Barriers to Access Palliative Care for Ethnic Minorities, Particularly South Asians in the UK: A Systematic review

(Fahad Khan)

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DECLARATION

I declare that this dissertation has been composed by myself, that the work contained herein is entirely my own, except where explicitly stated otherwise in the text, and that this work has not been submitted for any other degree or qualification, in whole or in part, except as specified.

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Date: 25 September 2024…………

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ABSTRACT

Background: SA constitutes the single largest ethnic minority in the UK; however, access to personal computer (PC) services remains a matter of concern. Thus, this dissertation seeks to identify the barriers to accessing palliative care in ethnic minorities, focusing on SA in the UK.

Methods: A systematic literature review was conducted. A literature search was conducted using online databases, including ProQuest, EBSCO, PubMed, and Google Scholar, to gather relevant academic sources. Search terms and keywords were entered into the database to access the relevant articles. After careful screening using the PRISMA tool and a review of the research articles, 14 articles were included in this systematic review.

Results: Thematic analysis of these 14 studies revealed four key themes and sub-themes. It was identified that three factors serve as barriers for the SA population when accessing PC services: acceptability, approachability, and adjustability. Acceptability includes the roles of culture and religion, family and religion, language barriers, and lack of knowledge or awareness. Approachability factors that serve as barriers include socioeconomic factors, racism, and low referral rate. Adjustability includes avoidance and lack of continuity of care. The fourth theme of the systematic review revolved around strategies to improve the acceptability, approachability, and adjustability of the SA population in the UK.

Conclusion: The findings of the study thus underscore the need to make PC more accessible and address the barriers faced by the SA community. It highlighted the differences that exist in accessing PC by different ethnic groups, including the SA community in the UK. Thus, this study calls for immediate actions to be taken by the government and policymakers to achieve equity in care and ensure that SA in the UK, like their White counterparts, can die more comfortably and peacefully.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

SA - South Asians

PC - Palliative Care

BAME - Black, Asian, Mixed, or other Ethnic minority groups

UK - United Kingdom

WHO - World Health Organization

SLR - Systematic Literature Review

CASP - Critical Appraisal Skills Programme

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

NHS - National Health Service

ONS - Office for National Statistics

EOL- End of life

CHAPTER 1: INTRODUCTION AND BACKGROUND

1.1. Introduction

The World Health Organization (WHO) emphasizes the need for culturally appropriate development of Palliative Care (PC) services to meet the needs of the global population (Sepúlveda et al. 2002). Consequently, researchers and practitioners have directed their attention to the removal of barriers to PC, particularly for ethnic minorities and other populations with different cultural and demographic backgrounds (Periyakoil et al. 2016; Nelson et al. 2023; Broom et al. 2013).

The following highlights that gaps in access to PC among ethnic minorities remain a major public health concern in the United Kingdom, as ethnic minorities continue to be locked out from such service delivery. Ethnically, the largest group is South Asian (SA) residents in the UK, who routinely complain about healthcare services in the area (Venkatasalu et al. 2013). Several barriers have been identified in the literature, including those pointed out by Jones et al. (2024) and Hawley (2017) regarding this population's access to PC. Some of the barriers include language, cultural and religious factors, and systematic issues of the health care system.

According to Faull and Blankley (2015), PC can be described as a specialized service geared towards promoting the well-being of patients with terminal diseases regarding their physical, emotional, and spiritual welfare. It is performed through relief of suffering and pain by correct identification, evaluation, and control of the symptoms. A PC is provided by a team of specialists across hospice, hospital, and community care, including employees in general practice (NHS, 2022).

According to a previous study, globally, there are approximately 56. Eight million people require PC every year, but only 14 per cent of these people receive PC. In the UK even with various attempts to enhance the quality of care that patients receive it is projected that one hundred thousand patients who could potentially benefit from PC never get to access such services before they succumb to death (UK Parliament, 2022). This means that ethnic minority groups, especially SA, have a restricted inability to participate in different activities that would enhance their access to healthcare services.

Providing PC is essential because it ensures comprehensive support that improves the quality of life of patients with terminal illness (Radbruch et al. 2020). As mentioned in the WHO (2019) document on "PC" it is the explicitly recognized human right of every individual and must be provided through integrated and person-centred health services. Moreover, PC ensures that patient suffering is significantly reduced through early identification, proper assessment and treatment of painful symptoms, and catering to the mental well-being of patients (Boston, Bruce, and Schreiber, 2011). Additionally, it addresses the practical needs of families/carers and provides bereavement counselling as a way to offer support to grieving members. A study conducted by Temel et al. (2010) also revealed that patients who received PC showed promising outcomes, including improved symptom management, fewer chances of hospitalization, and higher family and patient satisfaction (Temel et al. 2010). The 2021 UK Census has established that the UK has become more ethnically diverse than ever, with almost 18% of the entire population belonging to the Black, Asian, Mixed or other Ethnic (BAME) minority groups (Diversity UK, 2022). The SA population is the largest BAME group, representing 3% of the entire BAME population, which is equal to 141,000 (ONS, 2022).

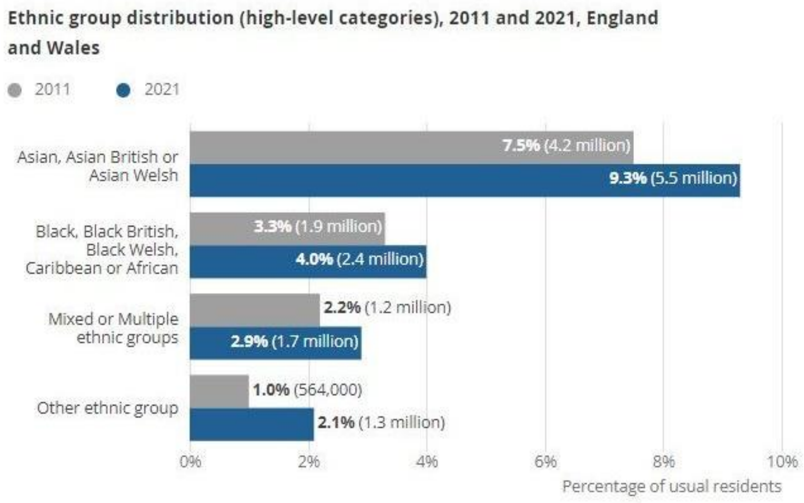


Figure 1 Ethnic group distribution in the UK (Source: ONS, 2021)

According to the London Government (2022), "BAME is an acronym used to define all ethnic groups, except White ethnic groups. It does not relate to country, origin, or affiliation." However, as mentioned previously, the largest BAME group in the UK was the SA population. Despite such a larger population, not much has been done to ensure that this SA cohort receives equitable healthcare services in the UK. Research also supports that SA in the UK faces significant differences in accessing PC services (Johnson et al. 2013). The most common barriers found to be the major reasons for the lower engagement of the SA community with PC include socio-demographic characteristics, health literacy, cultural values, religion or spirituality, negative experiences with the healthcare system, and cultural values (Hong et al. 2018). Similarly, Mohammed et al. (2017) also suggested that among certain minority ethnic communities, such as SA, people tend to care for their family members longer than any other community because of the implied moral duty or sense of responsibility. Ventakalasu et al. (2013) explained that those who identify as members of the SA ethnic group feel that they have an ethical or moral duty to care for and respond to the needs of the deceased, which contradicts their beliefs. It is critical to address these disparities and improve public literacy (Kings College London 2024).

This research seeks to understand and address these barriers through a qualitative systematic review that incorporates the viewpoints of SA, their families, and healthcare providers. This research also focuses on inequalities in the healthcare system in the UK and barriers such as language, culture, and socioeconomic factors that make access difficult for these minorities. Murray et al. (2015) suggest that understanding and addressing these language, culture, and socioeconomic barriers is essential for improving access to PC services and enhancing the quality of life for all irrespective of their characteristics.

1.2. Background and Current Context

1.2.1. Ethnic Minorities

Aker et al. (2023) define the term ethnic minorities as “a group of individuals within a community which has different cultural or national traditions from the main population. As mentioned above, the UK is home to approximately 18% of ethnic minorities. However, this research focuses on SA in the UK and the barriers they encounter when accessing PC. “SA trace their origins to South Asia or the Indian subcontinent, which can include Bangladesh, Pakistan, India, Nepal, Afghanistan, and other states” (Bose and Jalal, 2022). According to the estimates presented by the Minority Rights Group (2022), there are 1.41 million Indians, 1.12 million Pakistanis, 447,201 Bangladeshis, and other Asians. Another estimate by the Government of the UK (2024) presents a cumulative figure of 5 million SA in the UK.

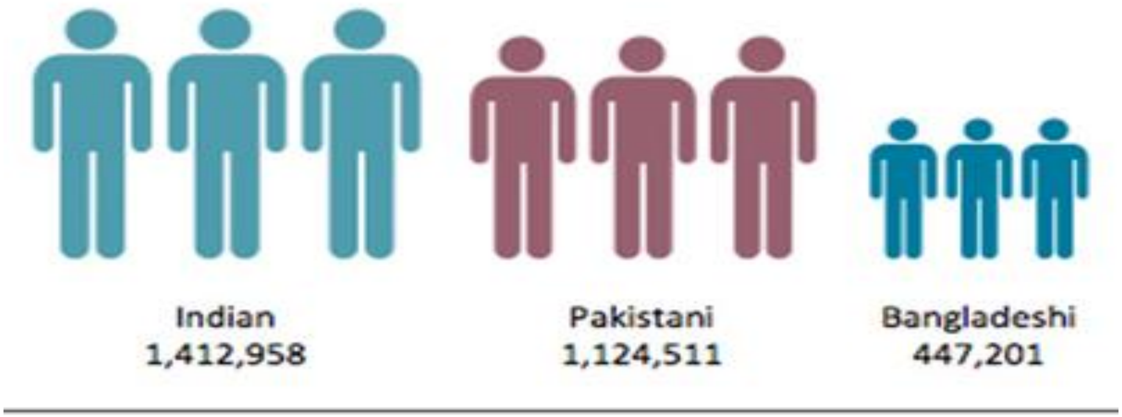


Figure 2 Population of the SA in the UK (Source: Minority Rights Group UK, 2022)

1.2.2. Palliative Care

The most common definition of PC, as provided by the World Health Organization (2020), is that it is an organized health service that seeks to improve the quality of life of patients and decrease their suffering. The commonly used methods for providing PC are timely and quick detection of symptoms and effective management (Teoli et al., 2019). This duty of managing symptoms is fulfilled by the interprofessional team, comprising nurses, doctors, social workers, chaplains, and psychologists. This inter-professional team manages the physical, psychological, and spiritual needs of patients with terminal or life-limiting diseases (NHS, 2022). Brighton and Bristowe (2016) also support that PC must be patient-centred and should not be limited to the patient but must also focus on the needs of the families/carers and be considerate of their sufferings and burdens.

However, PC is not readily available to the entire population. SA in the UK continues to struggle to access specialized healthcare services for several reasons. Hawley (2017) cited language barriers, cultural values, education, geography, and sociodemographic characteristics that limit or prevent the access of the SA community to quality end-of-life care. This decreased access to PC services for SA patients can result in increased suffering due to unmanaged symptoms, untreated pain, and psychological distress (Greenwood et al. 2015). Moreover, it can also lead to increased use of emergency rooms, intensive care services, and hospital admissions, ultimately increasing healthcare costs. Furthermore, it also increases ethical dilemmas for family members/caregivers between pursuing aggressive and invasive treatment and focusing on quality of life and comfort (Murray et al. 2015).

1.2.3. Barriers to Accessing Palliative Care

Research has highlighted the multiple barriers that SA in the UK face when accessing PC services. These barriers are categorized into cultural and religious, language, and systemic challenges.

Cultural and Religious Challenges

Jones et al. (2021) found that cultural practices and beliefs upheld by the SA community prevented them from receiving end-of-life care. Religious beliefs significantly influence decisions on pain management, hospice utilization, and withdrawal of life-sustaining treatments. In addition, end-of-life care is a taboo topic under certain religions, which hinders open discussion of these topics (Williams and Johnson, 2010). A majority of SA, particularly those with limited education, prefer traditional medicine over Western medical services, thus further hindering PC services (Koffman et al., 2014).

Language Challenges

Differences in language serve as a significant obstacle for SA in the UK because they are not able to communicate their medical information to care providers. According to the Office for National Statistics (2022), there are approximately 291,000 individuals whose main language is Punjabi, 270,000 speak Urdu, 199,000 speak Bengali, and 189,000 speak Gujarati. Similarly, care providers are unable to understand the information communicated to them, creating a significant communication gap, thus affecting informed decision-making and understanding of treatment options for people of SA ethnicity (Jadhav et al., 2020). Not having a representative of this language group within the PC service makes it difficult for the SA community to access the service and communicate its needs to health professionals.

Systemic Barriers:

Systemic issues, including institutional racism, inequalities in the access and delivery of healthcare services, lack of cultural representation in PC services, and socioeconomic disadvantages are also significant barriers to SA (Johnson, 2013). In addition, discriminatory attitudes, unconscious bias, and culturally insensitive practices decrease the willingness of ethnic minorities, particularly SA, to access PC services. Similarly, Bowers et al. (2022) suggested that the economic position of individuals belonging to the SA community also makes it difficult for them to access the necessary care for their terminal illnesses. Consequently, many people belonging to the SA ethnicity are forced to work in lower professions; thus, they do not earn enough to pay for such specialized services.

1.3. The Current Context of Palliative Care Access for Ethnic Minorities in the UK

The continued emphasis on equality and justice in the field of medical science has led to the acknowledgement of access problems faced by the SA community in the UK. Additionally, recent research on the topic also highlighted the common disparities that people of SA ethnicity in the UK face regularly. For example, a study conducted by Evans et al. (2021) revealed that SA patients are less likely to receive a referral to a PC service by care providers as compared to the white population. This disparity exists because most healthcare providers do not understand the cultural needs of this population and may misinterpret their needs because of language barriers. Often this lack of referral or delayed referrals to PC results in poor healthcare outcomes and less effective symptom management (Shabnam et al., 2020). Similarly, Hossain et al. (2022) found that ethnic minorities, including SA, in PC settings report high levels of unmet needs. These unmet needs include inadequate pain management, insufficient emotional support, and a lack of culturally appropriate care. This highlights the need for a tailored PC service for minority groups, including SA.

1.4. Rationale or Problem Statement

Disparities in access to PC for SA in the UK have become a public health concern (Barnato et al., 2009). Evans et al. (2021) also supported that ethnic SA despite their large population size are the most underrepresented population in PC services. They are also those whose needs are most frequently ignored due to language barriers and a lack of culturally appropriate care. Recent research on the topic has highlighted language, systemic barriers, and cultural and religious factors responsible for the underrepresentation of this subgroup. However, there remains a lack of comprehensive studies that fully explore the challenges and issues faced by SA from their perspective and that of their families and healthcare providers (Age, 2021). This lack of understanding makes it difficult to develop effective strategies that address these barriers and ensure that every member of the population receives quality PC. Gardner et al. (2018) suggested that this knowledge gap gives rise to health inequalities and challenges justice and the principle of fairness within society.

1.5. Research question

What are the different barriers and their role in accessing palliative care for ethnic minorities, particularly South Asians, in the UK?

1.6. Research Aim

This research aims to conduct a comprehensive systematic literature review to identify and determine the barriers and their role in limiting access to palliative care among South Asian (SA) ethnic minorities in the UK. It also seeks to address gaps in existing evidence and provide recommendations to improve healthcare equity and outcomes for these populations.

1.7. Research Objectives

The primary objective of this research is to explore and analyse the barriers that ethnic minorities face in accessing palliative care in the UK. This study aims to:

1. To explore and evaluate the barriers that limit access to palliative care among South Asians in the UK, including language barriers, cultural and religious differences, and socioeconomic challenges.

2. Analyse how family factors, cultural factors, and spirituality affect the decision-making process related to PC in the SA population.

3. This study provides evidence to fill the gap in current knowledge and provides recommendations for policy and practice changes to improve PC access for the SA population.

4. To provide evidence-based strategies aimed at overcoming these barriers, improving healthcare accessibility, and enhancing equity in palliative care for South Asian ethnic minorities in the UK.

1.8. Summary

Receiving end-of-life care is an explicit right for every person and offers significant advantages to people with terminal or life-limiting illnesses. Despite this, ethnic minorities, including the SA community, face several barriers to accessing PC in the UK, such as language, cultural and religious, and systemic challenges. Thus, this study seeks to understand these challenges from the viewpoint of the minority population, focusing on SA, their families, and healthcare providers, and recommends strategies to address and mitigate these challenges. The literature on this topic is discussed further in Chapter 2.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents an overview of the existing literature on the topic "How do barriers faced by SA in the UK affect their access to PC services?" to provide background and context for the research being conducted. The search terms and keywords used in the search are listed in Table 2. This helped the researcher understand the research that had already been conducted on the topic and the existing literature gaps that needed to be filled. Randolph (2019) also added that literature reviews help readers understand the relevance of research and where it fits in the current body of knowledge.

This chapter explains the role of ethnicity in limiting access to PC among SA in the UK. It is then followed by an exploration of the variety of challenges or barriers that limit minority ethnic communities, particularly SA, from accessing PC services in the UK. This chapter also presents a summary statement on the gaps identified in the existing body of knowledge and how this study seeks to fill them.

2.2 Ethnicity and Palliative Care in the UK

Several studies have highlighted inequalities in the provision and delivery of PC for those belonging to minority ethnic communities (Bajwah et al., 2021; LoPresti et al., 2016; Ornstein et al., 2020). However, these ethnic minorities are more likely to experience poor health than their white counterparts in the UK (Raleigh, 2023). This highlights the failure of the healthcare system in the UK to fulfil the delivery of equitable healthcare services, including PC, to ethnic minorities such as SA. In comparison, researchers such as Smith and Brawley (2014) and Walshe et al. (2009) often attribute this unequal access to be a product of cultural or religious characteristics rather than systemic errors in UK healthcare. Regardless of the probable cause, there is consensus that certain ethnic minorities in the UK, including SA, do not have equal access to PC services.

