted with the Dual Process (DPM) model. The model describes a process where individuals may go between two states: loss-orientated state and restoration-orientated work state (Stroebe & Schut, 1999). An important part of the model is oscillation, which is altering between these two processes (Stroebe & Schut, 1999) to be able to cope with bereavement and have optimal adjustment over time. Although Hinduism teachings would not encourage loss-orientated state, some participants explained going between both states when grieving a loss. Participants explained cultural expectations would encourage them into restorationorientated work state, with having to be practical with arrangements in the first instance of a loss (e.g. to prepare for rituals and customs and return back to work), but they acknowledged that regardless of the expectation to carry on with their day to day routine, they would notice at times they would be in the loss orientated state. This demonstrates that for some individuals they can use teachings of Hinduism to help make meaning and process bereavement, but for some they notice the teachings are difficult to follow and would appreciate to have time to be in the loss orientated state. Research has shown there is a judgment within the SA community if you are seen to be grieving a different way to the cultural norm (Garcia et al., 2020). Participants acknowledged different ways of grieving that could be helpful for them but explained feeling restricted, as they were worried about judgment if they deviated from cultural norms.

Obsessive grieving has been suggested to lead to chronic grief and depression and suppression of negative emotions has shown to have an impact on physical health (e.g. psychosomatic disorders, increased mortality from heart disease) and adverse health effects are shown in the literature (Parkes, 1998). Some participants did report experiencing symptoms of anxiety and depression

which impacted their day-to-day functioning, as they did not know how to manage or process the grief. This highlights how different individuals can process grief and the importance of acknowledging individual differences when supporting someone through a bereavement.

Within the bereavement literature, continuing a connection with the deceased is called a 'continuing bond' (Stroebe & Schut, 2005; Root & Exline, 2014). Historically CB has been viewed as a maladaptive loss reaction and a hinderance to resolving grief (Silverman & Klass, 1996). This theory has now shifted with time, with a view of understanding that it is a natural experience, and that connection with the deceased, provides solace for those impacted (Klass, 1993). Death does change a relationship, but the attachment can continue without the physical presence of both members (Root & Exline, 2014). Participants spoke about continuing a connection with the individuals they had lost and remembrance being important for grieving. As mentioned previously Gujaratis have a day, Shraadh, which helps them process their loss and make meaning. They explained it was helpful to celebrate the loss of a loved one by talking to family members or community members about their stories and reminisce about them together (Silverman & Nickman, 1996a; Tyson-Rawson, 1996).

5.4 Acculturation and impact on experience of bereavement

Firth (1997) highlighted younger family members who are from a working background and exposed to different cultural values of their peers from Britain, will have different values to their country of origin. Therefore, they may hold different views from their parents' generation, which can leave them feeling confused and disassociated from their culture. As participants have gone through migration and acculturation, differences in views were present (Lee & Mjelde-Mossey, 2004). For example, some younger participants explained how they would prefer to grieve by themselves rather than being expected to grieve with others. This value of independence has come from living within the UK. Many participants acknowledged the older generation prefers to grieve with others, which is in line with collectivist values which originate from Gujarat.

Research has highlighted traditional roles as a factor that impacts experiences of bereavement. For example, depending on whether you are a female or male, you may experience bereavement differently due to cultural expectations (Roberts et al., 2012). Hamid and Jahangir et al (2022), found that within SA families, extended family and community members are prioritised during the mourning phase, rather than the immediate family who have experienced the loss. Findings showed participants were expected to make tea and food, and they had no time to share their feelings (Hamid & Jahangir, 2022). Within this study, participants explained the view of traditional roles by their family and community as a factor impacting on participants' experience of bereavement. Female participants explained that when they experienced a loss, they were expected to make sure there was food during the Besvanu (mourning period) and ensuring others were attended to. Whereas male participants were expected to conduct specific rituals and customs.

The findings highlighted the differing views on rituals and customs that are expected to be followed after a loss. Commonly the younger generation would question the rituals and customs, whilst the older generation said that it was the expected way and how it has always been done. Differences in values were noticed among the participants from different generations; some of the younger generation preferred to privately deal with their loss and make their own decisions. Whereas the older generation preferred to keep strong family and community bonds, prioritising the well-being of others.

Some participants in the current study, explained that they felt the mourning period was not a helpful way for them to grieve and make meaning of their loss. For some, they were not able to acknowledge how they were feeling at the time of the loss and others were confused why certain practices were being done. Participants made reference to the younger individuals having a different view of how practices should be done in comparison to older individuals, and found this difficult to navigate within their families and communities.

5.5 Impact on bereavement and support needs

There have been conversations about addressing ethnic inequalities to increase accessibility to mental health services in the UK; however, despite initiatives, there has been little impact and SA communities are found to be utilising mental health services less than other ethnic groups (Prajapati & Liebling, 2020).

Participants explained a negative impact on their functioning and well-being when experiencing a bereavement; still prevalent today, there is stigma for accessing services for support because of how one may be judged in society. A systematic review conducted across 15 studies explored barriers to accessing and seeking help from services (Prajapati & Liebling, 2020). It found that SA individuals would not come forward due to feeling distanced from services, lack of trust, and perceiving it as a threat to their cultural identity.

5.6 Clinical implications

Participants thought about how they would like to see support and what that support means for them. They also highlighted the barriers to accessing support and what can help promote engagement. I will highlight here the suggestions from participants regarding what clinical implications would be important to consider to provide better support.

5.6.1 Importance of cultural competence

Research highlights that healthcare providers inadequately understand the experiences of individuals from different ethnic groups and their needs for support (Memon et al., 2016). The majority of participants in this study explained that they wished to see a therapist from a SA background to provide support. They felt by having an individual to speak to from the same background, it would help them to be more open as the individual would understand the cultural nuances that impact the bereavement experience. Research has shown that having a cultural framework in place can help an individual feel at ease and promote an individual to seek help because it reduces stigma for help

seeking behaviours. Stigma is shown to be a common factor that interferes with an individual decision to seek help or use services (Suresh & Bhui, 2006; Arthur et al., 2010). Many participants in this study spoke about how they would be judged if they were found to be having therapy because of the stigma it still holds today. Research has found that there is greater psychological distress and high suicidal rates among SA's, particularly women (Williams et al., 2015). Holding this in mind and acknowledging the gender disparity and impact this can have on wellbeing, it is important to be mindful that woman may be vulnerable to mental health with stress from expectations to follow.

This highlights the importance of a cultural framework to help therapists provide adequate support. Part of the process could be to include community members to help think about useful interventions for support. This can prompt insight for service providers which can be meaningful, as well as help to think about how to mediate pathways of support in the most appropriate way (Petersen et al., 2012).

Although research has traditionally suggested for service providers to become more culturally competent, recent research suggests moving away from the term competence and moving to the term cultural humility. Cultural competence as a term has been suggested to reproduce social stereotypes and create an imbalance of power between patients and providers (Tervalon, 1998).

Cultural humility is acknowledging that culture is not stagnant but rather a system of beliefs and values which changes and that is shaped by our interactions with others, media, institutions and socio-economic factors impacting our lives (Helen-Maria et al., 2020). It also incorporates intersectionality of considering different characteristics such as race, class, gender and sexual orientation. Research has found therapy outcomes are more positively associated when the clinician understands the client's cultural identity through asking questions which may have been missed (Owen et al., 2016).

Even though I was from a Gujarati background, I recognised that it was important to ask questions about their experience, which could have been different from mine. To try and ensure I explored and centred their experiences, I asked about their geographical location, whether they had a Gujarati

community around or present in some way, possible financial impact of the bereavement, and their experience of the grieving process. However, I am aware I could have asked about other factors which may have affected their experience, such as education, class, views on spiritual beliefs, and exploring gender.

Within this study participants came from different geographical locations, socio-economic background and sexual orientation which would have influenced how they experienced their bereavements. For example, some participants explained not being in a financial position to be able to access therapy, needing to work to manage day-to-day expenses and provide for their family. Another participant, identifying gay, shared how the presence of stigma and shame towards him and his partner impacted their grieving processes. By asking these questions, it allowed me to gain an understanding of their cultural identity. This highlights the importance to clinicians and researchers to acknowledge the importance of asking and not missing opportunities to understand an individual background and cultural identity to encourage a positive outcome.

5.6.2 Understanding how religion and spirituality may play a role

It is important to acknowledge different belief systems as they may serve as an explanation of why certain experiences may be present for an individual and reduce marginalisation (Sandhu, 2013). Participants identified following Hinduism and spiritual practices when they have lost a loved one. For many participants, this helped them make meaning of a loss and for some it was confusing because of the lack of understanding of what is culture and what is religion. It is important for clinicians to understand how religion and cultural practices are conducted during the mourning period and how this can impact the grieving process. It could be helpful to work with faith leaders to discuss the differences and to gain knowledge and also promote understanding of both domains, which can be factors that influence how a bereavement is experienced.

The Department of Health (2009) outlines best practice guidance to encourage clinicians to be mindful of individual spiritual and religious beliefs and needs, as it can help contribute to well-being. However, from participants experience it is shown that clinicians are still not aware of how cultural and religious beliefs may impact an individuals experience of bereavement. This highlights the need for training to be developed and delivered in services to help clinicians learn about different cultural and religious beliefs, to be able to implement best practice.

Literature highlighted the lack of awareness in ethnic groups of acknowledging what services are there to support (Memon et al., 2016). This study's findings showed that most participants were unaware that services existed to provide support with bereavement. Participants explained it would be helpful to hear about support services from their communities as this is where participants usually attend (e.g., functions, temple); this would be a way to increase accessibility and promote support for bereavement. This was particularly highlighted for the older generation, and this may be due to the mistrust that is within the system of accessing services.

5.6.3 Flexibility with engagement

The literature shows that individuals from ethnic groups are likely to have poor engagement, drop out of treatment, and lower retention rates due to social and cultural barriers (Dixon et al., 2016). Participants explained barriers such as lack of privacy, financial constraints, and stigma that impacted their ability to access services and engage. Therefore, it is likely that individuals will feel reluctance to ask for help when needed. This demonstrates the importance of services being aware of these barriers and trying to understand what they may be for the individual rather than the individual being perceived to 'disengage'.

5.6 Critical evaluation of the study

To date, this is the first study believed to explore the experiences of bereavement for the Gujarati population in the UK. It is anticipated that this study adds to the limited literature available on

understanding the bereavement experiences of those from a SA background. This research helps to bridge the gap highlighted in the review by (Mayland et al., 2021); showing the different levels of support this community may need, the format they may require and the understanding of cultural beliefs which are important in the bereavement process. Individuals were from different geographical locations in England, this is a strength as not all areas have a high number of SA individuals. The findings however may need to be interpreted with caution with individuals in SA countries, as values between those that are in England and in another country may differ (e.g. individualistic versus collectivist values).

The sample included twenty individuals from a Gujarati background; eight participants identified as male, and twelve participants identified as female. This gave a balance of perspectives, however it does not take into account different gender identities that may be present across the Gujarati community.

Participants varied in age (22 years old – 65 years old), which allowed a range of bereavement experience to be captured. Particularly highlighting the different views of those considered in the younger generation (0-40 years old) and older generation (40 years old and above), for example differences in expressing emotions and the development of growing older in age and then understanding loss. However, it is important to acknowledge, data is missing from views of those below 22 years and adults above 65 years.

Language within qualitative studies is an important factor to consider as it represents the data and the process in which the data is generated between participants and researchers (Hennink, 2008). Participants were offered a choice of an interpreter if they preferred to speak in Gujarati. However, they chose not to; this made sure that the data was representative of what they wanted to communicate, this is important as sometimes language can be misinterpreted.

Within this study, some individuals reflected on socioeconomic status and that being an impact to accessing support. As this was not a focus of this study, it would be helpful for future research to

explore how socioeconomic status may impact the ability to seek support (Department of Health, 2009).

It is important to consider the relation to the individual who passed away and the impact this can have on bereavement. Research shows that relationships to those who have passed away which have been close, supportive and a dependent figure in their life are likely to have an increased risk of grief symptoms (Lobb et al., 2010). Symptoms are grief are described to include chronic separation distress, longing to search for the loss of a loved one, loneliness, symptoms of traumatic distress such as disbelief, anger, shock and mistrust of others and somatic symptoms (Lobb et al., 2010). More than half the participant's experiences of loss were of a parent, and they all showed to have grief symptoms such a loneliness, longing to search for the loss of a loved one and disbelief and anger. The loss of a sibling was shown to be associated with less meaning/purpose in life and complicated grief in comparison to losing a friend (Herberman et al., 2013), as well as the participants felt the grief was harder to process than losing an aunt or cousin. It would be helpful for future research to explore bereavement experiences with different relations in family (e.g. cousin or aunt) to further understand differences or similarities.

Most of the losses were also sudden due to health conditions which also could have impacted the experience differently to an experience of loss that an individual may be prepared for. This could also be further explored in research to see similarities and differences on sudden versus prepared loss. Duration of loss in this sample was most commonly over 10 years which highlights the length of time it can take to process a bereavement and the difficulties an individual may be struggling with since the loss of their loved one.

By taking a broader inclusive response to experiences of bereavement, it allowed for differences and similarities to be highlighted of experience of bereavement within this population. Context of death and relationship to the loved one who passed, did show to have a difference in experiences of grieving such as the emotions experienced (e.g. blame, anger) and the lack of purpose in life which

was felt and duration in grieving. Similarities of bereavement experience across the participants were the stigma experienced of speaking about their mental health, cultural expectations to follow when a loss occurs, and barriers to support.

5.7 Future Research Considerations

Future research considerations for the current study are outlined in Table 15.

Table 15

Research considerations

Finding out from services that offer	**Future research consideration**	**How can it be done:**
	Research with faith leaders	Clarify the differences between rituals related to religion and rituals related to culture. Hold focus groups with faith leaders and community members on bereavement experiences.
	Understanding the role of conformity	Understanding how conformity plays a role and what stops individuals from asking questions would be helpful so that individuals can be provided with support to feel empowered to question and voice their feelings if they do not agree.
	Participatory action research, (PAR: Baum et al., 2006)	This research could be conducted by allowing participants to actively voice their views on the research that concerns their reality, empowering them to own their stories, and making changes they wish to see. Including individuals with lived experience in the research can help create social change by reshaping knowledge of how social, political, economic, and familial contexts are understood (Macdonald, 2012).
bereavement support how many individuals from a Gujarati population attend support It would be helpful to understand if individuals from		the Gujarati community are accessing services and what services can do to promote accessibility. If individuals are attending, it would be helpful to find out if the interventions being offered are helpful and effective; if not, it would be helpful to understand what a helpful intervention could be, which includes cultural sensitivity and understanding.
Further research with other subgroups within the South Asian population This study focused solely on individuals from a Gujarati background. If possible,		research should be conducted amongst other Indian or South-Asian groups (e.g., Bangladeshi or Nepalese communities) to notice the similarities and differences in bereavement experiences and further understand how an intervention can be applied across this group of individuals.
Cultural Humility		Many participants spoke of wanting more South-Asian therapists to be able to help provide support. However, with limited resources and a lack of therapists from a South Asian background, this can be difficult to provide. To help reduce the power imbalance between provider and service user, it would be helpful for all professionals from all backgrounds to think about building trust first and rapport. It would be helpful for professionals to go into temples and think about how we can work together and work with faith leaders rather than an approach of doing to them. It would be helpful for professionals to acknowledge in their work with individuals from a Gujarati background that models currently on bereavement are more suited to Western ideas and will not capture cultural nuances. It is also important to consider individual characteristics that may be at play, for example, sexual orientation, class and gender, which can impact how an individual from a Gujarati background experiences the loss of a loved one.