The report presented by Calanzani, Koffman, and Higginson (2013) on "Palliative and End-of-Life care for BAME in the UK" revealed that cultural and ethnic differences influence patterns of illness experiences, healthcare-seeking behaviour, and the utilization of healthcare services in the UK. Venkatasalu, Arthur, and Seymour (2013) found that SA are among the ethnic groups that report the lowest uptake of palliative or end-of-life care services in the UK because of a lack of awareness, lack of referrals, lack of information, negative experiences with healthcare services, structural racism, and conflicting ideas or views about hospice care. Despite this, Clarke et al. (2021) argued that the extent to which SA has been ignored in the provision of equitable PC cannot be determined because research on PC has not traditionally engaged with problems such as ethnicity, race, and racism. However, Evans et al. (2012) proposed that there is a proven under-use of end-of-life or PC services among ethnic minorities, such as SA.

A study conducted by Wilkinson et al. (2014) to understand how ethnicity impacts PC services utilisation in the UK revealed that ethnicity significantly influences the experiences and outcomes of SA patients when accessing PC services. They further elaborated that cultural beliefs, norms, and practices contribute to how certain ethnic groups, including SA, perceive and utilize PC services. Venkatasalu et al. (2014) also supported that SA culture is characterised by deeply ingrained family values and systems, a male-dominated society, preferences for alternative therapies, and religious or moral obligations to care for older people which influences and determines their health-seeking behaviour.

In contrast, Bajwah et al. (2021) conducted a service evaluation study of two London hospitals providing PC services to examine the association between ethnicity and socioeconomic deprivation with the timing of PC referral. A total of 334 patients were included in the study, of which 119 were from non-White ethnic groups, including 26 SA and 77% black. The findings revealed no relationship between ethnicity and the timing of PC referral. However, there is an association between socioeconomic deprivation and PC referrals. One probable cause of the difference between the findings of Wilkinson et al. (2014), Evans et al. (2012), and Bajwah et al. (2021) is that the study is limited in the selection of patients, that is, the participant groups were unequal. Of the 334 patients who were non-white, the limited sample size did not represent the entire population.

Nevertheless, Bajwah et al. (2021) successfully highlighted one important aspect not often considered when researching access to PC services among SA. Research has also supported a close link between socioeconomic deprivation and access to PC services (Bowers et al., 2022). According to statistics published by the UK government, the combined Bangladeshi and Pakistanis have the highest rate (33%) of economic inactivity, which limits their ability to acquire appropriate and timely PC services. Another study conducted by Coupland et al. (2011) found that the socioeconomic characteristics of the SA community in the UK are major barriers to accessing PC. These socioeconomic characteristics include limited educational achievement, limited employment opportunities, high rates of unemployment, and lower income than their Caucasian counterparts. Thus, Bowers et al. (2022) and Coupland et al. (2011) asserted that although there may not be a direct link between ethnicity and access to PC services, there exists an intersectionality between ethnicity and socioeconomic conditions in healthcare excess. This indirect link limits individuals from ethnic minority backgrounds, specifically SA, to experiencing socioeconomic challenges that limit their access or willingness to access PC services.

2.3 Challenges Limiting Minority Ethnic Communities, Particularly SA, from Accessing Palliative Care Services

The challenges, widely quoted in the literature, faced by the SA community when accessing PC, include religious and racial discrimination, cultural insensitivity, lack of information, an unfavourable attitude towards PC, and difficulty discussing life and death (Evans et al., 2012; Markham et al., 2014; Redman et al., 2008; Frank Harkin and Curie, 2013; Bajwah et al., 2024). Another study conducted by Brown et al. (2013) also showed similar results that SA in the UK hurts PC and life-sustaining treatment due to their religious and cultural affiliations as compared to the white population. Similarly, Clarke et al. (2019) regarded cultural associations, lack of education, inclination towards traditional medicine, and language or communication disparities as barriers limiting the access of ethnic minorities, specifically the SA community, to PC services.

2.3.1 The Perception of Health and Illness among SA

The perception of health and care among the SA population is contaminated by several factors, including religious affiliations, negative attitudes towards healthcare professionals, lack of trust in the healthcare system, alternative therapies, unhealthy decision-making styles, and family values (Lucas, Murray, and Kinra 2013). Many individuals belonging to SA culture believe that they are morally and religiously obliged to care for sick or older people, and an inability to do so makes them feel guilty and sad (Palmer et al., 2007; Patel et al., 2015). For SA Muslims, both life and death and trials from God test humans, thus placing their trust in God to treat their illness and give them health. Similarly, SA Hindus also believe that they must live their lives by the teachings of their dharma to avoid any illness, suffering, or pain (Patel et al., 2015). Owens and Randhawa (2014) argue that this “fatalistic approach” often contributes to their decision to not access PC services. On the other hand, Dosani et al.’s (2020) observational study explored the perception of PC among the SA population through semi-structured interviews and survey questions. The main exploratory findings of the study were: (i) different attitudes towards talking about death; (ii) an equal emphasis on minimizing pain and suffering and maximizing comfort; (iii) lack of knowledge about PC; and (v) that faith, spiritual beliefs, and cultural values do not necessarily hinder the acceptance of or access to PC services.

2.3.2 A Preference for Traditional Medicine

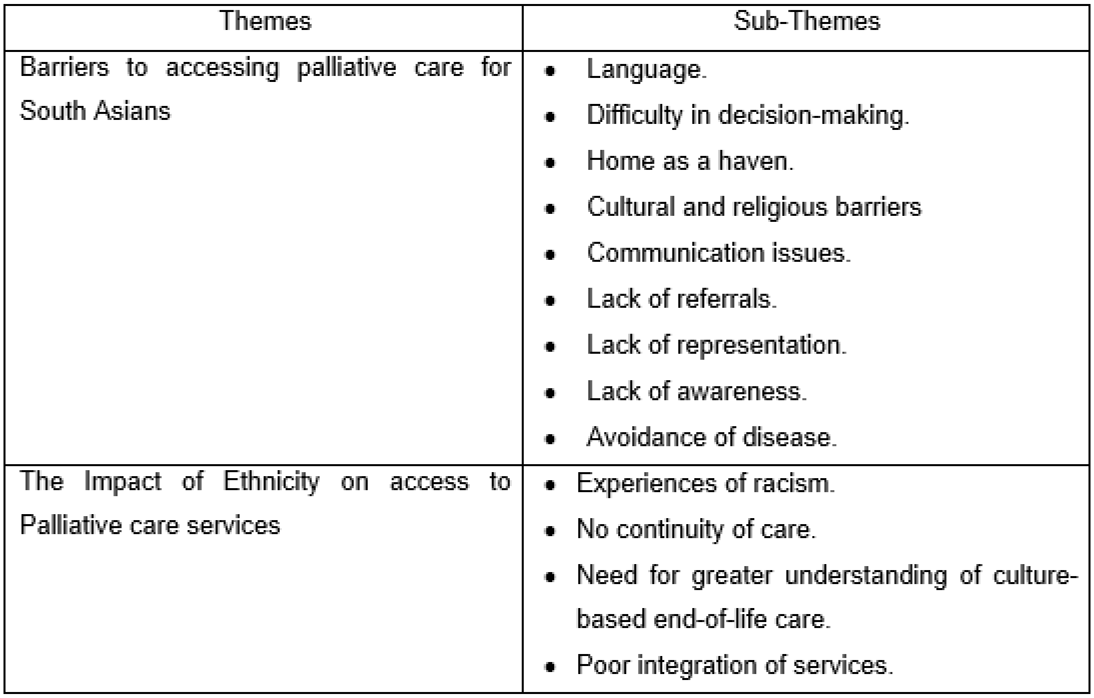
Ethnic minorities, particularly the SA community, prefer to use traditional medicine or health practices. Campbell and Amin (2014) found through their qualitative study that ethnic minority populations value traditional rituals and medicine. They suggested that traditional healers should be incorporated into PC services because they can offer appropriate spiritual, cultural, and psychological care. The choice to opt for traditional medicines is often influenced by family members, negative attitudes towards PC, prior experiences, socially reinforced beliefs, and the feasibility of using these practices, such as less cost and hassle (Evans et al., 2011; Griffiths et al., 2001). Moreover, the use of religious rituals in traditional medicine further strengthens faith in these practices, such as the recitation of specific “dua” or verses to seek healing and protection for physical illness and spiritual afflictions (Cain et al., 2018).

2.3.3 Language or Communication Barrier

The SA community in the UK mainly speaks Bengali, Urdu, or Punjabi, based on their national affiliation (Greenwood et al., 2015). Many of the older people in this community do not have a strong grip on English, which makes it challenging for them to effectively communicate their problems or needs. According to Hawley (2017), this language barrier leads to misunderstandings between patients and healthcare professionals regarding treatment options, difficulties in expressing concerns and symptoms, and challenges in comprehending medical information. Wilkinson et al. (2016) also regarded the language barrier as a major issue concerning PC for ethnic minorities. Moreover, Gunaratram et al. (2007) and Worth et al. (2009) asserted that language and communication barriers experienced by ethnic minorities in PC services put them at risk of inadequate or inefficient end-of-life care. Morton et al. (2016) further ascertains that the reason why this language barrier is not widely acknowledged and addressed in the healthcare system of the UK is that most of the research about the quality of end-of-life care is conducted with English-speaking and White populations. One of the participants, a care provider, recruited in Wilkinson et al. (2016) study responded: “Most of the ethnic minority participants will not be regarded as eligible for quality of PC studies because they won't agree to end of life care,. Or if they have, they can’t speak to, they’re not articulate enough to get into that conversation, or they won’t…..it’s not a cultural thing apart from the language.”

2.3.4 Decision-Making

In the SA community, decisions about seeking care, engaging with PC services, and adhering to treatment recommendations are often determined by cultural beliefs and norms, family dynamics, religious practices, and social structures or support networks (Shabnam et al., 2020; Dosani et al., 2020; Owens and Randhawa, 2004). Worth et al. (2009) suggested that individuals belonging to SA communities prefer collective decision-making involving family members, which contrasts with the individual autonomy practised in Western culture. Thus, their decisions about their own health are based primarily on what others think and would do in a similar situation rather than their own needs and views. Ventakalasu et al. (2013) believed that this cultural dissonance leads to a misunderstanding between healthcare professionals and patients/families, thus affecting the appropriateness and quality of PC provided to the SA population.



Themes	Sub-Themes
Barriers to accessing palliative care for South Asians	• Language. • Difficulty in decision-making. • Home as a haven. • Cultural and religious barriers • Communication issues. • Lack of referrals. • Lack of representation. • Lack of awareness. • Avoidance of disease.
The Impact of Ethnicity on access to Palliative care services	• Experiences of racism. • No continuity of care. • Need for greater understanding of culture-based end-of-life care. • Poor integration of services.

Table 1 Summary of Themes Found in LiteratureConclusion

To conclude, a systematic review of the literature already available on the chosen topic highlights that ethnic minorities face disparities when accessing PC services. SA are among the ethnic groups with the least uptake or usage of PC services due to the challenges or barriers they encounter. These barriers include, but are not limited to, cultural associations, lack of education, inclination towards traditional medicine, language or communication disparities, and collectivistic decision-making.

CHAPTER 3: METHODOLOGY

3.1. Introduction

This chapter outlines the methodology adopted to conduct this research on the topic of “understanding the barriers to accessing PC among ethnic minorities, focusing on SA in the UK.” It includes a description of the research design, including the inclusion and exclusion criteria, and the search strategy adopted to identify the relevant literature available on the selected topic. This chapter also includes details of the data extraction and synthesis procedure, the quality assessment tools used, and the strategies employed to address potential biases. Kazdin (2016) suggested that a structured methodology is essential to ensure that the research findings are reliable, valid, and comprehensive.

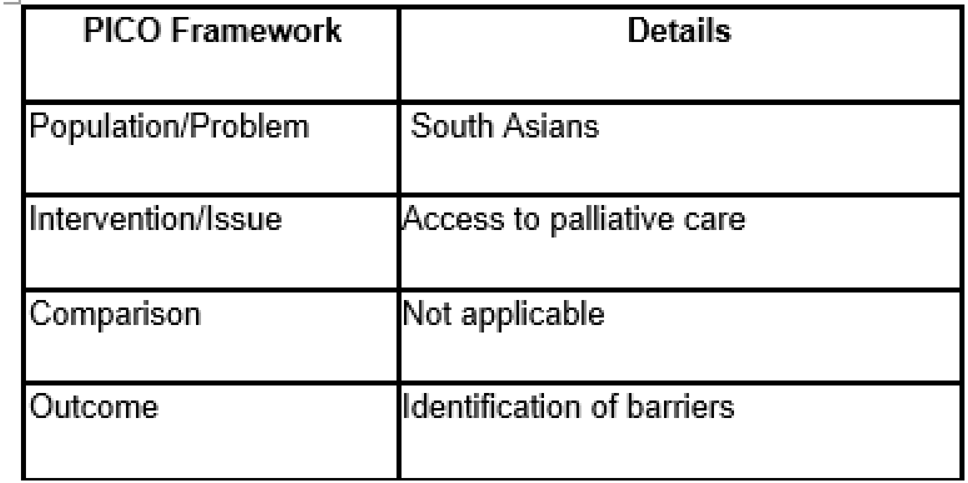
3.2. Systematic Literature Review (SLR)

A literature review is a general and sometimes informal survey of the literature on a given topic as an initial step in understanding a topic or developing a conceptual framework (Lame, 2019). Systematic reviews are a formal and well-defined approach to systematically answer well-defined research questions with minimal bias and thus provide a sound evidence base for decision-making (Purssell and McCrae, 2020). This systematic review aimed to reduce bias and inclusively identify all studies that address the barriers to access to PC among the SA population in the UK. Subsequently, by having stringent Inclusion and Exclusion criteria and critically evaluating the quality of the studies included in this review, the review not only provides valid conclusions but also a clear picture of the multiple and diverse nature of these barriers. It is also crucial to produce clear and concrete recommendations that can be used to guide policy and practice, thus laying the necessary groundwork for tackling healthcare inequality among this group of people.

3.3. Search Strategy

Aromataris and Riitano (2014) defined search strategy as an organized structure of search terms and keywords used to identify relevant literature from a database. It combines the key concepts of a search question to obtain the most accurate results. For this systematic review, a comprehensive search strategy was developed utilizing the “PICO” tool to identify the components to be included in the research question and identify alternative words that may be required for a more comprehensive search (Refer to Table 1). This PICO tool would also facilitate the development of eligibility criteria, which is an essential aspect of PRISMA (2009).

Table 2 PICO Table



PICO Framework	Details
Population/Problem	South Asians
Intervention/Issue	Access to palliative care
Comparison	Not applicable
Outcome	Identification of barriers

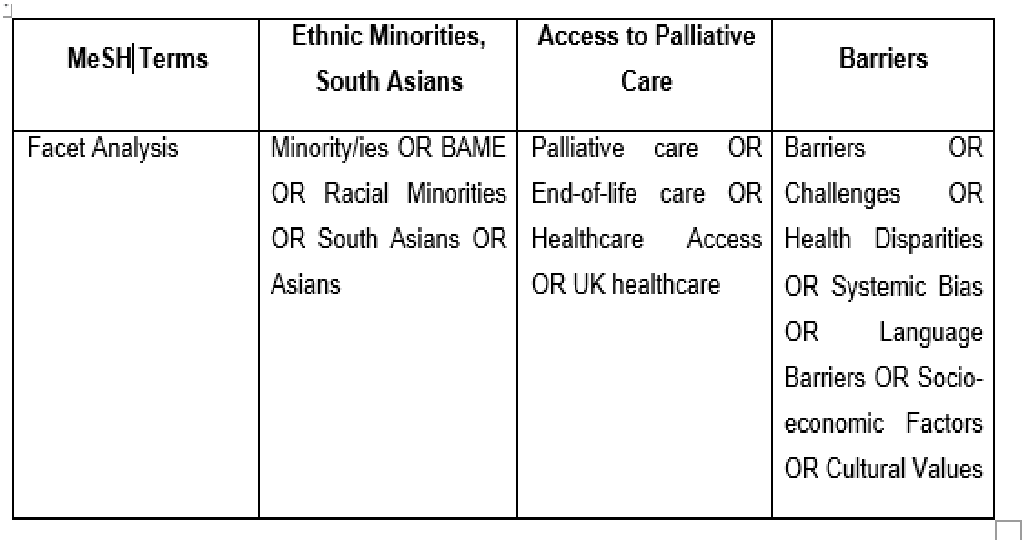
The rationale why the PICO framework is used instead of PEO (Population, Exposure, and Outcome) is that it is applied only when assessing an exposure or risk factor that may or may not have an impact on the outcome (Butler, Hall, and Copnell, 2016). However, this review focuses on identifying barriers to accessing PC among ethnic minorities, specifically SA. Hence, exposure to specific interventions or comparisons between interventions are not central to the research question. Thus, the PICO framework was deemed more appropriate for defining the search parameters and guiding the systematic review process.

3.4. Search terms

Search terms are defined as specific words or phrases or combinations of words or characters that are entered into search engines to specify a particular thing that needs to be searched on a database (Aromataris and Pearson). They are the essential element in a search strategy that helps to systematically identify relevant literature. According to Smith et al. (2011), search terms balance the specificity and breadth of the search and improve the reliability and quality of the systematic review.

Also, the use of synonyms is also important while searching for the literature because different authors utilise different terms to explain a similar concept (Westgate and Lindenmayer, 2017). Booth et al. (2016) also supports that including synonyms in the search process increases the chances of retrieving more relevant studies and enhances research inclusivity and thoroughness.

Through the PICO tool, it was identified that the "population" of interest in this current research was ethnic minorities, particularly SA residing in the UK. This was chosen to limit the scope of this study since ethnic minorities is a broad term. Additionally, the word "Asians" was included in the search term because this would help capture relevant studies that used different terms to define the SA population. The facet analysis also included other terms (Refer to Table 2). The "intervention" was identified as access to PC. Within the facet analysis, the word "end-of-life" care was also used as a MeSH term, as these are two words used interchangeably. Since "comparison" is not applicable to the research, the "outcome" of interest was the identification of barriers or challenges. To summarise, the research question developed seeks to focus on ethnic minorities, particularly, SA and the challenges or barriers they face in accessing PC in the UK.