5.8 Research reflexivity

Being an 'insider-outsider' researcher allowed me to be sensitive to exploring the experiences of bereavement with individuals from a Gujarati background. Being an 'insider' means having a greater understanding of the culture being explored (Pugh et al., 2000; Reed & Proctor, 1995; Tom-Orme, 1991). I have explored this project with the knowledge that I have acquired growing up within the Gujarati community. I am aware of the cultural nuances that may be highlighted, and how both stigma and shame can play a role with individuals coming forward to share their experiences. To be able to provide a space where participants felt safe and comfortable, I used pseudonyms to ensure confidentiality and scheduled interviews at a time when participants felt they could openly share their experiences with privacy. I acknowledged with participants that I was from a Gujarati background to make sure I was being transparent, and I offered reassurance of confidentiality.

Personal bereavement experiences can be difficult to speak about especially when speaking to strangers. Research suggests being an 'insider' researcher can help to build a rapport with participants (Gerrish, 1997; Kennedy, 1999; Platzer & James, 1997). Being an 'insider' allowed the participants to feel comfortable to speak openly about their experiences without fearing judgment, as I was able to be sensitive and empathetic towards participants when they explained the impact of cultural customs and expectations. Although my experiences of bereavement would be different to theirs, being from the same cultural background allowed familiarity which helped to build a rapport between me and the participant; this may have been different if the researcher was an 'outsider'. It is important to acknowledge that being an 'insider' has limitations, such as over-familiarisation, which can lead researchers to make judgments based on their views of the subjects rather than gaining objectivity of what has been said (Gerrish, 197). I did acknowledge myself at times during the interviews, assuming I knew what the ritual or custom was. I realised by asking the participants what the ritual or custom meant to them that sometimes there was a different understanding to my own. I

made sure to ask participants what the custom or ritual was, to make sure I got their account, limiting bias.

During the analysis of the results, I noticed I was assuming what something meant because of my experiences with bereavement and the community. To reduce the bias, I used bracketing, which helped me approach the interviews from a nonjudgmental stance. Through this method, I attempted to separate my direct experience of bereavement and be open to new information about individuals' experiences (Brinkmann & Kvale, 2015). I acknowledged that I held multiple hats such as being a researcher, being an individual who has experienced a bereavement and being an individual who identifies from the same community. By thinking through a lens of critical realism, I was able to promote objectivity and realise that there are multiple truths about how bereavement can be experienced. The findings were shared with supervisors, doctoral colleagues, and consultants at SLOW to maintain a stance of being critical of the interpretation of findings, which helped enhance the credibility (Lincoln & Guba, 1985).

6.0 Dissemination

This research will aim to be shared in the following ways outlined below, which was discussed with supervisors, consultants and participant in Table 16.

Table 16

Outline of dissemination ideas

Dissemination ideas
1) Research will be written up for publication. Conversation with participants who expressed wanting to stay involved will be asked if they would still like to be and resources can be codeveloped.
2) Presented at Life of Medical Science's 2024 research conference at the University of Hertfordshire.

3) The Results will be summarised, and a poster will be created to be shared on different platforms (e.g., community forums, Facebook) in both English and Gujarati.

4) Presentation to be made and shared orally at temples, community centres, and thirdsector organisations that work with individuals who have experienced a loss (e.g. SLOW and CRUSE). An interpreter who can speak Gujarati will also be involved to help translate the information.

5) Share findings with professionals as a first step to start thinking about how interventions can be tailored to be culturally sensitive and take into account the varied cultural nuances.

6) Look into NIHR additional funding opportunities to think about further research that can help support individuals from this population with bereavement experiences.

6.1 Conclusions

It is important to understand how individuals from different ethnic groups grieve so adequate support can be offered and services can be improved in the UK (Mayland et al., 2021). There is a significant need for services to become culturally competent, to consider how to approach ethnic groups, and to offer support that is sensitive to their cultural needs (Selman et al., 2022). The present study has highlighted the experiences of bereavement from those of a Gujarati background and sheds light on the barriers to accessing services. Implications have been made of what services, charities and organisations can do to help promote support for this population to improve wellbeing.

NIHR have mentioned the importance of promoting a voice for those underrepresented in research (NIHR, 2021); this thesis starts to add to knowledge about the Gujarati population, which has limited research. It is hoped that this research starts to bridge the gap of inequities in who receives formal bereavement support by identifying the barriers and raising awareness of bereavement experiences for this population.

6.2 Final reflections

While working with SLOW for my small-scale project to evaluate the service during the COVID-19 pandemic, I was struck by how many individuals from a SA background were involved in the research.

From my personal experiences of bereavement and those close to me who have experienced bereavement and shared their experiences with me, I knew there could be a lot more people seeking support.

During this research I have felt sadness and anger during interviews with hearing accounts of how they have experienced a bereavement and support they have been offered. I hope individuals felt they had a space where they could share openly how they felt and maybe even promoted them to think about having a space to speak about how they feel and get support. I'm left with thinking there is still a lot to do for movement to take place with improving support for this population with bereavement and I hope to disseminate the finding from this study in a way which will create action.

I have valued the opportunity to be able to explore this research topic in depth and it has transformed me as a person. I have gained insight into how views can be also very different from my own with cultural and religious beliefs and learnt to appreciate differences, it has made me more aware of the subtle cultural nuances I did not acknowledge.

This study has motivated me to advocate for individuals from ethnic groups who may not always get opportunities in research and to promote change. I hope to present the findings of this research in an appropriate and sensitive way and encourage reflections from service providers and the community so that we can create change.

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Appendix

Appendix 1 –

Interview schedule

Draft of interview schedule

Interview Schedule

Participant Psuedo name	**Date of interview:**
Points for framing interview:	
• **Introduce myself**	
• **Thank you for meeting with me. The aim of this study is to look at experiences of bereavement from a Gujarati background.**	

• **Before we start, I would like to ask you if you consent to being recorded via video and audio/Dictaphone. This is to ensure that I can capture what we talk about today in as much detail as possible which will help me to produce the findings of the research.**	
• **Everything we talk about today will only be used for the purposes of the research. In the write up of this study, your personal details will be anonymised and no one other than myself and my supervisory team will have access to your personal data. All personal data will be saved securely on a password protective drive.**	
• **Do you have any questions, and do you consent to take part and be recorded?**	
• ***Press record***	

• **Thank you for meeting with me. The purpose of this study is to explore your experience of bereavement from a Gujarati background.** • **This interview could take between 60-120 minutes to complete, however that will vary depending on how much you share with me. We can take a break if you need to at any point.** • **Within this interview, we would like you to think of bereavement and reflect on this in relation to the questions that will be asked throughout this interview. Some of these questions may elicit an emotional response, please know you have the choice to not answer if you feel you do not want to. If any of my questions feel uncomfortable or too distressing, please do let me know. You do not have to answer anything that you do not feel comfortable about.** • **Over the course of the interview and thereafter up until two weeks post completion of interview, you have a right to withdraw from the interview at any point and you do not have to give a reason.**	
• **Do you have any questions and are you ready to start?**	

• **We will start with some demographic questions**	• **How old are you?** • **How do you define your gender?** • **What is your work status?** • **What is your education level?** • **What is your relationship status?** • **What is your ethnicity?** • **Do you identify coming from Gujarati background?**
	• **What languages do you speak? E.g. English / Gujarati** • **Would you consider yourself as religious? If so, which religion do you identify with?** • **What country were you born in?** • **What country do you live in now?** • **Have you experienced a bereavement?** • **How many bereavements roughly have you experienced?** • **Have you received support after experiencing a bereavement?** • **Do you feel able to share your experiences in significant detail with me?** • **What area are you from? / where do you live- E.g. crawley** • **Does the area you live in have a Gujarati community and do you think it is helpful?**
Go on to topic questions	

- ***PROMPTS FOR ALL QUESTIONS: Can you say a bit more about that? Can you give me an example of that? Is that the same or different for others do you think?***

Information about bereavement experienced:

Would you please be able to tell me a little about a person you are holding in mind that you did lose? How did you lose them? Where did you lose them? (e.g., UK/India?). What were the circumstances around the loss?

Overview of Bereavement and mental health

- What does bereavement mean to you?

- How easy has it been to speak about bereavement? Is there any factors you feel make this easier or more difficult?

- Prompts: Community? / Family or friends? Stigma?
- Do you feel bereavement is impacted differently dependent upon gender? E.g. being male? • If participant has lost the person outside UK then ask: if that person had been in the UK, would it have changed how you experienced a bereavement?
- How do you feel Western bereavement may differ to how an individual may bereave in eastern? & do you think that affects grief in any way?

- Before you lost a person and grieved, did you think there was a particular way to grieve?

- Do you think there is only one way to grieve?

- How do you think you should grieve? Do you feel you can grieve freely?
- What is your understanding of mental health?

- Do you feel your MH may have been impacted due to bereavement, if so, how?

- Do you feel there are barriers to access services as an individual coming from a Hindu Gujarati background?

- Do you feel like MH services could be doing something to help? What would be useful?

Religion

- Are you religious?

- How does an individual from a Gujarati background go through bereavement if religious? Do you feel this is helpful in processing a bereavement?

- Are the ceremonies a helpful way to grieve?

- If not religious, what have you found helpful?

Social and coping

- Has bereavement impacted you emotionally? If so, how?

- How has bereavement impacted you relationally?

- Has anyone been particularly helpful when experiencing a bereavement? How has relationship within family been?

- Have you attended any support /counselling groups/ hospices? If not why? If so, what did you find helpful?

- Did you receive any support information sheets?

- Has any services been particularly helpful? If so what has helped it feel accessible?

- Do you feel services are culturally aware of your background and practises?

Practical difficulties

- How has bereavement impacted you practically?

- Are there any activities that have been easier to complete / harder to complete following bereavement? E.g., going to work, continuing with hobbies

- Have you experienced any financial difficulties? If so, how have you been supported? Is there any other support you would have liked?

Ending:

- *Share debrief information*
- *Check in: Do I feel concerned about anyone in the group or anything that came from the discussion today*

Appendix 2 - Poster for recruitment

Volunteers needed!!!

A QUALITATIVE EXPLORATION OF THE EXPERIENCE OF BEREAVEMENT AMONGST GUJARATIS IN THE SOUTH ASIAN COMMUNITY.

This research will be looking into how bereavement is experienced, the barriers that may be faced and how services can be improved to become more culturally aware.

Who can take part?

- Have a Gujarati background & living within the UK
- 18 years old +
- Open to different generations
- Experienced a bereavement at any point in their life
- Speak Gujarati and/or English
- Able to share experiences in significant detail with me

What does it involve?

1:1 face-to-face or online interviews sharing your experience with me.

If you would like to take part in this study, please contact: Shivani Patel on s.patel59@herts.ac.uk

This study has received ethical approval from the University of Hertfordshire Ethical Committee.
Protocol Number: LMS/PGR/UH/05419

University of Hertfordshire UH Ethics Committee

Appendix 3 – Ethical Approval

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO **Shivani Patel**

CC **Professor Daksha Trivedi**

FROM **Dr Simon Trainis, Health, Science, Engineering and Technology ECDA Chair**

DATE **22/08/2023**

Protocol number: LMS/PGR/UH/05419

Title of study: A qualitative exploration of the experience of bereavement amongst Gujaratis in the South Asian community.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Bina Sharma – Secondary supervisor

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Appendix 4 – Participant information sheet

PARTICIPANT INFORMATION SHEET

Project title: A qualitative exploration of the experience of bereavement amongst Gujaratis in the South Asian community.

Shivani Patel, Trainee Clinical Psychologist: Email: s.patel59@herts.ac.uk

Research Supervisors: Professor Daksha Trivedi, Email: d.trivedi@herts.ac.uk and Dr Bina Sharma, Email: bina.sharma@nhs.net

We would like to invite you to take part in a research study about understanding your experience of bereavement. Before you decide whether you would like to take part, we would like you to understand the purpose of the research and what it would involve for you. Please do talk to other people about the research or please feel free to contact us if there is anything that is unclear or if you have further questions. If you are happy to take part you will be asked to sign the consent form online.

What is the research about?

This research is being undertaken as part of a doctoral qualification in Clinical Psychology at the University of Hertfordshire.

There is a lack of evidence for bereavement care for ethnic minority populations who are less likely to access bereavement services. This could be due to services not being able to meet the specific needs of communities and not being culturally aware or sensitive. Therefore, we would like to understand the experience of bereavement from individuals who identify as South Asian Gujarati and understand what would be helpful ways to support.

Within the research, all identifiable data i.e. names, and addresses will be removed before being looked over and analysed by the research team. A pseudonym will be allocated to you by the researcher to protect your anonymity.

Why have I been asked to take part?

You will have heard about the study through your local organisation or word of mouth. You have been invited because you showed interested in volunteering, we are

inviting individuals who identify from a South Asian Gujarati background to share their experience of bereavement and support from services.

Do I have to take part?

No, it is entirely your decision whether you want to take part or not. If you decide to take part you will need to provide consent by filling in the consent form to show you have agreed to take part. You do not need to take part just because the organisation advertised this opportunity to you on their social media or website or because other people you know have spoken to you about it.

What will happen to me if I take part?

If you decide to take part in this study, you will be sent an information sheet in the first instance. If you agree to take part, you will then be invited for an interview which will be one-to-one unless an interpreter is needed.

The interview will last about 60 - 90 minutes and will take place online on Zoom by the researcher, however if it is difficult to access a computer a face-to-face meeting can possibly be arranged at the organisation/community space. At the beginning, it will include obtaining consent from you to take part in the study and then a collection of demographic details. After this is collected, the interview around the study will then begin.

If you would prefer to speak in Gujarati and English is not your first language an interpreter will be provided. This is optional. If you feel you do not want an interpreter present at any point or are uncomfortable then we will be happy to stop the interpreter. If you decide to have an interpreter present, the interview may go up to 90mins to make sure there is enough time to hear your view through the interpreter.

Are there any benefits in taking part?

By taking part, you will have the opportunity to share and reflect upon your experiences of support you have or have not received with bereavement and have a say in how services can be improved to provide support.

Are there any risks involved?