MeSH Terms	Ethnic Minorities, South Asians	Access to Palliative Care	Barriers
Facet Analysis	Minority/ies OR BAME OR Racial Minorities OR South Asians OR Asians	Palliative care OR End-of-life care OR Healthcare Access OR UK healthcare	Barriers OR Challenges OR Health Disparities OR Systemic Bias OR Language Barriers OR Socio-economic Factors OR Cultural Values

Table 3 Facet Analysis for Database Search

3.5. Databases

A literature search was conducted using online databases, including ProQuest, EBSCO, PubMed, and Google Scholar, to gather relevant academic sources. The reason for selecting these databases is that they provide access to extensive literature related to healthcare and social sciences. As per Booth (2016), searching multiple databases is important for conducting comprehensive literature. This also ensures a broader coverage of articles and reduces the risk of missing relevant studies.

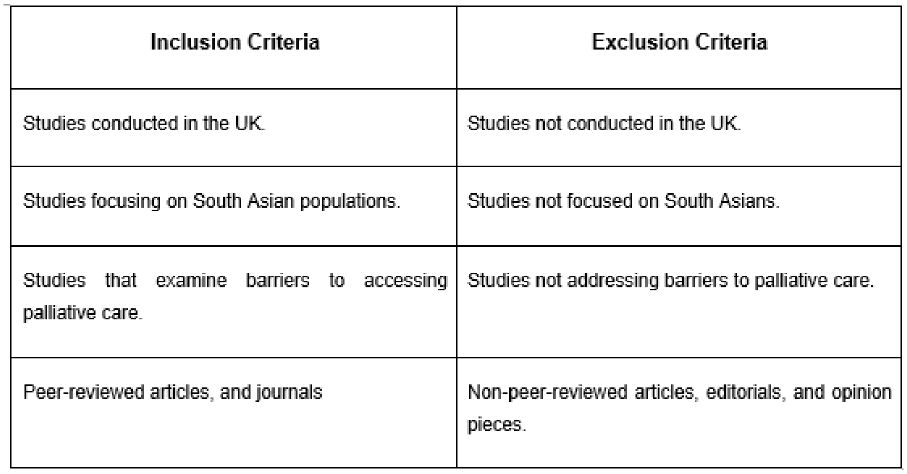
These relevant databases are essential for searching and getting access to peer-reviewed research articles, books, conference proceedings, and other academic sources.

Incorporating this diverse range of evidence is essential to enhance the credibility and reliability of the findings (Cooper et al., 2018). Therefore, this research, to identify and understand the differing perspectives of ethnic minorities related to the challenges in accessing PC, has searched different aspects on different engines. Such as, PubMed was used for medical literature, EBSCO for nursing and allied health, ProQuest for psychological aspects, and Google Scholar for interdisciplinary coverage. This was done to ensure that all the relevant articles are accessed, and the review has enough depth and breadth to achieve its developed research question.

The databases were all searched for studies that were published from 2010 to 2023 to include the most recent data available on the topic since healthcare in the UK is undergoing rapid changes. Boolean operators “OR” and “AND” were used to combine search terms and keywords to further facilitate the search process. Only papers written in the English Language were considered and included to ensure clinical relevance for each database (Cooper et al., 2018).

3.6. Inclusion/Exclusion Criteria

According to Smith et al. (2011), inclusion criteria in research are the characteristics that the studies must possess to be included in the review. Exclusion criteria are those characteristics that disqualify prospective studies from being included in the study. Snyder (2019) suggested that inclusion and exclusion criteria are important because they set boundaries for the review and reduce the chances of ambiguity. The inclusion and exclusion criteria developed for this research is demonstrated in Table 3.



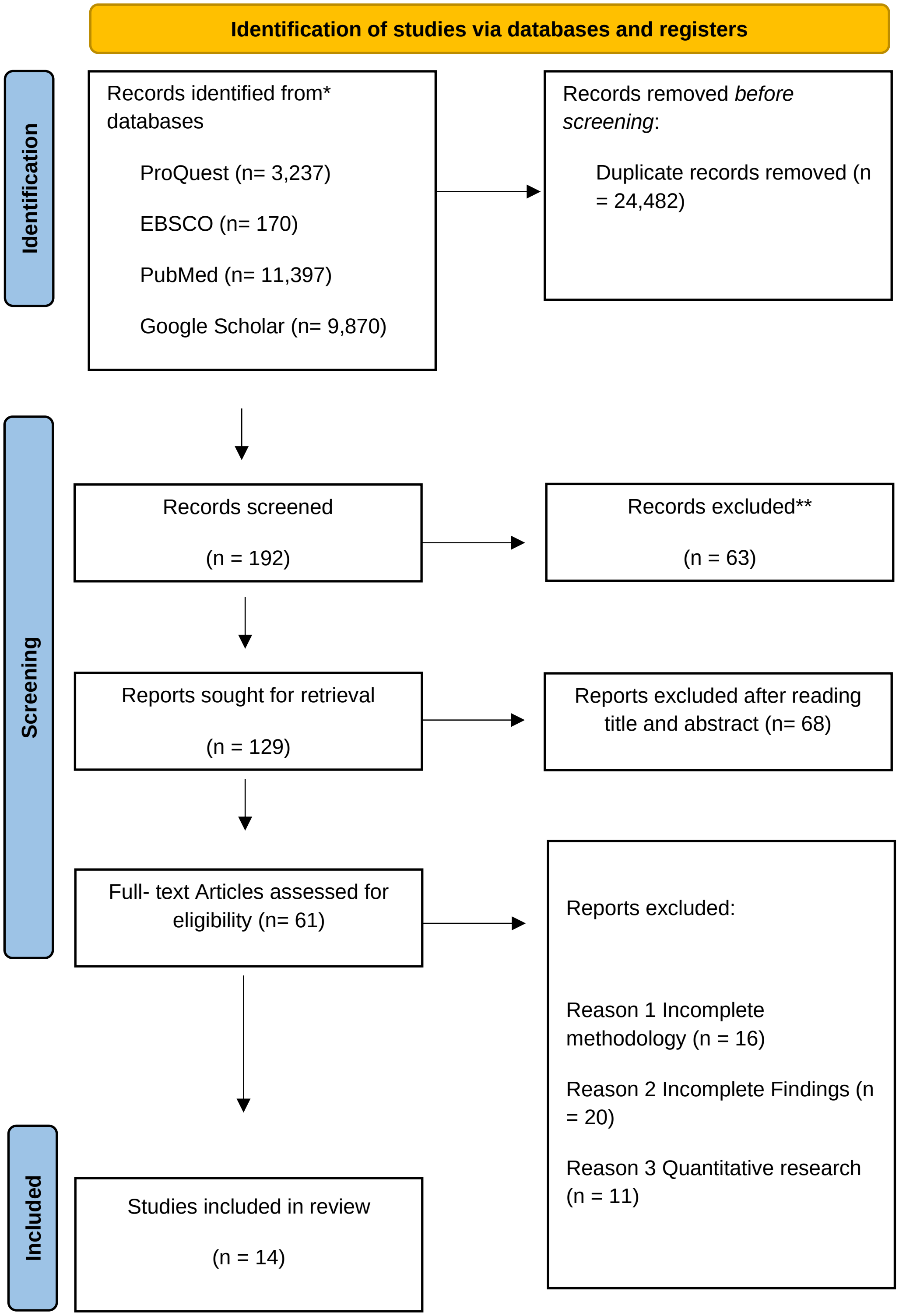
Inclusion Criteria	**Exclusion Criteria**
Studies conducted in the UK.	Studies not conducted in the UK.
Studies focusing on South Asian populations.	Studies not focused on South Asians.
Studies that examine barriers to accessing palliative care.	Studies not addressing barriers to palliative care.
Peer-reviewed articles, and journals	Non-peer-reviewed articles, editorials, and opinion pieces.

Table 4 Inclusion and Exclusion Criteria

3.7. Data Evaluation

The obtained data was evaluated using the CASP checklist for qualitative searches as part of this systematic literature review. The rationale for using this tool is to ensure that all the articles selected and included in the study are of optimum quality and do not contaminate the authenticity and validity of the findings (Long et al., 2022). Also, this tool can provide a basis for allocating numerical scores to the study to quantify the quality of the study, especially during study selection (Buccheri and Sharifi, 2017).

3.8. Search Results



Prisma flow chart

The search for relevant studies started with entering search words and key terms in the search engine, which led to the identification of 24,674 studies. To narrow the search keywords, including “SA” “UK” “Palliative OR End-of-Life care” are inserted. Furthermore, the inclusion and exclusion criteria were also applied, and Boolean operators were used. This decreased the number of hits to 192 articles. Initially, the search was only conducted using ProQuest and EBSCO; however, the inability to find articles that are relevant to the topic and fulfil the eligibility criteria caused the researcher to use PubMed and Google Scholar. Of these 192 articles, 63 were excluded because they were either conducted in countries other than the UK or focused extensively on the BAME community instead of SA. The use of such studies might have caused the research to lose its focus and also affected the overall validity of the findings. Also, as the healthcare systems differ across countries, it would not have been a suitable comparison. The remaining 129 articles were scanned for their titles and abstracts, and all studies that did not include the SA community in their studies were excluded. Also, opinion papers were discarded, and the rest 61 articles were fully screened out of these 16 were not included because either they had a missing methodology or used systematic review as their methodology, which could not be incorporated in the study. Moreover, the other 20 studies did not have a clear statement of findings and 11 used a quantitative methodology. Thus, only 14 studies were identified and used in this systematic review. These 14 studies were independently reviewed by two reviewers who screened the studies for relevance and extracted data.

3.9. Ethical Considerations

In research, ethics are defined as the principles that ensure that the participant's rights and confidentiality are protected as well as the integrity of the findings (Farrimond, 2017). Since the study has utilised a systematic literature review methodology it does not require ethical approval. However, it was still ensured that all the studies included had undergone ethical approval before publication. Moreover, only those studies were chosen that adhered to the ethical research standards, including informed consent and ethical treatment of participants. In addition, since avoiding bias is essential, it was ensured that the included studies have a reproducible and transparent methodology and are not based on personal preferences or conflicts of interest.

3.10. Chapter Summary

In this chapter, the systematic review laid the foundation by defining the PICO framework, outlining search strategies across multiple databases, and adhering to rigorous inclusion criteria. Ethical considerations were also paramount in selecting studies that had undergone ethical approval. The next chapter will delve into the findings extracted from the included studies, focusing on identifying and synthesizing literature available on accessing PC among ethnic minorities in the UK.

Chapter 4: Data Extraction and Evaluation

4.1. Introduction to the Chapter

This chapter seeks to present the collected information about the studies in a table format to summarise them and make them easy to compare. For this purpose, this chapter of the dissertation includes an evidence table that provides detailed information about each study included in the systematic review and a summary table that gives an overview of the findings. Alongside this, the chapter provides a brief introduction to the critical appraisal and quality assessment tools used to appraise the research paper and also highlights its importance, strengths, and limitations.

4.2. Data Extraction

The simple definition of data extraction is “the process of retrieving or collecting different types of data from several sources, many of which may be completely unstructured or poorly organized” (Jonnalagadda, Goyal, and Huffman, 2015). Through data extraction, the researcher attempts to consolidate, process, and refine data so it can be stored in an appropriate location to be transformed. According to Schmidt (2021), in a systematic review, data extraction is about capturing the essential characteristics of the included studies in a standardized and structured form. This extraction of data is important for assessing the risk of bias in individual studies and synthesizing their findings (Refer to Appendix A for the data extraction table).

4.3. Critical Appraisal and Paper Quality Assessment

Tod, Booth, and Smith (2022) define critical appraisal as a process of carefully and systematically examining a research or article to judge its value, relevance, and trustworthiness in a specific context. Systematic literature reviews that use various databases to find relevant research articles to be included can result in an overwhelming number of results, which can have different qualities. The process of critical appraisal reduces the burden on the researcher and allows them to focus on those studies, research, or articles that are the most relevant to their developed research question (Schmidt, 2021). This allows the researcher to utilize research evidence more efficiently and reliably to achieve the study's aims. Patel et al. (2022) further provides that critical appraisal ensures that the evidence used to support or negate the claims is of high quality.

4.4. Critical Appraisal Tool

Unlike other tools, a critical appraisal tool is described as a systematic instrument developed to examine and assess the reliability and quality of a research paper (Schmidt, 2021). It helps clinicians, researchers, and professionals to evaluate the relevance, credibility, and validity of research findings by carefully examining different aspects of the study, including its methodology, results, and potential biases (Crowe and Sheppard, 2011). Aside from this, other methods can be employed to critically appraise the rigour of the included studies in a systematic review. This includes the risk of bias tools such as ROBINS-1, Cochrane Risk of Bias tool, and GRADE tool. These tools are designed to examine the individual strengths of the studies (Todd et al., 2022). However, it is important to acknowledge that there are several tools available to appraise research evidence; however, it is crucial to choose the right appraisal tool. This is because different tools are tailored to evaluate different types of studies, such as quantitative studies, randomized controlled trials, systematic reviews, and observational studies (Tod et al., 2022). Using the right critical appraisal tool ensures a relevant and thorough evaluation, leading to more precise interpretations and informed decision-making (Long et al., 2020). The right critical appraisal tool is expected to assess the appropriateness of a research design, and rigour of the methodology, identify potential biases, assess the validity of the results, and examine if the findings are presented and concluded (Maeda et al., 2023). Additionally, the critical appraisal tool is also expected to identify if the conclusions made in the research are supported by enough data and can be applied to real-world settings.

4.5. Evaluation of the Studies using the CASP Tool

As mentioned above, there are many tools or methods available to perform critical evaluation of studies. However, the CASP tool is used for the current systematic review because it is highly regarded for its comprehensive and tailored approach to evaluating qualitative studies (Long et al., 2020). The reason why the CASP tool is used instead of Joanna Briggs Institute critical appraisal tool or AMSTAR 2 too is that it is specifically designed to assess and address the unique aspects of qualitative studies, such as research aims, methods of data collection, and data analysis techniques used (Buccheri and Sharifi, 2017). Moreover, it helps to assess the rigour of the qualitative research by examining factors, including research transparency, credibility of the findings, and quality of the evidence used (Quigley et al., 2019). The CASP tool is well-known for its versatility; it appraises a range of study designs. Moreover, it has a structured framework that ensures that every aspect of the qualitative study is evaluated (Long et al., 2020). However, one potential limitation of the tool is that it may be difficult to apply for beginners as compared to other appraisal tools (Harrison et al., 2017). Furthermore, the overemphasis on methodology sometimes overshadows other important elements like the study's relevance (Young and Soloman, 2009).

The CASP qualitative questionnaire used to critically appraise the selected studies consists of 10 questions, each of which is answered for each study (Refer to Appendix B).

4.5.1 Article 1

Clarke et al. (2023) employed a qualitative methodology to explore participants' stories about their access to PC. The CASP (2018) checklist for qualitative study requires a study to have a clear statement of the research aims. The reason is that clearly defined research aim and questionnaire ensure that the reader understands the goals and purpose of the study (Doody and Bailey, 2016). Similarly, Pruzan (2016) also supported that well-defined aims help the researcher to stay on track and not astray during the research process. Clarke et al.'s (2023) study has clearly described the aim mentioned in the abstract as well as in the introduction section.

Similarly, the research choice of qualitative methodology and narrative inquiry is appropriate and addresses the research aims sufficiently. Clarke et al. (2023), thus, recruited 27 participants to conduct interviews and focus groups. As per Malterud et al. (2016), a qualitative study must have a minimum of 12 participants to reach data saturation. While Creswell and Creswell (2018) suggested that any figure between 10 and 50 is sufficient depending on the type of research and research questions. The findings of the study revealed several key themes, such as "Places in the healthcare system where people get lost, such as circular referrals, lack of continuity of care and system politics. Issues with treatments and decision-making; and culturally sensitive healthcare issues such as language barriers, preferences for healthcare provider ethnicity, experiences of racism, the role of faith and religion and issues relating to personal care, respect and dignity.

4.5.2 Article 2

Ventakalasu, Arthur, and Seymour (2013) conducted focus groups and interviews with a total of 55 older adults between 52 and 78 years. CASP (2018) asks if the data collected in the research addresses the research issue. DiCicco-Bloom and Crabtree

(2006) present that qualitative interviews allow the research to explore behaviour and attitudes about a particular accept in detail and ensure that there is no impartiality. However, Ortiz (2015) argues that while using such a methodology, the researcher must be aware that a lack of privacy may lead the participants to alter their perspectives and opinions about the research topic, which negatively affects the findings. To cater to this issue, Ventakalasu, Arthur, and Seymour (2013) ensured that both focus groups, and individual interviews were conducted in the location preferred by the participant, i.e. their own home, the home of a family member, or community group etc.

The collected data was analysed using the constructivist grounded theory approach. CASP (2018) requires the data analysis procedure to be rigorous to ensure the integrity of the findings and protection against common issues, including data manipulation, selection bias etc. Mill, Bonner, and Francis (2006) found that a constructivist grounded theory approach has high ecological validity and allows one to discover new phenomena. On the other hand, O'Connor et al. (2018) argued that the findings may be subjective, and the process can be a bit complex. Two key themes emerged which present the perspective of SA participants towards PC. "The first theme 'avoidance as a cultural norm' relates to the relative absence of discussions around death and dying experienced by participants. Participants were neither expected to have discussions about their death and dying within their family nor to assume any involvement in decision-making. The second theme 'avoidance as protection' relates to beliefs and experiences about the delegation of decision-making to family members."