Although not the purpose of the interview, you may find that some discussion could be upsetting, for example, if you decide to share a personal experience. The researcher will support you during the interview if there is anything that you find upsetting. You will also be offered a debrief pack providing information about services and or resources in the community that may be of help.

What data will be collected?

Interviews will be collected via Zoom. The interview will be audio-recorded. Within the interview demographic survey will be collected and will be kept strictly confidential. Personal data will be handled securely during collection, analysis, storage and transfer. It will be password protected.

Will my participation be confidential?

The information collected in this study about you will be kept strictly confidential. Only members of the study team may be given access to data about you for monitoring purposes to ensure the research is following university regulations.

To protect your anonymity, you will be allocated a pseudonym within the interview by the researcher. We will not use your real name to protect your anonymity.

In the reports and publications, quotes will be used from the interviews to illustrate points being made.

Audio-recording and all information from the interview will be stored securely. The interview will be transcribed by myself, the main researcher and or a transcription service. For this I will follow ethical practices and all information about you will be handled in confidence. The transcription service will be a separate organisation to the interpreter service which will ensure anonymity.

What you say to the researcher is confidential, however, should you disclose anything which makes us worry about your safety or the safety of others, the researcher may feel it is necessary to share this with one of our supervisors. If this is the case, the researcher may need to ask you for further personal details. If this is the case, the researcher will of course discuss this with you as well as signposting you for support.

What happens if I change my mind?

Taking part is optional and you are free to withdraw without giving us a reason or your participation rights being affected. If you wish to withdraw please do let us know. You will be able to withdraw your data up to two weeks post interview, after this it will not be possible due to the nature of analysis.

What will happen to the results of the research?

Original recorded data from the interviews will be stored up till end of September 2024 and data will be anonymised and stored on OneDrive securely.

The study will be written up as part of our university work and we intend to submit it for publication in a peer-reviewed journal. A summary will also be shared to organisations and charities involved as well as other services that support with bereavement.

Research findings made available in any publications and or reports will not include information that can be directly identifiable without your consent. The results will be kept up to 10 years if there are any other secondary findings within this study so they can be analysed and written up.

Where can I get more information?

If you have any questions or would like to know more about the study, please do feel free to get in touch.

Details of the research team are provided here: Research leads:

Name: Shivani Patel, Email: s.patel59@herts.ac.uk

Research Supervisor – Professor Daksha Trivedi, Email: d.trivedi@herts.ac.uk and Dr Bina Sharma, Email: bina.sharma@nhs.net

What happens if there is a problem?

If you have any concerns about any aspect of the study, please do get in touch with the research supervisors: Prof Daksha Trivedi and Dr Bina Sharma

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

This study has received ethical approval from the University of Hertfordshire Ethical Committee.

Protocol number: LMS/PGR/UH/05419

Appendix 5 – Informed consent sheet

Consent form

- Please circle or highlight your response and sign the form send this form back to me.

I confirm that I have read and understood the information sheet for the study and have the opportunity to ask any questions I may have.

- Yes
- No

I feel comfortable to share my experiences around bereavement to the researcher.

- Yes •
  No

I understand that my participation is voluntary and that I am free to withdraw from participating at any time, without giving any reason, up until post two-week completion of interview.

- Yes
- No

I consent for my participation in the interview to be recorded (audio and visual) to aid transcription. These recordings will be stored on a password protected device and only the immediate study team will have access to them. The data will be stored up until all analysis, write up and submission of report is completed and if there is further exploration of findings to suggest another report (no longer than 10 years post interview).

- Yes
- No

I give consent for data to be used in secondary research if opportunity arises.

- Yes
- No

I understand that I can withdraw my data within up to two weeks post completion of the interview, however after this it will not be possible due to the nature of the analysis of this research.

- Yes
- No

I understand that the anonymised data collected in the study may be looked at by authorised individuals from the University of Hertfordshire, the research group and regulatory authorities where it is relevant to my taking part in this study. I give my permission to these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in the study.

- Yes
- No

I understand that a pseudonym name will be allocated to me by the researcher and will be used by the research team. I understand they will also allocate a pseudonym for any individual I may speak about in relation to experience of bereavement (if mentioned during the interview) in order to ensure my contribution is anonymous.

- Yes
- No

Signature of participant……...…Date……

Signature of (principal)
investigator……Date……

SHIVANI PATEL
……

This study has received ethical approval from the University of Hertfordshire Ethical Committee.

Protocol number: LMS/PGR/UH/05419

Appendix 6 - Debrief sheet

Project title: Understanding experiences of bereavement from a South Asian Gujarati community and how meaningful support can be implemented.

Thank you for taking part in this study. We appreciate the time you have given and hope through this study we will gain a better understanding of how individuals from a South Asian Gujarati background experience bereavement and gain a sense of what may be helpful or unhelpful during this time.

If you would like to know more about the study and the findings, please do get in touch.

Please contact us on:
Name: Shivani Patel, Email: s.patel59@herts.ac.uk

Research Supervisors – Professor Daksha Trivedi, Email: d.trivedi@herts.ac.uk and Dr Bina Sharma, Email: bina.sharma@nhs.net

We will be keeping the data anonymised to protect confidentiality.

If after taking part in this study it has left you with any feeling of distress and you feel you may require further support, please contact any of the following below:

- Researchers involved in the study
- Samaritans on 116 123 / NHS – 111
- Your local crisis team
- CRUSE - https://www.cruse.org.uk

Thank you again for your time and support with this project.

Codes

Search Project

Name	Files	References	Created on	Created by	Modified on	Modified by
being present in last m	6	12	06/04/2024 16:24	SP	08/04/2024 21:47	SP
social circumstances	4	6	07/04/2024 21:28	SP	15/04/2024 13:03	SP
Sudden versus not sud	18	33	18/01/2024 08:55	SP	16/04/2024 16:37	SP
Western Vs Eastern pe	19	44	18/01/2024 08:45	SP	16/04/2024 16:36	SP
Culture	1	1	12/04/2024 13:36	SP	14/04/2024 19:42	SP
cultural competence o	15	30	05/04/2024 21:35	SP	12/04/2024 18:17	SP
Cultural facade	6	13	14/04/2024 20:25	SP	15/04/2024 14:43	SP
Cultural pressure	3	4	12/04/2024 21:34	SP	16/04/2024 15:44	SP
Cultural way of proces	20	143	20/01/2024 13:39	SP	16/04/2024 15:47	SP
Decisions being made	8	13	14/04/2024 19:50	SP	16/04/2024 15:46	SP
Impact of cultural prac	4	5	15/04/2024 09:58	SP	15/04/2024 11:43	SP
self awareness	2	3	08/04/2024 10:53	SP	15/04/2024 09:11	SP
Education. lack of underst	18	60	18/01/2024 08:53	SP	15/04/2024 12:40	SP
Funeral like a wedding	4	4	14/04/2024 20:12	SP	15/04/2024 10:02	SP
Gender differences	17	66	18/01/2024 08:43	SP	15/04/2024 12:39	SP
Generational difference	14	54	18/01/2024 08:43	SP	15/04/2024 12:34	SP
ignorance is bliss	3	5	06/04/2024 16:34	SP	14/04/2024 20:27	SP
Judgments	0	0	12/04/2024 18:14	SP	12/04/2024 18:14	SP
judgement of others	6	10	06/04/2024 08:25	SP	15/04/2024 12:35	SP

Appendix 7 – Initial codes NVIVO and example of transcript coded

Codes

Search Project

Name	Files	References	Created on	Created by	Modified on	Modified by
Practical Impact	16	43	18/01/2024 11:46	SP	15/04/2024 08:57	SP
processing loss	15	97	05/04/2024 21:52	SP	16/04/2024 15:45	SP
emotions experienced	15	65	05/04/2024 20:53	SP	15/04/2024 09:07	SP
last wishes being fufill	3	4	08/04/2024 19:03	SP	12/04/2024 20:24	SP
memories being trigge	8	10	06/04/2024 15:27	SP	15/04/2024 09:59	SP
personal characteristic	5	20	07/04/2024 20:30	SP	12/04/2024 17:25	SP
privately dealing with l	12	27	05/04/2024 20:01	SP	16/04/2024 15:39	SP
remembering the love	13	23	06/04/2024 08:41	SP	14/04/2024 20:51	SP
The relationship to the	16	36	26/01/2024 16:24	SP	16/04/2024 15:22	SP
Time	7	12	15/04/2024 08:53	SP	16/04/2024 15:39	SP
ways to grieve	20	52	18/01/2024 11:27	SP	15/04/2024 14:38	SP
Support	4	4	14/04/2024 19:31	SP	15/04/2024 11:53	SP
Social support	19	106	18/01/2024 09:27	SP	16/04/2024 16:37	SP
someone going throu	9	11	05/04/2024 22:32	SP	14/04/2024 20:12	SP
The unknowns	7	19	08/04/2024 19:40	SP	15/04/2024 09:05	SP
People pleasing	6	11	13/04/2024 19:26	SP	14/04/2024 19:35	SP
Questions	6	9	12/04/2024 19:08	SP	16/04/2024 15:48	SP
Traditional roles	7	14	18/01/2024 08:40	SP	16/04/2024 16:37	SP
Understanding of bereave	20	42	18/01/2024 09:50	SP	08/04/2024 21:18	SP

Appendix 8

106
00:10:32.540 --> 00:10:48.760
Raj: I think this, and I know it is within our community. I think it's very difficult to access this, I think. And I am saying that on more of a generic level, because I, personally haven't tried it just because, like I said, I didn't want to. But you know, just talking to other friends and family from similar backgrounds. It is very difficult to have a conversation fully open conversation without being judged about how you feel, or how you see that loss of life or that bereavement because one person might see it completely different to another. And that's just the way it is. That's what makes us different, right? But I think within our community. There's almost that. Oh you know, just toughen up kind of thing, almost indirectly said, just get over it all, you'll forget about it, or let let's distract this person from this, etc. But I think what helps personally is being completely honest and open about it, and actually talking about it on a more regular basis. The more you talk about it the more normal it becomes. But unless you talk about it's almost like, Oh, should I talk about it? So I think that's what helps regardless of who? What? Who the person needs? That the person your grieving. I think just generally talking and accepting, especially within the family, outside help, maybe I suppose. Some people may not want to go there like I didn't but within the family within, suppose our adults, and like I said, how they deal with it is very different to what the younger generation would prefer to deal with. So I think that's the difficult part. And you know now, going through what I've gone through. If a younger person or similar age individual goes through a similar process. I see it very differently. I can almost feel or sense what's going through their head, so I tackle it very differently to how other people tackle it with me.

Shivani Patel: Can you say a little bit more about I guess you spoke to different generations taking it differently and I am wondering what was your experience of the older generations perhaps telling you?

Raj: They just didn't talk about it, they didn't even address it. So from my mum going or being taken to hospital to then me seeing her lying on the death bed. There was no talk. There was no explanation. There was no addressing the situation. It was almost like I was made to feel very dumb. I was kept in the neighbor's house. But I could see everything out the window, but yet nobody saying what's going on, so it's like I knew what had happened, but I needed somebody to spell it out to me. Do you know what I mean? It's like you can see it, but I want somebody to confirm it because you're scared to confirm it yourself. But yeah, that never happened. And then all of a sudden, I'm being told about the news, and within 5 minutes, I'm expected to accept it and to see her, and to say, my goodbyes. So that's a very quick kind of you know… it's too quick to take all of that in. And this is not just anyone else you know, you've got a mum, you're talking about your mum. You've got a lot going through your head. And I think that's what was difficult. And then, even after that, so you know, the days has passed and I suppose I'm trying to process it. Understand it. But yeah, I never really fully got to, because nobody again talked about it

140
00:14:22.090 --> 00:14:32.849
Shivani Patel: So the fact of yeah older generation keeping things quiet, not really speaking to help you understand it, its hard.

141
00:14:33.320 --> 00:14:36.060
Raj: Oh, yeah the later explanation that was given was oh you were too young to understand any of it, but let me make that decision, not you.