4.5.3 Article 3

Markham, Islam, and Faull (2014) conducted a study to understand why the local BAME communities in the UK do not use hospice services and identify ways through which their access to specialist PC services can be increased. For this purpose, the researchers conducted informal discussion groups with members of the BAME public. According to Murphy (2014), informal group discussions promote quick information sharing and ensure more honest and open discussions about difficult topics. In opposition, Burn et al. (2019) took a different stance and stated that informal group discussion can lack focus and structure, has limited generalisability, and may be difficult to analyse because of the unstructured nature of dialogue. Keeping in view the CASP (2018) criteria for ethical consideration, the researchers obtained verbal consent from the participants of the discussion group members and confidentiality was assured by anonymizing all the extracts from discussion groups.

The thematic analysis of the collected data revealed that among the SA population, the information about PC services was limited, and participants valued end-of-life care when informed about the services. Many participants described that they wanted to die with a comfortable heart. The participants also reported that the GPs in healthcare service often did not know or did not refer patients for further assistance.

4.5.4 Article 4

Moss et al. (2022), unlike others, took a different stance and used the Community Readiness Model to identify the barriers that influence how SA communities' access and use PC services. For this purpose, ten key stakeholders working in the PC services were approached and recruited. Following the CASP (2018) criteria, the research aim of the study was presented in the abstract and introduction section. The recruited stakeholders were asked to fill out a questionnaire and attend a focus group discussion.

As per Akylidiz and Ahmed (2021), focus groups in qualitative studies are effective because they allow the researcher to engage in deeper conversations and observe body language. While Gill et al. (2008) countered that focus groups are time-consuming and it may be difficult to engage all participants in the discussion. The themes derived from the thematic analysis include a lack of awareness of palliative and end-of-life care services in the communities, continued focus on end-of-life care planning instead of taking a holistic approach, poor integration of services, a need for a greater understanding of good end-of-life care for culturally diverse communities, and a need for specific attention to what good end-of-life care is for different faith communities.

4.5.5 Article 5

Phillips and Taylor (2011) in their article outline a hospice apprentice programme that aims to promote and expand the use of specialist palliative and end-of-life care services for a SA community. The project aimed to improve health outcomes and community cohesion for individuals belonging to the BME community. To assess the effectiveness of this programme, the researchers used narrative inquiry using interviews and discussions.

Clandinin and Caine (2013) believe that narrative inquiry is useful to reveal a deeper understanding and unique perspectives of a situation. In contrast, Lindsay and Schwind (2016) implied that to effectively use narrative inquiry as a methodology the researcher must have a vast understanding of the topic and participants' life experiences to realistically and effectively understand their opinions. CASP's (2018) checklist asks if qualitative research is the right methodology to be used to address the developed research goal. For this study, the use of narrative inquiry was accurate because it allowed to give voice to the marginalised people whose perspectives are often ignored and not incorporated (Green, 2013). It was found through the inquiry that the project improved the chances of recruitment for district nurses, enhanced multidisciplinary working, and laid the foundation for an increase in referrals to PC for the BAME community.

4.5.6 Article 6

Worth et al. (2009) undertook a prospective, longitudinal, qualitative study using in-depth interviews to examine the care experiences of SA Muslims and Sikh patients in Scotland with life-limiting conditions. The study also sought to understand the reason behind difficulties faced by this community in accessing services and how they might be mitigated. For this purpose, the researchers purposively selected 25 SA Sikh and Muslim patients, 20 health professionals, and 18 family carers. CASP (2018) requires researchers to elaborate on the recruitment strategy adopted. According to Rai and Thapa (2015), purposive sampling allows the researcher to integrate people with certain traits of interest or characteristics, which helps to explore the chosen scientific phenomena.

However, a counterargument was presented by Campbell et al. (2020) that purposive sampling decreases generalisability and findings are only applicable to the sampled population. The sampling technique was appropriate in the context of the current research because it allowed the researcher to only integrate the population of interest, i.e. people belonging to a specific ethnicity. The findings of the study highlighted that most PC services remain inefficient in providing culturally responsive and appropriate care. Barriers to access include resource constraints, religious and personal discrimination, lack of awareness among the SA population about palliative or end-of-life care, and difficulty talking about death. Out of them the most vulnerable population are those who have recently migrated to the UK, have limited English proficiency, do not have family members, and dying of non-malignant diseases.

4.5.7 Article 7

Similarly, Ventakalasu, Seymour, and Arthur (2013) utilised a qualitative methodology using focus groups and semi-structured interviews to explore the expectations, beliefs, and attitudes of older SAs living in East London about dying at home. The benefits of using this methodology, as quoted by Magaldi and Berler (2015), include access to reliable and comparable data, greater flexibility, and more detailed and rich responses. Adams (2015) analysed that semi-structured interviews are highly vulnerable to research bias, particularly observer bias which can lead to inaccurate and invalid findings. The collected data was analysed using the constructivist grounded theory.

Although the study was highly rigorous, it failed to consider the relationship between the researcher and the participant. Varga-Dobai (2012) suggested that qualitative researchers must consider this relationship because the more trusting and closer relationship developed with the participant, the richer and more authentic data can be collected. Furthermore, Griffis et al. (2008) added that rich and authentic data reveals the complexities of the phenomenon under investigation. The findings of the study suggest that for many SA participants dying in their homeland is essential because their family members would be able to perform the cultural and religious rituals more openly. Moreover, they see their “home as a haven” where can safely practice their religious and cultural rituals associated with death. All in all, they believe that cultural and religious practices at the time of death would give them a peaceful death experience.

4.5.8 Article 8

Owens and Randhawa's (2004) article investigate the difficulties faced the professionals trying to develop “culturally competent” PC for SA patients dealing with cancer in the UK. For this purpose, a phenomenological methodology was devised, and 10 semi-structured interviews were conducted with PC staff who work at home and in community-based settings. Eberle (2014) suggests that phenomenology is an exceptional method in qualitative studies to understand subjective experiences and obtain insights into people’s motivations and actions.

Owens and Randhawa (2004) also justified their use of phenomenological methodology by stating that “this methodology is adopted to gain a detailed insight into the experiences of staff, and the meanings and understandings which they attach to their work in a culturally diverse context.” The analysis revealed that for many professionals, caring for ethnic minorities demonstrated a self-critical and reflexive approach. Many interviewees believe that training in cultural competence is valuable but does not account for the emotional investments and complexities associated with caring for minority ethnic patients in community and domestic settings.

4.5.9 Article 9

Samanta, Samanta, and Madhloom (2017) employed a qualitative approach to explore the attitudes, beliefs, and values of SA Muslims and Hindus related to their perception of issues associated with end-of-life care. For this purpose, the researchers conducted two focus groups that lasted for two hours. A total of 12 participants were selected for this study; among which 6 were male and 6 were female within the age range of 28 and 72 years. On the CASP (2018) criteria, the ethics were carefully considered in the research and consent was obtained before digitally recording the discussion of the participants.

Aguinis and Henle (2004) presented that Ethics is essential to protect the participants' dignity and to ensure that their welfare and research are well-kept. In research where ethics are lapsed, it results in significant harm to human subjects, students, and the public which ultimately snatches the essence of human welfare from the research. The key concepts that emerged through the analysis of the collected data, include the key concepts that we elaborate upon are (a) an intrinsic right to religious and faith-based values at end-of-life; (b) the right to respect for freedom of religion at end-of-life; and (c) culture-dependent spiritual beliefs about death.

4.5.10 Article 10

Randhawa et al.'s (2003) article presents the findings of an exploratory study that assessed the role of communication in the delivery of effective and efficient PC service to SA living in Luton, UK. Swedberg (2020) ascertained that an exploratory study gives context to the research problem and helps the researcher become familiarise with the topic, form hypotheses, test theories, and make conclusions. On the other hand, Makri and Neely (2021) argued that the interpretation of the data collected from exploratory research can be biased and judgmental. Also, the sample size of such studies is smaller thus limiting the generalisability. One essential strength of the study, as per the CASP (2018) criteria, is this study addressed the importance of the relationship between the researcher and participant.

The participants were allowed to specify the gender of the interviewer and the language in which they would like the interview to be conducted. As per Varga-Dobai (2012), this would increase the comfort of the participants, and they would be more likely to share honest and true opinions. Randhawa et al. (2004) found that it was found that the PC services provided are, in most cases, valued and seen as being effective. However, as the service providers who were interviewed readily recognized, there were areas where improvements could be made. The main issues were found to be the need to inform SA populations of the availability of PC services and the need to improve communication between patients and service providers.

4.5.11 Article 11

Brown et al. (2013) used a literature review methodology to explore the interface between SA culture and PC for children, young people, and families. The rationale for using literature review as a methodology could be the fact that it allows researchers to identify areas that need more research and assess the current state of the topic (Snyder, 2019). In comparison, Van Lange Paul et al. (2015) contend that literature reviews are vulnerable to selection bias which can affect the reliability of the findings. The researchers thus explored several electronic databases, including Medline, CINAHL, and ClinPSYC. As per Homte et al. (2022), utilising multiple search engines increases the probability of including many relevant studies. The findings of the literature review revealed that families of SA participants understand key health concepts, such as disease and health, from the interactions between personal experience and cultural lifestyle, including family values, faith, and language.

4.5.12 Article 12

Likewise, Turner and Flemming (2019) also conducted a thematic analysis of qualitative studies to synthesise all qualitative evidence on how socioeconomic factors affect access to preferred places of death in the UK. For this purpose, the researchers used multiple electronic databases, including Cochrane Library, MEDLINE, Embase, CINAHL, Scopus, PsycINFO, and ASSIA. A total of 12 studies were made a part of this literature review. The thematic analysis of these studies leads to the development of two key themes, human factor and environmental factor. The human factor included available support networks and interaction between individuals and decision-making. At the same time, environmental factors constitute location and resources available. Only a limited number of studies directly studied the influence of socioeconomic deprivation on access to PC services.

4.5.13Article 13

Clarke et al. (2022), unlike others, focused on the provision of five key considerations on how data can be collected to improve the quality of research conducted on the link between ethnicity and PC. They presented that there is a need for improving ethnic group categories to capture the diversity in ethnicity and allow people to recognize their own identities. Secondly, the questions regarding ethnicity must be made societally and socially sensitive and data must be collected as infrequently as possible. Moreover, appropriate training and resources must be made available to the staff collecting ethnicity data to ensure richness in data. Furthermore, there is a need for the responsible collection of ethnicity data so that there is no ‘cherry picking’ and accurate representation is ensured. Finally, building public trust in data collection and data security must be prioritized.

4.5.14 Article 14

Fang et al. (2016) conducted a scoping review to explore patterns, behaviours, and attitudes of end-of-life care by spiritually and culturally diverse groups and identify the gaps in the practice and delivery of end-of-life care. Scoping reviews are largely valued for their ability to identify research gaps, clarify key concepts, flexibility, and inclusion of a wide variety of study methodologies and designs (Munn et al. 2018). However, it must also be acknowledged that scoping reviews may lack depth, do not include quality assessment of the articles thus increasing chances of risk of bias, and may lead to possible overgeneralization (Pham et al. 2014). The search using fourteen websites and electronic databases lead to the identification of several barriers and enablers. These barriers include cultural differences among healthcare providers, the relationship between people approaching end-of-life care and their family members, culturally insensitive care, language barriers, racial personal and religious discrimination, lack of culturally tailored care, and lack of awareness.

4.6. Chapter Summary

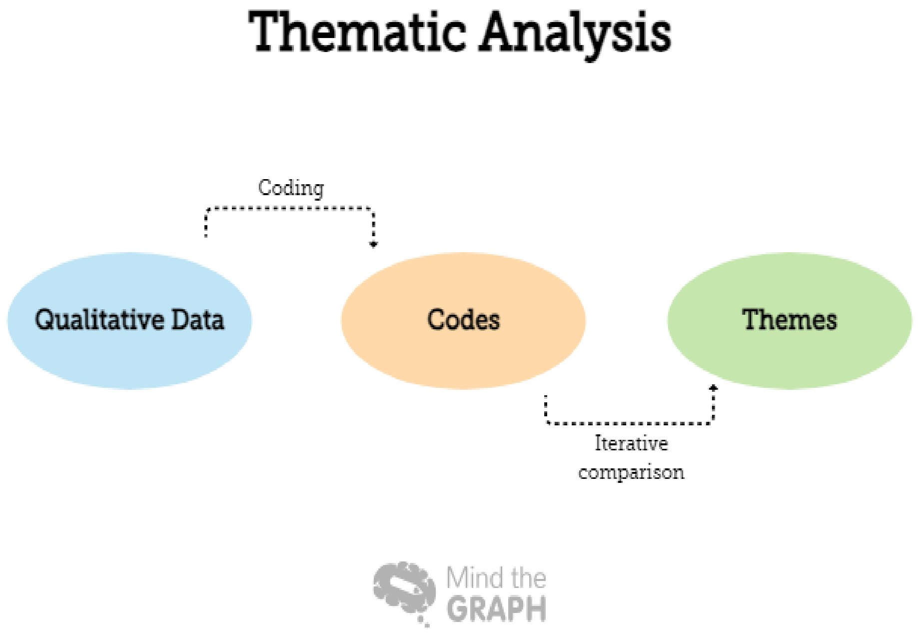
To summarize, data extraction and quality assessment is an essential aspect of systematic reviews that enhances the validity and reliability of the review’s findings. Thus, an appropriate quality appraisal tool, the CASP qualitative checklist, was selected and applied on the selected articles carefully. The next chapter will discuss the findings of those articles in a broader context.

Chapter 5: Data Analysis and Evaluation

5.1. Introduction

This chapter presents an analysis of the obtained data from the included studies. It includes the details of the thematic analysis performed and the thematic analysis framework chosen to derive themes from the extracted data. In addition, this chapter also highlights the characteristics of the included studies, including the location, methodology, and data analysis used. Finally, it presents a detailed synthesis of the included studies; identifying the themes and sub-themes that emerged during the analysis.

5.2. Thematic Analysis



(Figure 2 Thematic Analysis Salomao, 2023).

Thematic analysis is a technique employed in analyzing and describing patterns or themes in qualitative data. It is usually used to give a comprehensive and rich assessment of multifaceted occurrences through participants' processes, views, and perceptions (Kiger and Varpio, 2020). Apart from thematic synthesis, other approaches to the analysis of the qualitative data in an SLR are framework analysis, ground theory, and narrative synthesis (Bulmer, 2017). The rationale behind using a thematic analysis tool for this systematic review is that it offers the researcher flexibility and a comparatively easier tool to be used by a novice (Riger, and Sigurvinsdottir, 2016). However, Neuendorf (2018) argued that this flexibility often leads to inconsistent results; thus, it is essential to be vigilant while using this technique.

5.3. Data Analysis Tool

Braun and Clarke's (2006) thematic framework is a structured method for analyzing qualitative data through six phases: Familiarization, coding, theme development, theme review, definition and writing. Despite its intent to offer systematicity of rigor and consistency it also possesses significant limitations. Some of the criticism levelled at it has to do with its potential to distort data by reducing them to broad themes and by not allowing for fine-grained analysis (Byrne, 2022). The drawback of this conceptual framework is that it is rigid and can be less sensitive to subtle or developing patterns. While the systematic approach improves the consistency, on which the framework is built, this proves that the framework can hinder deeper information analysis, which underlines the importance of the careful application of the framework and the consideration of the alternatives (Joffe, 2011). Other approaches to thematic analysis that can be used, include framework analysis, content analysis, and constructivist grounded theory.

5.4. Characteristics of the Identified Studies

All of the 14 studies were conducted in the UK (Clarke et al, 2023; Ventakalasu, Arthur, and Seymour, 2013; Markham, Islam, and Faull, 2014; Moss et al. 2023; Philips and Taylor, 2011; Worth et al., 2009; Ventakalasu, Seymour, and Arthur, 2014; Owens and Randhawa, 2004; Samantha, Samatha, and Madhloom, 2017; Randhawa et al., 2003; Brown et al., 2013; Turner and Flemming, 2019; Clarke et al., 2022; and Fang et al., 2016). Out of 14, 2 conducted in-depth qualitative interviews (Clarke et al. 2023; Worth et al. 2009) while 2 used semi-structured interviews (Randhawa, 2004; Randhawa et al. 2003), 1 used informal discussion (Markham, Islam, and Faull, 2014), 1 used focus group

(Samanta, Samanta, and Madhloom, 2017), 2 used focus group and interviews (Ventakalasu, Seymour, and Arthur, 2014; Ventakalasu, Arthur, and Seymour, 2013), 1 employed questionnaire and focus group discussions (Moss et al., 2023), and 1 made use of interviews and discussions (Phillips and Taylor, 2011). The remaining four sufficed on using the literature review methodology (Brown et al. 2013; Turner and Flemming, 2019; Clarke et al., 2022) and 1 conducted a scoping review (Fang et al. 2016).