Shivani Patel: Yeah so I am hearing all these expectations of you being

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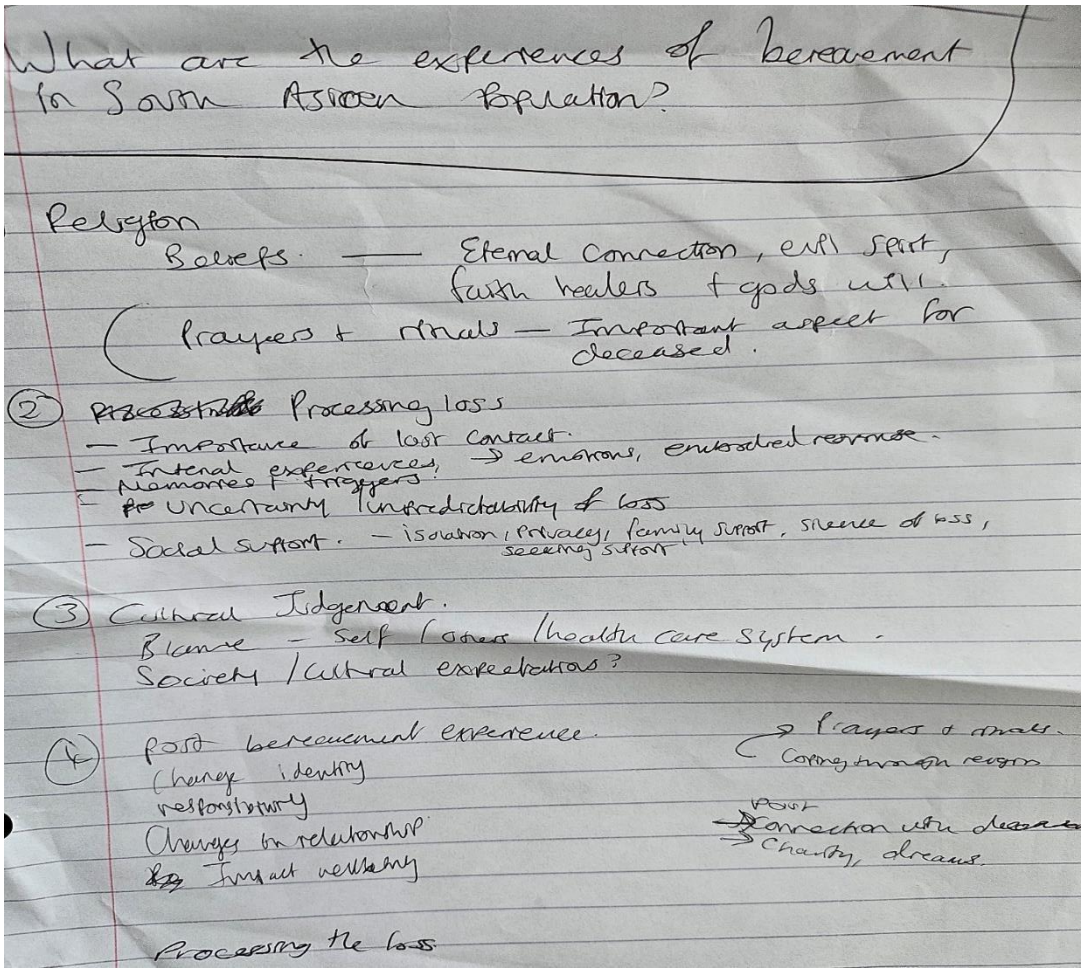
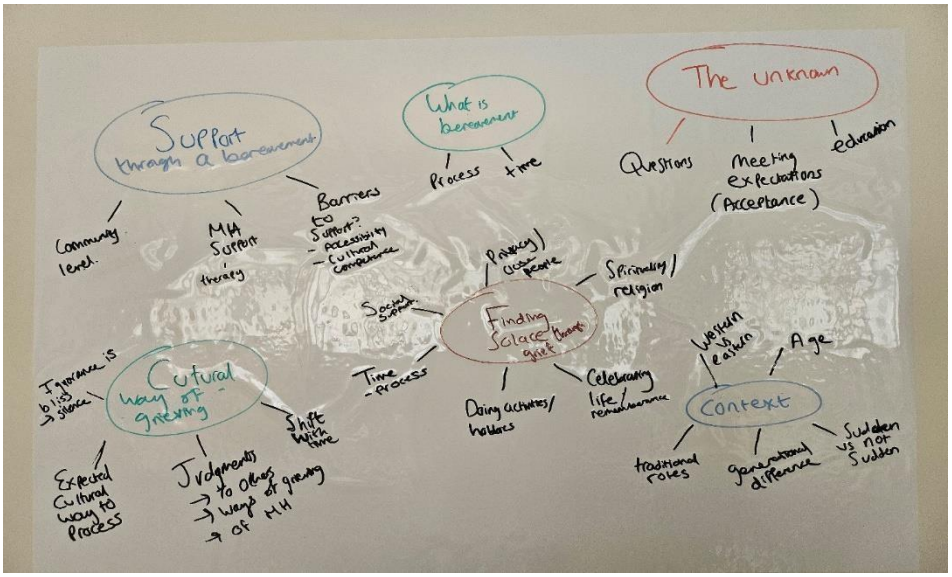
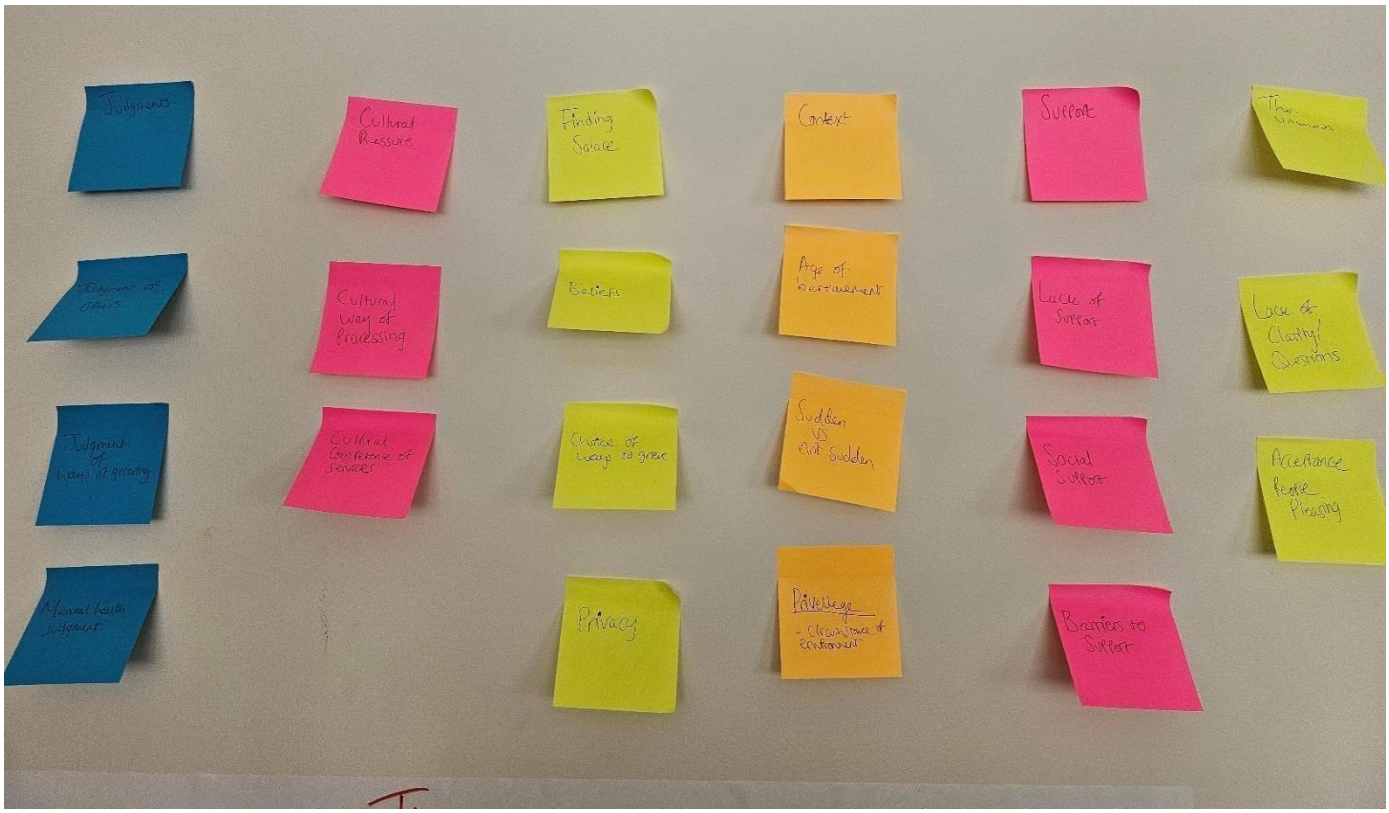
Appendix 8 - Clustering



Appendix 9 – Clustering themes (Mind map)



Appendix 10 Organising themes (Post it notes)



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Appendix 10– Snapshot of table of suggested potential main quotes

Western versus eastern	Alisha: I think it's very different actually. I mean, first of all, the fact that they don't even have to go through the 7 to 9 nights of sitting and rituals, you know. They are allowed to just sort of go through their thoughts on their own. They might have support or family, but just to grieve. So yeah, they're allowed to do that. Whereas, you know, when do we get the time to even do that? Aarti: They just, they don't have like such a long process. It's kind of like when the person passes, the family get together for that one day, and with them I feel like it's more of a celebration of life, whereas with us it's more like, it's not a bad thing as well the way that we deal with it either, but it's more like we will properly grieve them, whereas with them they would appreciate everything that they've done in this life and celebrate it. Whereas with us, it's like you should be crying, you should be doing this, the 12 days, you can't go here, you can't drink alcohol, you can't... it's just a lot of can't, whereas with them, it's very free-flowing like they'll do what the person likes and things like that. Jay: But I just think within the Eastern communities, there's a lot of stuff, that people just don't want to talk about. Whereas, maybe the western community, they're a bit more open about it.

Appendix 11 Table of theme names being considered and reorganised

Examples in red are the changes we considered.