5.5. Emerging Themes from Included Studies

Analysis of the included studies lead to the identification of the following themes and subthemes:

Figure 3 Themes and Sub-Themes Identified

Author	**Themes Explored**												
	Acceptability				**Approachability**			**Adjustability**		**Strategies to Improve Acceptability, Adjustability, and Affordability**			
	Culture and Religion	**Role of Family Members**	**Lack of Knowledge or Awareness**	**Language Barrier**	**Socioeconomic Factors**	**Low Referrals**	**Racism and Discrimination**	**Avoidance**	**Lack of Continuity of Care**	**Making Palliative care more culturally tailored**	**Improve communication**	**Data Collection and Research**	**Accommodating faith-bases values**
Clarke et al. (2023)	Yes	No	No	Yes	No	No	Yes	No	Yes	Yes	No	No	No
Ventakalasu, Arthur, and Seymour (2013)	Yes	Yes	No	Yes	No	No	No	Yes	No	No	No	No	No
Markham,	Yes	Yes	Yes	Yes	No	Yes	No	No	No	No	No	No	No

Islam, and Faull (2014)													
Moss et al. (2023)	No	No	Yes	No	No	No	No	Yes	No	No	No	No	No
Philips and Taylor (2011)	Yes	Yes	Yes	No	No	Yes	No	No	No	Yes	Yes	No	No
Worth et al. (2009)	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	Yes
Ventakalasu, Seymour, and Arthur (2014)	Yes	Yes	Yes	No	No	No	No	No	No	No	No	No	No
Owens and Randhawa (2004)	Yes	No	No	No	No	Yes	Yes	No	No	No	No	No	No
Samanta, Samanta, and	No	No	No	No	No	No	No	No	No	Yes	No	No	Yes

Madhloom (2017)													
Randhawa et al. (2015)	No	No	No	Yes	No	No	No	No	No	No	No	No	No
Brown et al. (2013)	Yes	Yes	No	Yes	No	No	No	No	Yes	No	No	No	No
Turner and Flemming (2019)	No	Yes	Yes	No	Yes	No	No	No	No	No	No	No	No
Clarke et al. (2022)	No	No	No	No	No	No	No	No	No	No	Yes	No	No
Fang et al. (2016)	Yes	No	No	Yes	Yes	No	No	No	No	No	No	No	No

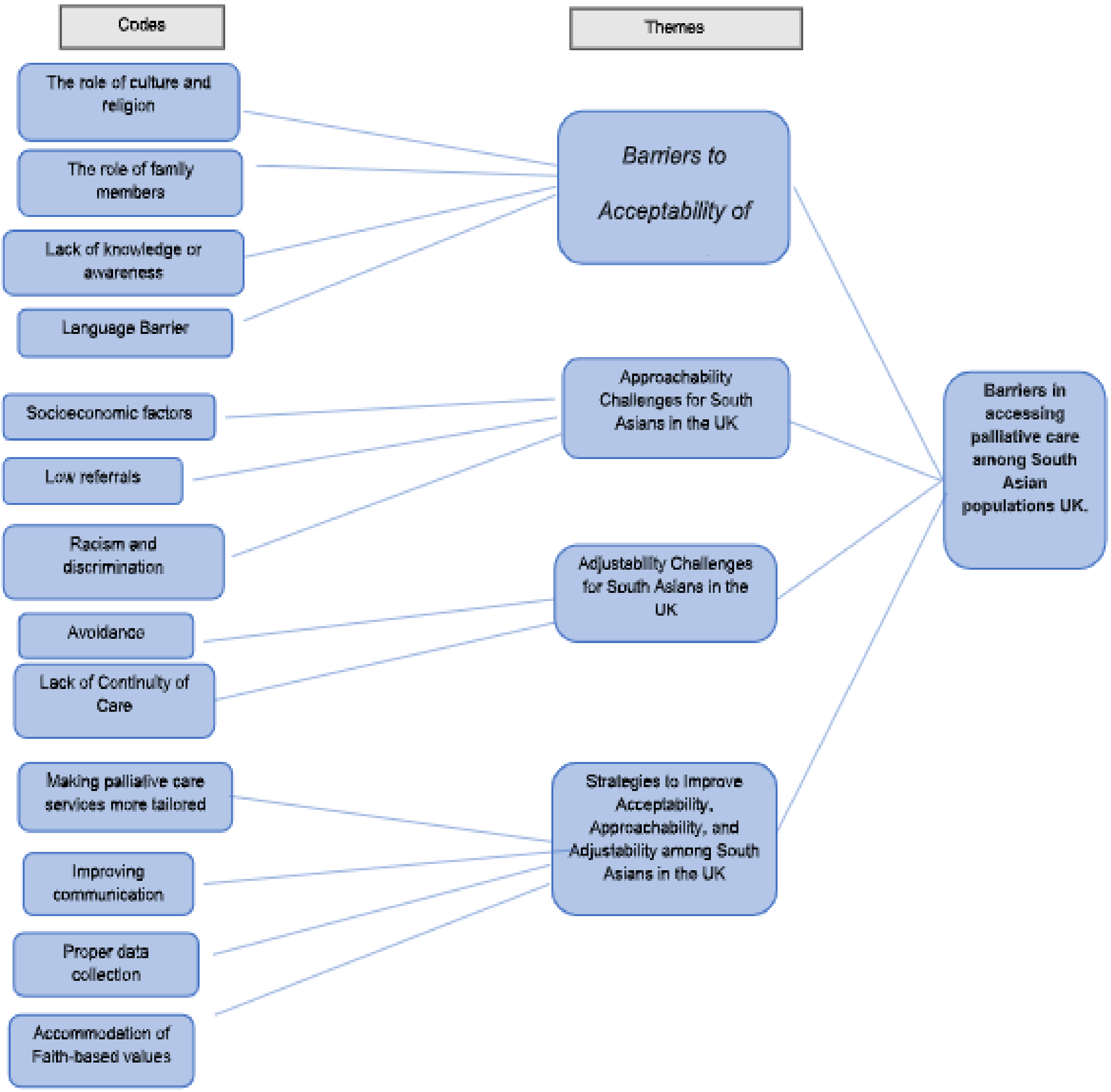


Figure 4 key Themes and subthemes

5.5.1. Barriers to Acceptability of Palliative Care Services among SA

All included studies in the review found that acceptability is among one of the many that lead to an underuse of PC services by SA in the UK. This suggests that there exist certain issues that need to be acknowledged and addressed to ensure that SA, like their white counterparts, develop an acceptability for utilising PC services.

5.5.1.1 The Role of Culture and Religion

Culture and religion strongly influence how PC services are perceived and approached by the SA community. This is highlighted and indicated in all 11 studies included in the review, which include: Clarke et al. (2023), Venkatalasu, Arthur, and Seymour (2013), Markham, Islam, and Faull (2014), Philips and Taylor (2011), Worth et al. (2009), Ventakalasu, Seymour, and Arthur (2014), Owens and Randhawa (2004), Brown et al. (2013), and Fang et al. (2016). Thus, highlighting that culture and religion must be integrated into PC services to make it more inclusive.

Clarke et al. (2023) also found culture to be a major constituent in shaping participants' experiences of PC services. Likewise, Venkatasalu, Arthur, and Seymour (2013) found in the participants' interview that individuals of SA culture do not prefer talking about death and dying, and planning end-of-life care, thus decreasing their access to PC services. Similarly, Markham, Islam, and Faull (2014) found that younger participants believe that SA culture restricts them from disclosing and talking about their illness and want to stay at home among their families. In contrast, findings from Philips and Taylor (2011) indicated that it is a rather poor understanding of the cultures and beliefs of health professionals that serve as a barrier for SA when accessing PC services. Similarly, Worth et al.'s (2009) study also revealed a different perspective on SA. The findings suggest that the SA population shows reluctance to receive PC from professionals having different cultural values than them, Ventakalasu, Seymour, and Arthur's (2014) results revealed that "dying at home" is a part of their culture and they should respect their culture even if they are not in their country. In comparison, Owens and Randhawa (2004) found that PC staff also perceive culture as the major barrier to providing quality PC services to the SA community. Also supported by Brown et al.'s (2013) review that since the roots of PC services have their origin in White Christian culture, professionals face considerable challenges when providing care for any ethnic minority population, including SA. However, Fang et al. (2016) also found in their scoping review that there exist disparities in PC services between the SA population and people from Western culture. The factors that can explain this disparity, include different conceptualization of PC, lack of healthcare coverage, historical contexts etc.

5.5.1.2. The Role of Family Members

Ventakalasu, Arthur, and Seymour (2013), Markham, Islam, and Faull (2014), Philips and Taylor (2011), Worth et al. (2009), Ventakalasu, Seymour, and Arthur (2014), Brown et al.

(2013), and Turner and Flemming (2019) found “the role of family members” as significant in determining the decision to access PC services. Ventakalasu, Arthur, and Seymour’s (2013) second theme “avoidance as protection” talks about how in SA culture family members are expected to make decisions regarding care. Further supported by the findings of Brown et al. (2013) that in SA culture care decisions are to be made by the family members or after mutual discussion with family members. Correspondingly, Turner and Flemming (2019) also found that in SA culture family is responsible for making key decisions about life and health. Subsequently, Philips and Taylor (2011) also found that end-of-life decisions in the SA community are more family-focused. This was further stressed by the study of Markham, Islam, and Faull (2014) where participants expressed that most of the decisions made in PC settings must be family-centric because they would not want their families to suffer. Similarly, Ventakalasu, Seymour, and Arthur (2014) found a common theme in their participants' responses that would like to die at “home” where they are surrounded by their families. In comparison, Worth et al. (2009) found that family members may serve as a barrier by withholding important information from the healthcare professional or because they feel entitled to decide about the patient’s needs.

5.5.1.3 Lack of Knowledge or Awareness

Markham, Islam, and Faull (2014), Moss et al. (2023), Philips and Taylor (2011), Worth et al. (2009), Venkatasalu, Seymour, and Arthur (2014), and Turner and Flemming (2016) highlighted lack of awareness or knowledge as another major barrier limiting access of SA community to PC services in the UK. In their study, Markham, Islam, and Faull (2014) while discussing the theme of “perceived barriers to PC” mentioned that many participants showed a lack of awareness about available services. Similarly, Moss et al.’s (2023) finding also highlighted that there is a lack of awareness about end-of-life or PC in the SA community. In addition, Philips and Taylor (2011) also included a lack of awareness or knowledge of PC services as a major factor contributing to poor access to PC among for SA population. A similar finding was also reported in Worth et al. (2009) discussion that lack of awareness and knowledge of PC services among SA is a common factor contributing to poor access. Also, Venkatasalu, Seymour, and Arthur (2014) highlighted in the discussion section that many of their participants did not talk about hospice care because of their lack of awareness or familiarity with hospice care. In comparison, Turner and Flemming (2016) took a different stance that it is the lack of awareness of spiritual and cultural diversity among healthcare professionals that restricts the access of the SA community to PC services.

5.5.1.4 Language Barrier

Studies, including Clarke et al. (2023), Ventakalasu, Arthur, and Seymour (2013), Markham, Islam, and Faull (2014), Worth et al. (2009), Randhawa et al. (2003), Brown et al.

(2013), and Fang et al. (2016), indicated that language serves a significant barrier for SA population accessing PC services.

Clarke et al. (2023) and Fang et al.’s (2023) findings characterised “language” as a primary barrier to PC for the SA population. Similarly, participants in Ventakalasu, Arthur, and Seymour’s (2013) study reported that language difficulties made it difficult for them to be involved in discussions with doctors regarding end-of-life care. Also backed by the participants recruited by Markham, Islam, and Faull (2014) they were not aware of PC because much of the information communicated to them was not in their language. Similarly. Worth et al. (2009) also found in their study that SA participants are reluctant to access PC services because they feel isolated due to the use of language by professionals that they do not understand. Whereas, Randhawa et al.’s (2003) finding indicated that the language barrier also makes it difficult for healthcare professionals in PC settings to monitor and alleviate the symptoms of SA patients effectively. At the same time, Brown et al. (2013) also highlighted that language largely determines how health and illness are perceived by SA families.

5.5.2 Approachability Challenges for SA in the UK

Studies included in the review also indicated that SA approachability to PC services is low as compared to their White counterparts. The common factors that contribute to this low approachability, include:

5.5.2.1 Socioeconomic Factors

Socioeconomic variables, including lower income and lack of healthcare insurance, impact the ability of the SA community to access PC which is evident in the findings of studies including Worth et al. (2009), Turner and Flemming (2019), and Fang et al. (2016). One of the participants from Worth et al.’s (2009) study declared that asking for financial assistance from others is a major hurdle to accessing PC because what would people think? Similarly, Fang et al. (2016) also includes socioeconomic status as the potential factor explaining why PC for SA is not the same as people from Western culture. However, Turner and Flemming’s (2019) thematic synthesis of qualitative evidence revealed no such association between socioeconomic status and accessing PC.

5.5.2.2 Low Referrals

Studies, including Markham, Islam, and Faul (2014), Philips and Taylor (2011), Worth et al. (2009), and Owens and Randhawa (2004) highlighted low referral rates to PC for SA patients. The findings from Markham, Islam, and Faul's (2014) informative discussion group revealed that there was a lack of appropriate referrals which may be a major reason why the SA community do not use PC services. Similarly, Phillips and Taylor (2011) in their apprenticeship program found that there is a shortage of referrals for patients from the SA population group. Likewise, Worth et al. (2009) also found that among the many factors that contribute to poor access to PC for SA, low numbers of referrals are the most significant one. Subsequently, Owens and Randhawa (2004) also found through semi-structured interviews that referral pathways for SA patients are different. However, unlike Markham, Islam, and Faul (2014), Phillips and Taylor (2011), Worth et al. (2009), and Owens and Randhawa (2004), Clarke et al. (2023) identified that SA patients receive circular referrals in the UK healthcare system where they were bounced between different healthcare organisations or providers or specialists, which often decrease their motivation or willingness to access PC services.

5.5.2.3 Racism and Discrimination

Racism and Discrimination have also been found as a recurring theme in studies like Clarke et al. (2023) and Owens and Randhawa (2004). This highlights that healthcare services in the UK, despite its advancements, are still plagued with discrimination and racism which reduces the access of many ethnic and racial minorities, including SA, to PC services. There were participants in Clarke et al.'s (2023) study who narrated their experiences of racism in PC services. In the same way, Owens and Randhawa (2004) highlighted that at times fixed ideas about sameness and difference can lead to behaviours of racism or stereotyping of minority ethnic communities, such as SA. However, Worth et al.'s (2009) findings highlighted something different than Clarke et al. (2023) and Owens and Randhawa (2004). He found that the SA population experience poor service provision, which is sometimes perceived as racially motivated. In addition, some patients and families were reluctant to seek PC services because they perceived them as racist.

5.5.3 Adjustability Challenges for SA in the UK

The studies included in the review have also highlighted that SA is reluctant to access PC services. This suggests that many SA suffering from terminal illnesses do not access PC services because they feel that they will either not be heard or their needs will not be met.

5.5.3.1 Avoidance

Ventakalasu, Arthur, and Seymour (2013) and Moss et al. (2022) also included Avoidance of death or death-related subjects as the probable reason why SA do not access PC services. In their study, Ventakalasu, Arthur, and Seymour (2013) that in SA culture death is a topic to avoid, so there is hardly any or no discussion related to death or any death-related planning either due to family circumstances or due to practical difficulties. Correspondingly, while discussing the findings of the interviews Moss et al. (2022) mentioned that avoidance is the probable reason why the SA community have limited knowledge of PC services.

5.5.3.2 Lack of Continuity of Care

Out of the 14 included studies, Clarke et al. (2023), Worth et al. (2009), and Brown et al. (2013) indicated that there is a lack of continuity of care for the SA population which leads to hindered communication with healthcare providers, leading to gaps or delays in treatment. The participants in Clarke et al. (2023) study narrated in their qualitative interviews and focus group discussions that they experienced a "lack of continuity of care" in PC services. Also, a dominant theme more evident in the interviews of the SA population in Worth et al. (2009) study is that service provision is not as effective for this population, specifically continuity-of-care which is a key feature of effective care. Correspondingly, Brown et al. (2013) also found that there is an established inequity in service provision and uptake of PC services by the SA population and their families because they are less likely than the rest of the UK population to receive continuity of PC.

5.5.4 Strategies to Improve Acceptability, Approachability, and Adjustability among South-Asian Community in the UK

Studies integrated in the review and discussed in theme 1 have highlighted the barriers that the SA community faces when accessing PC services. This underscores a need for bringing about changes and advancements in PC services in the UK to ensure that SA, like the White population, has equal access to quality end-of-life care services.

5.5.4.1 Making Palliative Care Services More Culturally Tailored

It was indicated in the findings of the studies, including Philips and Taylor (2011), Clarke et al. (2023), Worth et al. (2009), and Samanta, Samanta, and Madhloom that PC services needed to be made more culturally sensitive to ensure that SA individuals accessing PC services do not feel isolated, discriminated, or ignored. Clarke et al. (2023) thus suggested the use of a cultural humility model by PC services to enhance the quality of care for people belonging to SA culture. Similarly, Philips and Taylor (2011) also found through their apprenticeship program that access to PC and end-of-life care services can be significantly improved by making them more culturally appropriate. Subsequently, young participants in Worth et al.'s (2009) study also perceived that PC can be beneficial if they provide culturally sensitive care so families can overcome false stereotypes. Also, Samanta, Samanta, and Madhloom (2017) believe that making PC services more culturally tailored will promote inclusiveness, integration, and embedment.

5.5.4.2 Improving Communication

Philips and Taylor (2011) and Worth et al. (2009) identified that the SA population needs improved communication within PC services, so they are better able to communicate with and understand the information being provided by the healthcare professional. Philips and Taylor (2011) found that through the implementation of the Community Readiness Model, they were able to improve the communication channel among health professionals and between the SA community and health professionals, which has improved their awareness. Also, it improved the ability of the apprentices to challenge historical and negative cultural practices within the PC services. On the other hand, Worth et al. (2009) identified that engaging interpreting services within the PC services would deal with the language barriers and replace over-reliance on families to communicate the needs of the patients.

5.5.4.3 Proper Data Collection and Research

Clarke et al. (2022), unlike Worth et al. (2009), Samanta, Samanta, and Madhloom (2017), Clarke et al. (2023), Clarke et al. (2022), and Phillips and Taylor (2011), believed that to improve access to PC, it is important to undertake proper data collection and research for understanding ethnic disparities and address the prevalent barriers.

5.5.4.4 Accommodation of Faith-Based Values

Worth et al. (2009) and Samanta, Samanta, and Madhloom (2017) identified the need for accommodating faith-based values in PC services to make them more inclusive and promote their acceptance in the SA community. Samanta, Samanta, and Madhloom (2017) found through their empirical study that faith is an important part of SA identity, not being able to hold or practice it at end-of-life care decreases their willingness to access these services, thus their reduced access to PC services. To promote inclusion, faith must be made an essential component of PC services and allowed to be practised as a universal human right. Similarly, Worth et al. (2009) also found that their participants communicated the need for practising their faith at the end of their lives for a peaceful death experience.

5.6 Chapter Summary

This chapter has highlighted the main themes identified in the 14 included studies, which include systemic barriers, personal factors serving as barriers, communication issues and evidence-based recommendations to improve SA's access to PC. These have been further divided into over-arching themes which were discussed in the chapter.

Chapter 6: Discussion

6.1 Introduction

This chapter critically appraises the systemic barriers to access to PC amongst SA communities in the UK. This chapter will argue that the cultural, socioeconomic, and systemic factors are critical to explaining the inequities of this ethnic group in accessing PC. Therefore, this critical overview becomes essential, as it points to the interaction of these barriers and, simultaneously, brings to light the importance of tailored interventions and policy reforms to bridge these disparities to improve access and outcomes of PC for SA in the UK.

6.2 Systemic Barriers Analysis

Culture, language, lack of access, and perception are all structural issues that make it difficult for SA people to access PC in the UK. They are institutional racism, cultural appalling, and socioeconomic deprivation. According to Greenwood et al. (2015), the barriers stated above tend to intertwine with one another; this makes it even more difficult for the patient. However, a critical evaluation shows that while institutions are depicted as having biases, the literature lacks coverage of how comprehensively racism affects, for instance, the distribution of resources and overall healthcare among SA. Clarke et al. (2023) also point out other socio-economic vulnerabilities which affect families hailing from South-Asian origin and put them in a disadvantaged position by not being able to afford superior care. However, there is a limited discussion on how such economic struggles are worsened by racism within healthcare institutions.

Prejudice as a social problem is still present and evident all over the region. According to Ventakalasu et al (2013) bi-culturally trained personnel, few if any, healthcare professionals have adequate training and education in cases concerning the cultural and religious identity of patients of SA descent, there are always misunderstandings and distrust as a result. However, the solution that is offered is that cultural competence training needs to be implemented in the institutions and agencies is useful to ponder whether it is enough to address such ingrained racist' beliefs or if more drastic changes need to be made at the systems levels. Markham et al. (2014) argue that there is a lack of appropriate policies that can effectively address the problems facing ethnic minorities. Thus, most of these barriers including socio-economic disadvantages are probably common to all ethnic minority groups, but some barriers like language and culture barriers may be more obviously found in SA. According to Philips and Taylor (2011), technology-related barriers are not considered in policymaking and minority experiences are simplified for the sake of policymaking.

Therefore, to eliminate them it is necessary to implement several coordinated strategies. This encompasses cultural competency training but also changes in health system policies and legislation that seek to enhance SA's utilization of health services and guarantee that they are fairly treated in health organizations.

6.3 Impact on Patient Outcomes

Patient results of SA are worse due to insufficient culturally appropriate care, more admissions, uncontrolled symptoms, and overall dissatisfaction. Temel et al. (2010) showed that culturally sensitive PC has a positive impact on the level of satisfaction of the patient as well as the frequency of avoidable hospitalization. Thus, culturally competent care is essential in the management of an individual's health and other related aspects for enhanced results to be achieved. However, the analysis of the papers presented in this review indicates that though the utility of these competencies has been established, many clinical practitioners still lack the required training in the same, which implies that the current approaches used in training may not be sufficient.

Furthermore, Jones et al. (2024) mentioned that systemic racism in healthcare systems results in disparities in referral to PC for the SA community in comparison to the White community. This evidence held not corroborative of the theoretical benchmark of culturally induced socio-spatial barriers for women; also pointed towards institutional policy and practice deficits. A better strategy would be to consider individual cultural competence and advances in the care delivery system that would prevent discrimination and exclusion.

6.4 Cultural and Religious Standards

Cultural and religious beliefs play a significant role when the SA population seek the services of PC. According to Koffman et al. (2014), the community holds a cultural belief which makes them avoid any interferences with what is considered traditional by white physicians regarding family-centred care. This is in contrast with the study by Mohammed et al. (2017) where they highlight the role of the family in decision-making while at the same time pointing out the lack of coherence of these cultural practices as a reason for the lack of care.

This is relevant because it shows a lack of provision where healthcare service delivery addresses the issues of religious beliefs for clients. Despite the importance of using cultural beliefs in care, a major problem that has been highlighted in this argument is the failure of caregivers to keep a balance between medical advice and cultural beliefs where caregivers may end up misinforming the patients or being mistrusted by the patients. This could be relevant to establishing specific training for nurses, doctors and other healthcare providers to create awareness about such cultural practices and how they can be incorporated into their routine practices (Schmidt et al. 2021).

6.5 Discussion on Avoidance and Family Roles

SA’s preference not to seek PC services is because of their culture when it comes to death. This study done by Ventakalasu et al. (2013) found that avoidance is a cultural defence mechanism which was in many ways facilitated by religion and the inability to talk about death. This shows that cultural machinery can hinder HCWs’ ability to talk to the patient about the need to receive care at the end of their lives. On the other hand, Owens and Randhawa (2004) established that decision-making by families to participate in PC leads to late admission to the program.

This is important because family-integrated roles and culture-based avoidances put difficulty in offering timely PC services. Another strategy might be to engage community leaders and religious leaders and try to bring new discussions about the availability of PC to SA people while trying to fit it into the cultural context of SA families with the help of doctors (Martina et al., 2022).

6.6 Impact of Language Barriers

This aspect emphasizes that overcoming a language barrier reduces access to and quality of PC as it affects communication and the whole experience of the provided care. Poor communication between them and care providers may lead to misunderstandings, misdiagnosis, and poor treatment planning, thus failing to adhere to the patient's needs and preferences (Worth et al. 2009). While interpreters and translation materials may be available, these solutions often fail to communicate effectively across the gap because of the subtleties in language and cultural expression, which may defy direct translation (Randhawa et al. 2003).

Critically, the reliance on family members to interpret further complicates care; this might introduce biases or lead to incomplete translations of what was said, especially in susceptible areas like prognosis or decisions regarding the end of life (Samanta et al. 2017). Lack of proper communication strategies and approaches in a culturally sensitive way may increase feelings of exclusion and mistrust among SA patients, which further deters their use of services for PC (Owens and Randhawa, 2004). To counteract these barriers, a more robust approach should focus on culturally competent communication training in healthcare providers themselves, integrating bicultural healthcare workers, which would go a long way in improving the quality of patient-provider interactions and care (Green et al. 2018).

6.7 Socioeconomic Disadvantages

Socioeconomic disparities are one of the main barriers to the utilization of PC by SA, reflecting the broader systemic inequities within the UK healthcare system. Low-income levels, low employment, and a lack of healthcare resources particularly burden many SA, all contributing factors in minimizing access to specialized care services, including those for PC (Philips and

Taylor, 2011). These socioeconomic challenges sometimes intersect with other cultural and language barriers, adding to the disadvantage and further limiting access to care (Clarke et al. 2023).

Significantly, a lack of financial means further exacerbates the level and quality of care accessed. For instance, in comparison to their counterparts, SA from lower socioeconomic backgrounds are more likely to rely on public health services that do not always provide palliative services suited to their needs (Worth et al. 2009). This strategy may involve relying on emergency services or acute care, which is needed to be more credibly prepared to provide comprehensive PC. Thus, the health inequities are likely to be exacerbated (Venkatasalu et al. 2013). Such a socioeconomic barrier requires proper policy intervention involving financial incentives, considering the availability of culturally competent PC within the catchment areas of underserved communities (Venkatasalu et al. 2013).

6.8 Recommendations for Improvement

The systemic barriers to accessing PC among SA require a multidimensional intervention that involves policy reforms, improved cultural competencies among practitioners, and engagement with the community. One recommendation is to develop and institute compulsory training in cultural competence for health professionals regarding the specific needs and preferences of SA communities (Clarke et al. 2023). The latter aspect includes training that can provide beyond superficial cultural awareness to equip service providers to interactively communicate and engage in patient care from diverse backgrounds, which helps improve care outcomes (Philips and Taylor, 2011).

The other essential recommendations are community-based outreach programs that develop in active collaboration with SA community leaders and faith-based organizations. This will go a long way in improving awareness and acceptability of PC by framing it in contexts that are culturally relevant and sensitive to common misconceptions (Venkatasalu et al. 2013). Interventions in policies should, however, emphasize the integration of more bilingual and bicultural health professionals into the composition of a PC team to act better in the role of connectors and bridge builders in ensuring chapatis between care planning and the values of patients. (Samanta et al. 2017).

In addition, these financial barriers can be cushioned through the provision of subsidies or financial support plans for low-income SA families to ensure equal utilization of PC services regardless of income status. These may include subsidizing transportation costs to and from the healthcare facilities, covering home-based services for PC patients, and subsidizing medication and other PC services or needs (Worth et al. 2009).

A critical review of these recommendations indicates that, apart from enhancing accessibility and quality in PC for SA, this set of recommendations will lead to increased trust and engagement between SA communities and healthcare providers. These recommendations need sustained commitment from policy brokers and healthcare institutions to equity and inclusivity in healthcare delivery. These would also involve continuous evaluation and change so that the emerging needs of the SA communities are effectively met (Moss et al. 2023). The above comprehensive and culturally sensitive approach aims to rectify such systemic barriers and bring the UK closer to achieving equitable PC.

6.9 Implications for Policy and Practice

The findings of this critical analysis hold significant implications for policy and practice regarding providing PC. First, there is a clear need for policy reforms that explicitly address the needs of the SA population concerning culture and language framed into the broader policy context of healthcare equity (Clarke et al. 2023). It includes the development of national guidelines on the need to incorporate cultural competence in all levels of the delivery of PC, thereby making access to information available, culturally accepted, and relevant to diverse patient populations (Venkatasalu et al. 2013).

From a practice angle, healthcare providers must adopt a more holistic approach that considers the social, cultural, and economic contexts of SA patients. This may require incorporation into alternative models of care to facilitate care for traditional medicine and family-centred decision-making valued highly by the concerned communities (Philips and Taylor, 2011). Moreover, the healthcare system should invest in high-quality data collection mechanisms for monitoring disparities in access to care and outcomes among ethnic minorities while using this information in ongoing service delivery improvements (Moss et al. 2023). Eventually, all these policy and practice changes will be necessary to strip the systemic barriers to creating an inclusive environment of PC that respects and meets the needs of all patients.

6.10 Strengths and Limitations

The critical analysis in this chapter offers an in-depth inquiry into the systemic barriers impacting access to PC for SA individuals in the UK. One strength of this analysis is its comprehensive approach, integrating findings from multiple studies into a nuanced understanding of the barriers faced by this community (Clarke et al. 2023). A critical lens provides a deeper exploratory scope into interconnected cultural, socioeconomic, and systemic factors that would make the view holistic and far more complete than a simple description of these barriers (Venkatasalu et al. 2013).

However, there are limitations to consider. The reliance on qualitative studies means that findings may not be generalizable across all SA subgroups, as cultural and religious practices can vary significantly within this population (Samanta et al. 2017). The chapter is also primarily informed by studies conducted within the UK context. Consequently, findings may not generalize to other countries with different healthcare systems and cultural matrices of relationships (Worth et al. 2009). Thus, future studies must focus on more representative populations and address how such potential barriers play out in geographic contexts different from those studied. Although many limitations are discussed here, this review gives some insights that will be helpful. At the same time, policymakers and planners implement targeted interventions to improve access to PC among SA.

6.11 Chapter Summary

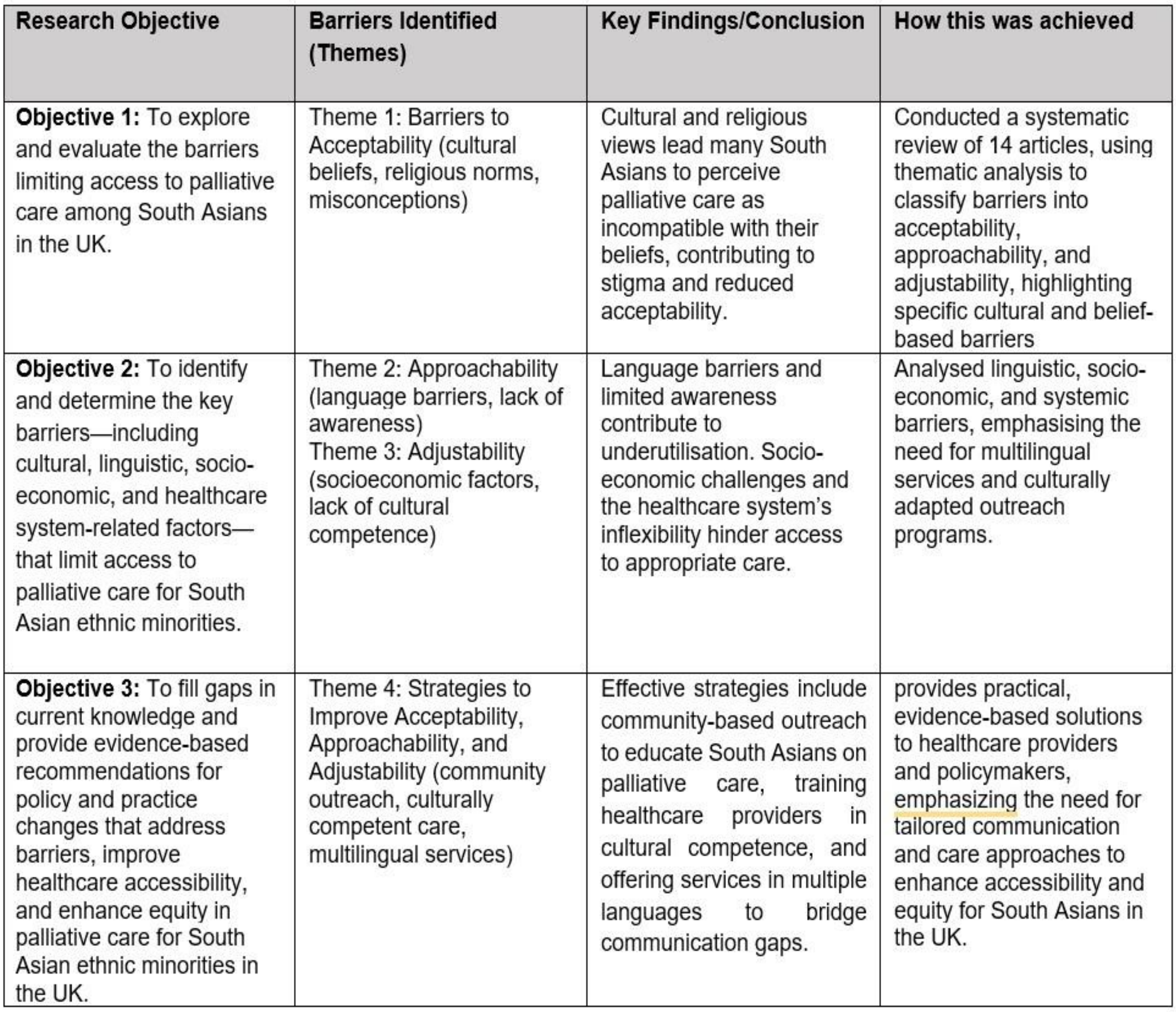
The chapter provides a critical analysis of access to PC for SA living in the UK, highlighting interactions between cultural and socioeconomic factors and institutional barriers. The report points out the critical challenges: insensitive cultural practices, inadequate language proficiency, and socioeconomic disadvantage, with recommendations for improvement supported by evidence. Implications for policy and practice emphasize that culturally competent models of care should be developed along with targeted interventions to reduce these inequities. Although there is a limitation to generalizing its findings, the review makes a strong foundation from which future efforts can be made to improve access to and quality of PC for SA communities within the UK.

Chapter 7: Conclusion

7.1. Introduction

This chapter summarises the study's topic, aim, research question, main findings, significance, and concluding thoughts. This systematic review aimed to identify barriers to palliative care (PC) for South Asian (SA) ethnic minorities in the UK, resolve evidence gaps, and make suggestions for enhancing healthcare equality and outcomes. The findings' implications, as well as recommendations for future practice and study, are presented. This table summarises the research objectives.

Table 4: Research Objectives



Research Objective	Barriers Identified (Themes)	Key Findings/Conclusion	How this was achieved
Objective 1: To explore and evaluate the barriers limiting access to palliative care among South Asians in the UK.	Theme 1: Barriers to Acceptability (cultural beliefs, religious norms, misconceptions)	Cultural and religious views lead many South Asians to perceive palliative care as incompatible with their beliefs, contributing to stigma and reduced acceptability.	Conducted a systematic review of 14 articles, using thematic analysis to classify barriers into acceptability, approachability, and adjustability, highlighting specific cultural and belief-based barriers
Objective 2: To identify and determine the key barriers—including cultural, linguistic, socio-economic, and healthcare system-related factors—that limit access to palliative care for South Asian ethnic minorities.	Theme 2: Approachability (language barriers, lack of awareness) Theme 3: Adjustability (socioeconomic factors, lack of cultural competence)	Language barriers and limited awareness contribute to underutilisation. Socio-economic challenges and the healthcare system's inflexibility hinder access to appropriate care.	Analysed linguistic, socio-economic, and systemic barriers, emphasising the need for multilingual services and culturally adapted outreach programs.
Objective 3: To fill gaps in current knowledge and provide evidence-based recommendations for policy and practice changes that address barriers, improve healthcare accessibility, and enhance equity in palliative care for South Asian ethnic minorities in the UK.	Theme 4: Strategies to Improve Acceptability, Approachability, and Adjustability (community outreach, culturally competent care, multilingual services)	Effective strategies include community-based outreach to educate South Asians on palliative care, training healthcare providers in cultural competence, and offering services in multiple languages to bridge communication gaps.	provides practical, evidence-based solutions to healthcare providers and policymakers, emphasizing the need for tailored communication and care approaches to enhance accessibility and equity for South Asians in the UK.

7.2. Implications of Findings

The following implications are drawn from the findings:

- **Cultural Competency and Policy Reform**: Culturally competitive models of care should be given priority. Religious and cultural competency training, which includes the SA population, is crucial to helping respective healthcare workers.
- **Improved Language Services:** Based on these findings, communication barriers in health care services call for policies that promote the employment of those who understand different languages and provide translation tools.
- **Community Outreach Programs**: This means that increasing awareness about PC services among the SA population is necessary. Community interventions should aim to increase knowledge and change the perception of the indigenous population regarding PC.
- **Government and Policy Action**: Policymakers must target eradicating institutional prejudice and structural racism; boosting the numbers of recommendations; as well as enhancing the palatability of PC to SA.