Theme	Sub-themes
Understanding bereavement and process?	**What is bereavement?** **Internal and external ways of processing** **Age – Age and understanding** **Sudden Versus not sudden – Being prepared for a death** **Western versus eastern**
The after math	**Impact on wellbeing and functioning** **Relational changes**
Coping with grief	**Time to self** **Religion and spirituality** **Distraction / Hobbies** **Remembrance and celebrating life**
Cultural influence on grieving	**The expected way to grieve** **Judgments of others** **Ignorance is bliss** **The unknown – why do we do things, tell us why, allow us to ask questions, explain why**
Knowledge and awareness	**Educate us** (why we do things, allow us to question, psychoeducation on MH impact)
Support through a bereavement	**Engage at a community level -** **Barriers faced by our population** (privacy, language, being able to understand culture, money, cultural stigma) **Accessibility** – people that had experience of therapy/ people that mentioned they did not know they could get support **Knowledge and awareness** – education of MH,
Generation and Traditional roles influence	

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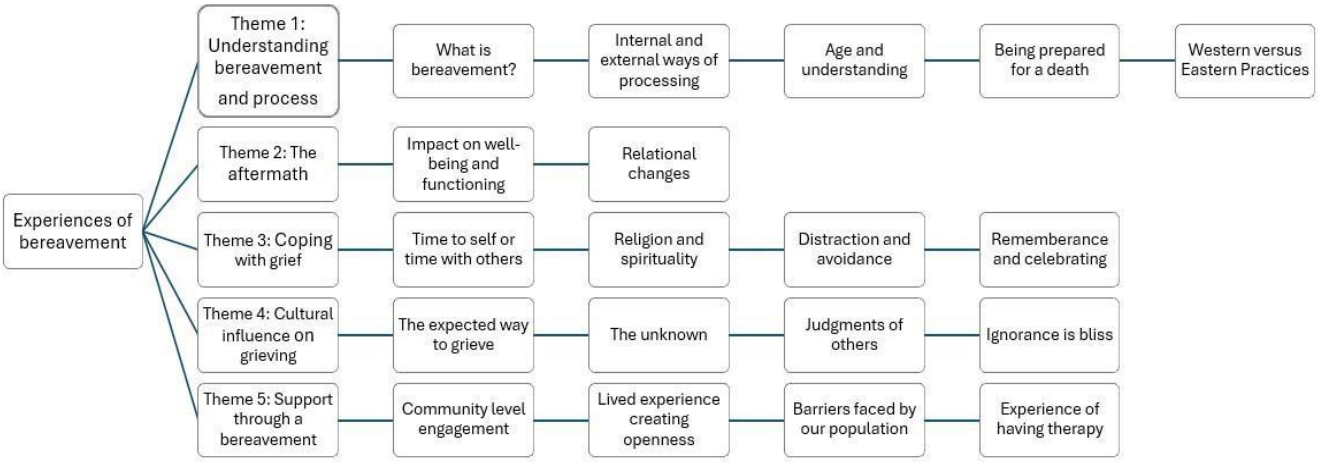
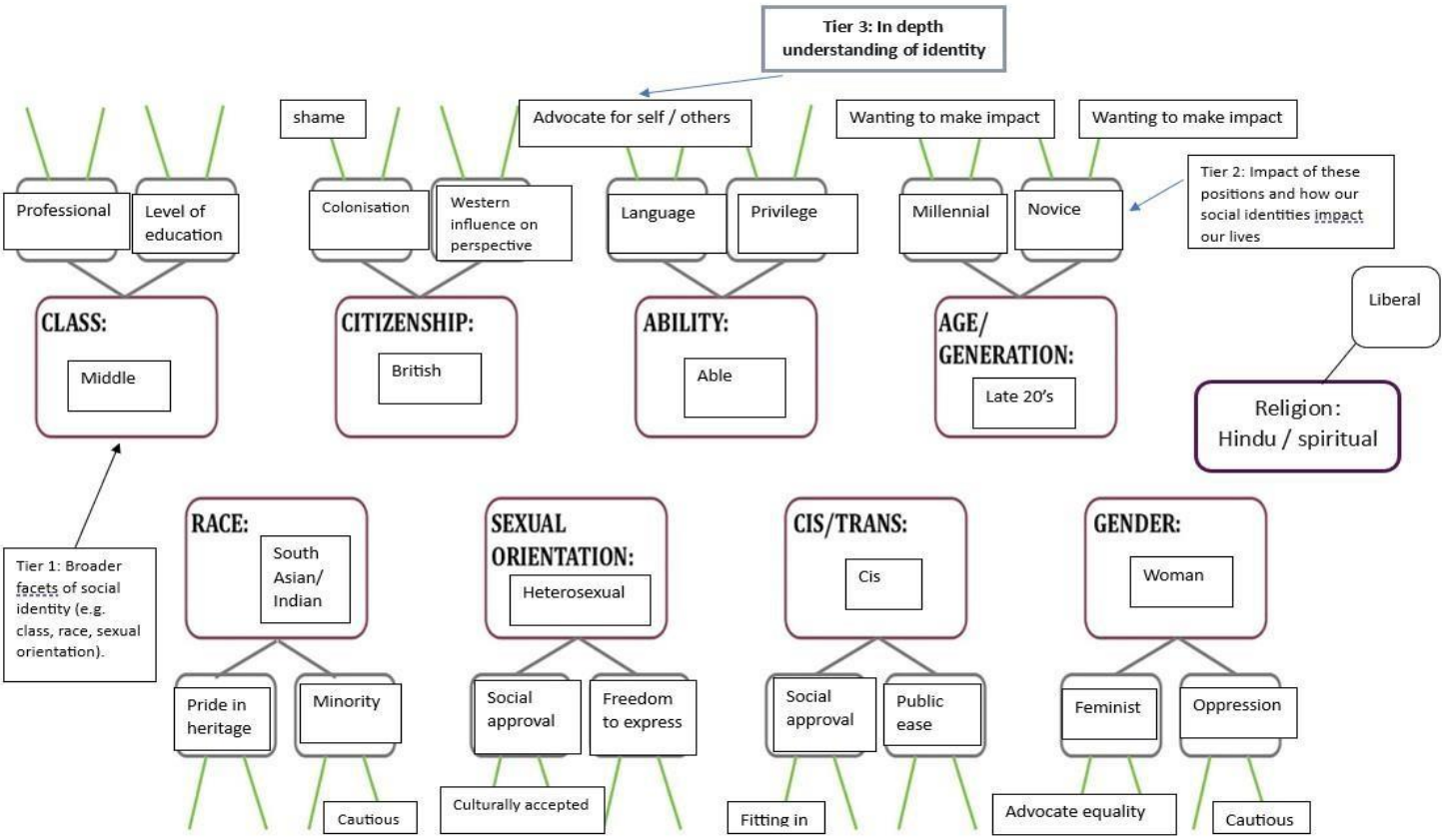
Appendix 12 – Thematic map



Appendix 13 Social Identities map



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Appendix 14 – Excerpts from reflective diary

Reflexive journal excerpts

When showing the codes to my peer, I highlighted the code of people pleasing. I felt the data presented individuals trying to please their family, thus doing certain practises and rituals. She allowed me to reflect on how that linked with perhaps cultural expectations and how this could be experienced as a lack of freedom of choice. We also acknowledged there was data to suggest unknowns of why particular customs or rituals were done and it felt more fitting that it was about not knowing.

I highlighted the code of age being a factor for understanding a bereavement and my view of age being influenced by cultural views (parents making decisions for children on whether they can understand something or not). My peer reflected to me that as a person who identified as White British, in her family age would have also been considered a factor in explaining a loss and protecting from funerals. This made me think about it being more of a universal code than directly under cultural influence.

Appendix 15 – reflections from interviews