7.3 Scope and Limitations

Scope

It is also important to note that this study was aimed mainly at the UK and considered the specificity of the healthcare system, culture, and population density of this area. Since the findings were done within the UK context, the conclusion that is deduced is right from the experiences of UK SA and the barriers they face in accessing PC. This focus also ensures that an elaborate analysis of policies and practices within the UK is conducted. However, it also narrows down the generalisability of these findings for other healthcare systems, especially for the ones existing in countries with different approaches to healthcare delivery or with different cultural backgrounds.

Limitations

- **Geographic Focus**

Some exceptions, for example, the articles reviewed for this paper originate from UK-based studies hence it is difficult to generalize findings to other regions. Healthcare systems in other countries, especially in the Western world may lack similar systemic problems or cultural barriers regarding PC access. Consequently, the recommendations that one is likely to derive from this study, may not apply to the general population.

- **Reliance on Qualitative Data**

In this research, I have included mostly qualitative data collection techniques, which give detailed information about users but may not be highly objective. These findings are therefore suggestive and might not necessarily represent the complexities within the diverse subgroups of SA who might be disagreeing in practice, beliefs and culture, religion and practices. Due to using qualitative data, the findings of the study are in a way analytical and may not be generalized to all other communities or persons who belong to the South Asia heritage around the globe. Such limitations suggest that further research must incorporate quantitative research methodologies, and increase the geographical generalisability of participants, and the demographic diversity of participants to achieve considerably more general findings.

7.4 Recommendations for Practice

Some of the practice recommendations are:

- Cultural Competency Training: It is recommended to provide culturally competent training to the healthcare provider to enable the provision of culturally sensitive PC to the SA population. Also, it will allow them to become more respectful and integrate their beliefs to ensure equitable access to comprehensive end-of-life care (Papadopoulos et al. 2022).
- Language Support Services: To address language barriers, it is recommended that PC services hire multilingual healthcare staff, interpreters and translated informational material to facilitate communication between SA patients and healthcare providers. This will ensure that patients and their family members adequately understand the treatment options and make informed decisions about their care (Campbell et al. 2021).
- Community Engagement and Outreach: Community outreach programs are considered effective in increasing engagement and awareness about PC services, and their benefits, and encourage their utilisation (Yosick et al. 2019). Thus, it is recommended that community health workers and liaisons be involved in fostering trust and facilitating access to PC services for the SA population.

7.3. Recommendations for Future Research

1. Broaden Geographic Scope:

Future research should cover countries that have many SA people residing in them including North America, New Zealand, Australia and Middle Eastern areas like Saudi Arabia, and Kuwait. Cross-sectional research could reveal broad trends and difficulties with providing ethnic minority patients with PC to create appropriate kinds of interventions.

2. Explore Systemic Racism in Depth: Explore Systemic Racism in Depth:

Future research should examine the details of how racism is experienced at systemic levels and on different healthcare procedures for SA and the impact of racism on their PC. Understanding prejudice in healthcare is crucial where its impact is most detrimental to ethnic minorities' well-being.

3. Longitudinal Studies:

Design long-term research with follow-ups to evaluate the effectiveness of the measures designed to increase culturally sensitive approaches in the delivery of healthcare. These studies should assess the long-term impact of training and policies, for example, language support services on, healthcare accessibility and satisfaction among SA communities.

7.4. Conclusion

This research on the topic "Barriers to accessing PC for ethnic minorities, particularly SA, in the UK" was conducted to identify what are the different barriers to accessing PC for ethnic minorities, particularly SA, in the UK. For this purpose, a systematic review methodology was adopted, and 14 relevant research articles were selected and included. The thematic analysis of these 14 studies, revealed four key themes and several sub-themes. It was identified that three factors serve as barriers for the SA population when accessing PC services, including acceptability, approachability, and adjustability.

The acceptability includes the role of culture and religion, the role of family and religion, the language barrier, and lack of knowledge or awareness. Approachability factors that serve as barriers include socioeconomic factors, racism, and low referral rates. Adjustability includes avoidance and lack of continuity of care. The fourth theme of the systematic review revolved around strategies to improve the acceptability, approachability, and adjustability of the SA population in the UK. These recommendations, include making PC services more culturally tailored, proper collection of data and research, improving communication, and incorporating faith-based values.

The findings of the study thus underscore the need to make PC more accessible and address the barriers faced by the SA community. It highlighted the differences that exist in accessing PC by different ethnic groups, including the SA community in the UK. The evidence incorporated in the study suggested that PC services remain largely inaccessible for the SA community in the UK due to several factors, which range from racism and discrimination to lack of awareness or knowledge and language barriers. It is thus established that being affiliated with a particular ethnic group in the UK largely determines how readily accessible PC services will be to the individual. This study thus calls for immediate actions to be taken by the government and policymakers to achieve equity in care and ensure that SA in the UK, like their White counterparts, can die more comfortably and peacefully.

References

Adams, W.C., (2015). Conducting semi-structured interviews. *Handbook of practical program evaluation*, pp.492-505. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781119171386.ch19 (Accessed: 08 July 2024).

Aguinis, H. Henle, C.A., (2004). Ethics in research. *Handbook of research methods in industrial and organizational psychology*, pp.34-56. Available at: https://books.google.com.pk/books?hl=en&lr=&id=TW8BCgAAQBAJ&oi=fnd&pg=PA34&dq=ethics+in+research&ots=xQ2ajguc1s&sig=vJgWUvdX3O0h9TaNLxETrs9_xow&redir_esc=y#v=onepage&q=ethics%20in%20research&f=false (Accessed: 08 July 2024).

Aker, N., Frost, R., Walters, K., West, E. and Davies, N., (2023). Health inequalities for older people from minority ethnic groups receiving palliative care and end of life care: A scoping review protocol. *Plos one*, *18*(5), p.e0285109. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10153691/ (Accessed: 19 July 2024).

Akyıldız, S.T. and Ahmed, K.H., (2021). An overview of qualitative research and focus group discussion. *International Journal of Academic Research in Education*, *7*(1), pp.1-15. Available at: https://dergipark.org.tr/en/pub/ijare/article/866762 (Accessed: 08 July 2024)

Bajwah, S., Edmonds, P., Yorganci, E., Chester, R., Russell, K., Lovell, N., Marsh, L. and Sleeman, K.E., (2021). The association between ethnicity, socioeconomic deprivation and receipt of hospital-based palliative care for people with COVID-19: A dual center service evaluation. *Palliative Medicine*, *35*(8), pp.1514-1518. Available at: https://journals.sagepub.com/doi/pdf/10.1177/02692163211022959?download=true&__cf_chl_tk=7QjYqpZ5WuU9mZ0HvdVk24jFk5p61TqDbxBPbJpqcLU-1721711350-0.0.1.1-9706 (Accessed: 23 July 2024).

Barnato, A.E., Anthony, D.L., Skinner, J., Gallagher, P.M. and Fisher, E.S., (2009). Racial and ethnic differences in preferences for end-of-life treatment. *Journal of General Internal Medicine*, *24*, pp.695-701. Available at: https://link.springer.com/article/10.1007/s11606-009-0952-6 (Accessed: 19 July 2024)

Bose, S. and Jalal, A., (2022). *Modern South Asia: history, culture, political economy*. Routledge. Available at: https://www.taylorfrancis.com/books/mono/10.4324/9781003224488/modern-south-asia-sugata-bose-ayesha-jalal (Accessed: 19 July 2024).

Bowers, S.P., Chin, M., O'Riordan, M. and Cardiff, E., (2022). The end of life experiences of people living with socio-economic deprivation in the developed world: an integrative review. *BMC Palliative Care*, *21*(1), p.193. Available at: https://link.springer.com/article/10.1186/s12904-022-01080-6 (Accessed: 23 July 2024).

Braun, V. and Clarke, V., (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), pp.77-101. Available at: https://www.tandfonline.com/doi/abs/10.1191/1478088706QP063OA (Accessed: 16 August 2024).

Broom, A., Good, P., Kirby, E. and Lwin, Z., (2013). Negotiating palliative care in the context of culturally and linguistically diverse patients. *Internal Medicine Journal*, *43*(9), pp.1043-1046. Available at: https://onlinelibrary.wiley.com/doi/pdf/10.1111/imj.12244?casa_token=eqnsP6iDCG4AAAAA

%3AvBUOl0He-55JTL21KkhBxRwJ170xL9aErmCB3ijZD9bkkNHuSU4T1VcwY3kQaSGzxUVn9uQtmVG6 (Accessed: 09 August 2023).

Broom, A., Good, P., Kirby, E. and Lwin, Z., (2013). Negotiating palliative care in the context of culturally and linguistically diverse patients. *Internal Medicine Journal*, *43*(9), pp.1043-1046. Available at: https://onlinelibrary.wiley.com/doi/pdf/10.1111/imj.12244?casa_token=eqnsP6iDCG4AAAAA%3AvBUOl0He-55JTL21KkhBxRwJ170xL9aErmCB3ijZD9bkkNHuSU4T1VcwY3kQaSGzxUVn9uQtmVG6 (Accessed: 09 August 2023).

Brown, E., Patel, R., Kaur, J. and Coad, J., (2013). The interface between South Asian culture and palliative care for children, young people, and families—A discussion paper. *Issues in comprehensive pediatric nursing*, *36*(1-2), pp.120-143. Available at: https://www.tandfonline.com/doi/abs/10.3109/01460862.2013.787131 (Accessed: 23 July 2024).

Buccheri, R.K. and Sharifi, C., (2017). Critical appraisal tools and reporting guidelines for evidence-based practice. *Worldviews on Evidence-Based Nursing*, *14*(6), pp.463-472. Available at: https://sigmapubs.onlinelibrary.wiley.com/doi/abs/10.1111/wvn.12258 (Accessed: 18 July 2024).

Bulmer, M., (2017). Concepts in the analysis of qualitative data. In *Sociological research methods* (pp. 241-262). Routledge. Available at: https://www.taylorfrancis.com/chapters/edit/10.4324/9781315129952-16/concepts-analysis-qualitative-data-martin-bulmer (Accessed: 16 August 2024)

Burm, S., Boese, K., Faden, L., DeLuca, S., Huda, N., Hibbert, K. and Goldszmidt, M., (2019). Recognizing the importance of informal communication events in improving collaborative care. *BMJ quality & safety*, *28*(4), pp.289-295. Available at: https://qualitysafety.bmj.com/content/28/4/289.abstract (Accessed: 08 July 2024).

Byrne, D., (2022). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & quantity*, *56*(3), pp.1391-1412. Available at: https://link.springer.com/article/10.1007/s11135-021-01182-y (Accessed: 16 August 2024).

Cain, C.L., Surbone, A., Elk, R. and Kagawa-Singer, M., (2018). Culture and palliative care: preferences, communication, meaning, and mutual decision making. *Journal of pain and symptom management*, *55*(5), pp.1408-1419. Available at: https://www.sciencedirect.com/science/article/pii/S0885392418300277 (Accessed: 23 July 2024).

Calanzani, N., Koffman, J. and Higginson, I., (2013). Palliative and end-of-life care for Black, Asian and Minority Ethnic Groups in the UK: Demographic profile and the current state of palliative and end of life care provision. *London: King's College London, Cicely Saunders Institute*. Available at: https://abdn.elsevierpure.com/en/publications/palliative-and-end-of-life-care-for-black-asian-and-minority-ethn (Accessed: 20 August 2024).

Calanzani, N., Koffman, J. and Higginson, I.J., (2013). Palliative and end-of-life care for Black, Asian and Minority Ethnic groups in the UK. Available at: https://www.researchgate.net/publication/267762679_Palliative_and_end_of_life_care_for_Black_Asian_and_Minority_Ethnic_groups_in_the_UK (Accessed: 23 July 2024).

Campbell, L.M. and Amin, N.N., (2014). A qualitative study: potential benefits and challenges of traditional healers in providing aspects of palliative care. *Rural and Remote Health*, *14*(2), pp.15-23. Available at: https://www.rrh.org.au/journal/article/2378 (Accessed: 23 July 2024).

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D. and Walker, K., (2020). Purposive sampling: complex or simple? Research case examples. *Journal of research in Nursing*, *25*(8), pp.652-661. Available at: https://journals.sagepub.com/doi/abs/10.1177/1744987120927206 (Accessed: 08 July 2024).

Clandinin, D.J. and Caine, V., (2013). Narrative inquiry. In *Reviewing qualitative research in the social sciences* (pp. 166-179). Routledge. Available at: https://www.taylorfrancis.com/chapters/edit/10.4324/9780203813324-17/narrative-inquiry-jean-clandinin-vera-caine (Accessed: 08 July 2024).

Clarke, G., Crooks, J., Trotter, S., MacArtney, J., Hussain, J., Bhatti, R., Mirza, Z. and Bennett, M., (2023). Access to palliative care by people from South Asian communities in the UK: a qualitative study using Narrative Inquiry. *BMJ Supportive & Palliative Care*, *13*(Suppl 1), pp.A16-A16. Available at: https://www.proquest.com/openview/98434bbc045cc4443f54a15222b1b787/1?pq-origsite=gscholar&cbl=2040968 (Accessed: 4 August 2024).

Clarke, G., Hussain, J.A., Allsop, M.J. and Bennett, M.I., (2022). Ethnicity and palliative care: we need better data–five key considerations. *BMJ Supportive & Palliative Care*, *13*(4), pp.429-431. Available at: https://spcare.bmj.com/content/13/4/429.abstract (Accessed: 4 August 2024).

Clarke, G., Hussain, J.A., Allsop, M.J. and Bennett, M.I., (2023). Ethnicity and palliative care: we need better data–five key considerations. *BMJ Supportive & Palliative Care*, *13*(4), pp.429-431. Available at: https://spcare.bmj.com/content/13/4/429 (Accessed: 23 July 2024).

Coupland, V.H., Madden, P., Jack, R.H., Møller, H. and Davies, E.A., (2011). Does the place of death from cancer vary between ethnic groups in South East England? *Palliative medicine*, *25*(4), pp.314-322. Available at: https://journals.sagepub.com/doi/abs/10.1177/0269216310395986 (Accessed: 23 July 2024).

Creswell, J.W. and Creswell, J.D. (2018). Research design: Qualitative, quantitative and mixed methods approaches (5th ed). Thousand Oaks: SAGE. Available at: https://www.ucg.ac.me/skladiste/blog_609332/objava_105202/fajlovi/Creswell.pdf (Accessed: 08 July 2024).

Crowe, M. and Sheppard, L., (2011). A general critical appraisal tool: an evaluation of construct validity. *International journal of nursing studies*, *48*(12), pp.1505-1516. Available at: https://www.sciencedirect.com/science/article/abs/pii/S0020748911002598 (Accessed: 05 July 2024).

DiCicco-Bloom, B. and Crabtree, B.F., (2006). The qualitative research interview. *Medical education*, *40*(4), pp.314-321. Available at: https://asmepublications.onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2929.2006.02418.x (Accessed: 08 July 2024)

Diversity UK. (2023, March 20). Census 2021 data reveals the ethnic make-up of the UK population. Diversity UK. Available at: https://diversityuk.org/census-2021-data-reveals-ethnic-make-up- of-uk-population/#:~:text=According%20to%20the%202021%20Census. (Accessed: 19 July 2024).

Doody, O. and Bailey, M.E., (2016). Setting a research question, aim and objective. *Nurse* *researcher*, *23*(4). Available at: https://journals.rcni.com/nurse-researcher/setting-a-research-question-aim-and-objective-nr.23.4.19.s5 (Accessed: 08 July 2024).

Dosani, N., Bhargava, R., Arya, A., Pang, C., Tut, P., Sharma, A. and Chasen, M., (2020). Perceptions of palliative care in a South Asian community: findings from an observational study. *BMC Palliative Care*, *19*, pp.1-10. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7491098/ (Accessed: 23 July 2024).

Eberle, T.S., (2014). Phenomenology as a research method. *The SAGE Handbook of qualitative data analysis*, pp.184-202. Available at: https://www.torrossa.com/en/resources/an/5018778#page=209 (Accessed: 08 July 2024).

Evans, M. and Johnson, P. (2021). Institutional Racism in Healthcare: The Impact on Access to Palliative Care for Ethnic Minorities. Journal of Ethnic and Cultural Diversity in Social Work, 30(4), pp. 350-365.

Evans, N., Meñaca, A., Andrew, E.V., Koffman, J., Harding, R., Higginson, I.J., Pool, R. and Gysels, M., (2012). A systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom. *Journal of pain and symptom management*, *43*(2), pp.261-286. Available at: https://www.sciencedirect.com/science/article/pii/S0885392411003757 (Accessed: 23 July 2024).

Fang, M.L., Sixsmith, J., Sinclair, S. and Horst, G., (2016). A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping review. *BMC geriatrics*, *16*, pp.1-14. Available at: https://link.springer.com/article/10.1186/s12877-016-0282-6 (Accessed: 4 August 2024).

Frank Harkin and Curie, M. (2013). *Report: Palliative and end-of-life care for Black, Asian and Minority Ethnic (BAME) groups in the UK Demographic profile and evidence on the current state of palliative and end-of-life care provision*. [online] Available at: https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_exec-summary.pdf. (Accessed: 23 July 2024).

Gill, P., Stewart, K., Treasure, E. and Chadwick, B., (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*, *204*(6), pp.291-295. Available at: https://www.nature.com/articles/bdj.2008.192 (Accessed: 08 July 2024).

Government UK (2023). *Economic inactivity*. [online] www.ethnicity-facts-figures.service.gov.uk. Available at: https://www.ethnicity-facts-figures.service.gov.uk/work-pay-and-benefits/unemployment-and-economic-inactivity/economic-inactivity/latest/. (Accessed: 23 July 2024).

Green, A., Jerzmanowska, N., Green, M. and Lobb, E.A., (2018). 'Death is difficult in any language': a qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. Palliative medicine, 32(8), pp.1419-1427. Available at: https://journals.sagepub.com/doi/abs/10.1177/0269216318776850 (Accessed: 12 September 2024).

Green, B., (2013). Narrative inquiry and nursing research. *Qualitative Research Journal*, *13*(1), pp.62-71. Available at: https://www.emerald.com/insight/content/doi/10.1108/14439881311314586/full/html (Accessed: 08 July 2024).

Greenwood, N., Holley-Moore, G., and Ellmers, T. (2015). Language Barriers in Healthcare: The Importance of Effective Communication. Health & Social Care in the Community, 23(3), pp. 283-291. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7201401/ (Accessed: 20 July 2024).

Griffis, K., Thadani, V. and Wise, J., (2008). Making authentic data accessible: The sensing the environment inquiry module. *Journal of Biological Education*, *42*(3), pp.119-122. Available at: https://www.tandfonline.com/doi/abs/10.1080/00219266.2008.9656124 (Accessed: 08 July 2024).

Griffiths, C., Kaur, G., Gantley, M., Feder, G., Hillier, S., Goddard, J. and Packe, G., (2001). Influences on hospital admission for asthma in south Asian and white adults: qualitative interview study. *Bmj*, *323*(7319), p.962. Available at: https://www.bmj.com/content/323/7319/962.full (Accessed: 23 July 2024).

Gunaratnam, Y., (2007). *Improving the quality of palliative care*. London: Race Equality Foundation. Available at: http://www.better-health.org.uk/sites/default/files/briefings/downloads/health-brief1.pdf (Accessed: 23 July 2024).

Harrison, J.K., Reid, J., Quinn, T.J. and Shenkin, S.D., (2017). Using quality assessment tools to critically appraise ageing research: a guide for clinicians. *Age and ageing*, *46*(3), pp.359-365. Available at: https://academic.oup.com/ageing/article/46/3/359/2654237 (Accessed: 05 July 2024).

Homte, J.K., Batchakui, B. and Nkambou, R., (2022). Search engines in learning contexts: a literature review. *International Journal of Emerging Technologies in Learning (iJET)*, *17*(2), pp.254-272. Available at: https://www.learntechlib.org/p/220473/ (Accessed: 08 July 2024).

Hossain, M.Z., Tarafdar, S.A., Kingstone, T., Campbell, P. and Chew-Graham, C.A., (2022). From detection to preparing for the end-of-life: A qualitative exploration of the South Asian family carers' experiences of the journey with dementia. *Health & Social Care in the Community*, *30*(6), pp.e5135-e5144. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.13930 (Accessed: 18 July 2024).

Joffe, H., (2011). Thematic analysis. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*, pp.209-223. Available at: https://onlinelibrary.wiley.com/doi/book/10.1002/9781119973249#page=212 (Accessed: 16 August 2024).

Johnson, G.A. and Vindrola-Padros, C., (2017). Rapid qualitative research methods during complex health emergencies: A systematic literature review. Social Science & Medicine, 189, pp.63-75. Available at https://www.sciencedirect.com/science/article/pii/S0277953617304628 (Accessed: 24 August 2024).

Johnson, P. and Evans, M. (2013). Exploring Systemic Racism in Healthcare: A Focus on Palliative Care Services for South Asians. Journal of Healthcare Disparities, 22(3), pp. 198-210. Available at: https://www.liebertpub.com/doi/abs/10.1089/jpm.2013.9468

Jones, T., Luth, E.A., Lin, S.Y. and Brody, A.A., (2021). Advance care planning, palliative care, and end-of-life care interventions for racial and ethnic underrepresented groups: a systematic review. *Journal of pain and symptom management*, *62*(3), pp.e248-e260. Available at: https://www.sciencedirect.com/science/article/abs/pii/S0885392421003249 (Accessed: 18 July 2024).

Jonnalagadda, S.R., Goyal, P. and Huffman, M.D., (2015). Automating data extraction in systematic reviews: a systematic review. *Systematic reviews*, *4*, pp.1-16. Available at: https://link.springer.com/article/10.1186/s13643-015-0066-7 (Accessed: 05 July 2024).

Kiger, M.E. and Varpio, L., (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical teacher*, *42*(8), pp.846-854. Available at: https://www.tandfonline.com/doi/abs/10.1080/0142159X.2020.1755030 (Accessed: 16 August 2024).

Krug, K., Miksch, A., Peters-Klimm, F., Engeser, P. and Szecsenyi, J., (2016). Correlation between patient quality of life in palliative care and burden of their family caregivers: a prospective observational cohort study. BMC palliative care, 15, pp.1-8. Available at: https://link.springer.com/article/10.1186/s12904-016-0082-y (Accessed: 23 August 2024).

Lindsay, G.M. and Schwind, J.K., (2016). Narrative inquiry: Experience matters. *Canadian Journal of Nursing Research*, *48*(1), pp.14-20. Available at: https://journals.sagepub.com/doi/abs/10.1177/0844562116652230 (Accessed: 08 July 2024).

London Government. (2022). *BAME | London City Hall*. Available at: www.london.gov.uk. https://www.london.gov.uk/who-we-are/what-london-assembly-does/questions-mayor/find-an-answer/bame (Accessed: 19 July 2024).

Long, H.A., French, D.P. and Brooks, J.M., (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, *1*(1), pp.31-42. Available at: https://journals.sagepub.com/doi/full/10.1177/2632084320947559 (Accessed: 18 July 2024).

LoPresti, M.A., Dement, F. and Gold, H.T., (2016). End-of-life care for people with cancer from ethnic minority groups: a systematic review. *American Journal of Hospice and Palliative Medicine®*, *33*(3), pp.291-305. Available at: https://journals.sagepub.com/doi/abs/10.1177/1049909114565658 (Accessed: 23 July 2024).

Lucas, A., Murray, E. and Kinra, S., (2013). Health beliefs of UK South Asians related to lifestyle diseases: a review of qualitative literature. *Journal of obesity*, *2013*(1), p.827674. Available at: https://onlinelibrary.wiley.com/doi/full/10.1155/2013/827674 (Accessed: 23 July 2024).

Maeda, Y., Caskurlu, S., Kozan, K. and Kenney, R.H., (2023). Development of a critical appraisal tool for assessing the reporting quality of qualitative studies: a worked example. *Quality & Quantity*, *57*(2), pp.1011-1031. Available at: https://link.springer.com/article/10.1007/s11135-022-01403-y (Accessed: 05 July 2024).

Magaldi, D. and Berler, M., (2020). Semi-structured interviews. *Encyclopedia of personality and individual differences*, pp.4825-4830. Available at: https://link.springer.com/referenceworkentry/10.1007/978-3-319-24612-3_857 (Accessed: 08 July 2024).

Makri, C. and Neely, A., (2021). Grounded theory: A guide for exploratory studies in management research. *International Journal of Qualitative Methods*, *20*, p.16094069211013654. Available at: https://journals.sagepub.com/doi/full/10.1177/16094069211013654 (Accessed: 08 July 2024).

Malterud, K., Siersma, V.D. and Guassora, A.D., (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative health research*, *26*(13), pp.1753-1760. Available at: https://journals.sagepub.com/doi/abs/10.1177/1049732315617444 (Accessed:

08 July 2024).

Markham, S., Islam, Z. and Faull, C., (2014). I never knew that! Why do people from Black and Asian Minority Ethnic groups in Leicester access hospice services less than other groups? A discussion with community groups. *Diversity and Equality in Health and Care*, *11*(3). Available at: https://www.proquest.com/openview/2d15a0ec58cfd5c40e9de42b8537389c/1.pdf?pq-origsite=gscholar&cbl=2033334 (Accessed: 4 August 2024).

Martín-Martín, J., Pérez-Díez-del-Corral, M., Olano-Lizarraga, M., Valencia-Gil, S. and Saracíbar-Razquin, M.I., (2022). Family narratives about providing end-of-life care at home. Journal of Family Nursing, 28(1), pp.17-30. Available at: https://journals.sagepub.com/doi/abs/10.1177/10748407211025579 (Accessed: 25 August 2024).

Mills, J., Bonner, A. and Francis, K., (2006). The development of constructivist grounded theory. *International journal of qualitative methods*, *5*(1), pp.25-35. Available at: https://journals.sagepub.com/doi/full/10.1177/160940690600500103 (Accessed: 08 July 2024).

Minority Right Group, (2022). South Asians in the United Kingdom. Available at: https://minorityrights.org/communities/south-asians/ (Accessed: 20 August 2024).

Minority Rights Group. (2022). *South Asians in the United Kingdom*. Minority Rights Group. Available at: https://minorityrights.org/communities/south-asians/#:~:text=In%20the%20UK%20the%20term (Accessed: 19 July 2024).

Moss, P., McNally, T., and Venkatasalu, M. (2022). Cultural Norms and End-of-Life Care: Understanding Avoidance in South Asian Communities. Journal of Palliative Care, 38(1), pp. 12-18. Available at: https://journals.sagepub.com/doi/abs/10.2190/OM.69.3.c

Moss, R.H., Hussain, J., Islam, S., Small, N. and Dickerson, J., (2023). Applying the community readiness model to identify and address inequity in end-of-life care in South Asian communities. *Palliative Medicine*, *37*(4), pp.567-574. Available at: https://journals.sagepub.com/doi/full/10.1177/02692163221146587 (Accessed: 4 August 2024).

Munn, Z., Peters, M.D., Stern, C., Tufanaru, C., McArthur, A. and Aromataris, E., (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, *18*, pp.1-7. Available at: https://link.springer.com/article/10.1186/s12874-018-0611-x (Accessed: 08 July 2024).

Murphy, J.A., (2014). Library learning: Undergraduate students' informal, self-directed, and information-sharing strategies. *Partnership: The Canadian Journal of Library and Information Practice and Research*, *9*(1). Available at: https://journal.lib.uoguelph.ca/index.php/perj/article/view/2491 (Accessed: 08 July 2024).

Nelson, K.E., Wright, R., Peeler, A., Brockie, T. and Davidson, P.M., (2021). Sociodemographic disparities in access to hospice and palliative care: an integrative review. *American Journal of Hospice and Palliative Medicine®*, *38*(11), pp.1378-1390. Available at: https://journals.sagepub.com/doi/pdf/10.1177/1049909120985419?casa_token=vLMZX8JWctgAAAAA:QyRzQzzTMzsg-RT-0eQ0frnzM4K6o4Nvexpq4ZNVU9aFFKlXT6h-snvCwclNhTExTMERO4LY0w (Accessed: 02 August 2024).

Nelson, K.E., Wright, R., Peeler, A., Brockie, T. and Davidson, P.M., (2021). Sociodemographic disparities in access to hospice and palliative care: an integrative review. *American Journal of Hospice and Palliative Medicine®*, *38*(11), pp.1378-1390. Available at: https://journals.sagepub.com/doi/pdf/10.1177/1049909120985419?casa_token=vLMZX8JWctgAAAAA:QyRzQzzTMzsg-RT-0eQ0frnzM4K6o4Nvexpq4ZNVU9aFFKlXT6h-snvCwclNhTExTMERO4LY0w (Accessed: 02 August 2024),

Neuendorf, K.A., (2018). Content analysis and thematic analysis. In *Advanced research methods for applied psychology* (pp. 211-223). Routledge. Available at: https://www.taylorfrancis.com/chapters/edit/10.4324/9781315517971-21/content-analysis-thematic-analysis-kimberly-neuendorf (Accessed: 31 August 2024).

NHS, (2022), April 6). *End of Life Care*. NHS. Available at: https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/ (Accessed: 19 July 2024).

O'Connor, A., Carpenter, B. and Coughlan, B., (2018). An Exploration of Key Issues in the Debate Between Classic and Constructivist Grounded Theory. *Grounded Theory Review*, *17*(1). Available at: https://www.researchgate.net/profile/Barry-Carpenter/publication/331501681_An_Exploration_of_Key_Issues_in_the_Debate_Between_Classic_and_Constructivist_Grounded_Theory/links/5c7d8491299bf1268d390ebf/An-Exploration-of-Key-Issues-in-the-Debate-Between-Classic-and-Constructivist-Grounded-Theory.pdf (Accessed: 08 July 2024).

Office for National Statistics. (2022, December 22). *Population of England and Wales*. GOV.UK. Available at: https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/population-of-england-and-wales/latest. (Accessed: 19 July 2024).

Ornstein, K.A., Roth, D.L., Huang, J., Levitan, E.B., Rhodes, J.D., Fabius, C.D., Safford, M.M. and Sheehan, O.C., (2020). Evaluation of racial disparities in hospice use and end-of-life treatment intensity in the REGARDS cohort. *JAMA network open*, *3*(8), pp.e2014639-e2014639. Available at: https://jamanetwork.com/journals/jamanetworkopen/article-abstract/2769692 (Accessed: 23 July 2024).

Ortiz, A.M., (2015). The qualitative interview. In *Research in the college context* (pp. 47-61). Routledge. Available at: https://www.taylorfrancis.com/chapters/edit/10.4324/9781315740447-3/qualitative-interview-anna-ortiz (Accessed: 08 July 2024).

Owens, A. and Randhawa, G., (2004). 'It's different from my culture; they're very different': providing community-based,'culturally competent'palliative care for South Asian people in the UK. *Health & social care in the community*, *12*(5), pp.414-421. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2524.2004.00511.x (Accessed: 4 August 2024).

Palmer, B., Macfarlane, G., Afzal, C., Esmail, A., Silman, A. and Lunt, M., (2007). Acculturation and the prevalence of pain amongst South Asian minority ethnic groups in the UK. Available at: https://academic.oup.com/rheumatology/article/46/6/1009/2899496 (Accessed: 23 July 2024).

Pask, S., Pinto, C., Bristowe, K., Van Vliet, L., Nicholson, C., Evans, C.J., George, R., Bailey, K., Davies, J.M., Guo, P. and Daveson, B.A., (2018). *A framework for complexity in palliative care: a qualitative study with patients, family carers and professionals. Palliative medicine, 32(6), pp.1078-1090*. Available at: https://journals.sagepub.com/doi/abs/10.1177/0269216318757622 (Accessed: 23 August

2024).

Patel, J.J., Hill, A., Lee, Z.Y., Heyland, D.K. and Stoppe, C., (2022). Critical appraisal of a systematic review: a concise review. *Critical care medicine*, *50*(9), pp.1371-1379. Available at: https://journals.lww.com/ccmjournal/abstract/2022/09000/critical_appraisal_of_a_systematic_review__a.9.aspx (Accessed: 05 July 2024).

Patel, N.R., Chew-Graham, C., Bundy, C., Kennedy, A., Blickem, C. and Reeves, D., (2015). Illness beliefs and the sociocultural context of diabetes self-management in British South Asians: a mixed methods study. *BMC family practice*, *16*, pp.1-12. Available at: https://link.springer.com/article/10.1186/s12875-015-0269-y (Accessed: 23 July 2024).

Patel, N.R., Chew-Graham, C., Bundy, C., Kennedy, A., Blickem, C. and Reeves, D., (2015). Illness beliefs and the sociocultural context of diabetes self-management in British South Asians: a mixed methods study. *BMC family practice*, *16*, pp.1-12. Available at: https://link.springer.com/content/pdf/10.1186/s12875-015-0269-y.pdf (Accessed: 20 August 2024).

Pham, M.T., Rajić, A., Greig, J.D., Sargeant, J.M., Papadopoulos, A. and McEwen, S.A., (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research synthesis methods*, *5*(4), pp.371-385. Available at: https://onlinelibrary.wiley.com/doi/full/10.1002/jrsm.1123 (Accessed: 08 July 2024).

Philips, L. and Taylor, V., (2012). Addressing the palliative care needs of minority groups. *Primary Health Care*, *22*(1). Available at: https://journals.rcni.com/primary-health-care/addressing-the-palliative-care-needs-of-minority-groups-phc2012.02.22.1.26.c8915 (Accessed: 4 August 2024).

Pruzan, P., (2016). *Research methodology: the aims, practices and ethics of science*. Springer. Available at: https://books.google.com.pk/books?hl=en&lr=&id=uWShCwAAQBAJ&oi=fnd&pg=PP5&dq=research+aims&ots=JqHqVwPwMx&sig=a6PhKudCXdGoMgePVfEzb3J4BSY&redir_esc=y#v=onepage&q=research%20aims&f=false (Accessed: 08 July 2024).

Quigley, J.M., Thompson, J.C., Halfpenny, N.J. and Scott, D.A., (2019). Critical appraisal of nonrandomized studies—a review of recommended and commonly used tools. *Journal of Evaluation in Clinical Practice*, *25*(1), pp.44-52. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/jep.12889 (Accessed: 05 July 2024).

Rai, N. and Thapa, B., (2015). A study on purposive sampling method in research. *Kathmandu: Kathmandu School of Law*, *5*(1), pp.8-15. Available at: https://d1wqtxts1xzle7.cloudfront.net/48403395/A_Study_on_Purposive_Sampling_Method_in_Research-libre.pdf?1472466369=&response-content-disposition=inline%3B+filename%3DA_STUDY_ON_PURPOSIVE_SAMPLING_METHOD_IN.pdf&Expires=1723097278&Signature=aM7riwtrZsu55g3XWFCk2-ZRWucJCCY6tcaRzTxMsz5FSoGND8MJluQuSh4F8KvVey7vEnz6xVhEi-hfO0u-BKWzDpEY7g24RwcFQsactdSP7W38AwIjqCSIsY6d~xX0OmdrelK80m6vNQVFdVLckASnOZImgc3oyy0UtDoT9iNQ2Tff6An3bG~hoN7gG5a-3o4jZFsiWqR3RKPZF1ly1QK8VwaRNVk83UB9O8JuKHOPV7J~ukBOiANYqAj1d1SUHD~x1PZRiJKTFD3Peil3zIp14J2cLZnQYVrXP5skeG81gcn-LjgGBKabCjvAdlb0mAUydWzp9QSexfCzkJa2Dw__&Key-Pair-Id=APKAJLOHF5GGSLRBV4ZA (Accessed: 08 July 2024).

Raleigh, V. (2023). *The Health Of People From Ethnic Minority Groups In England*. [online] The King’s Fund. Available at: https://www.kingsfund.org.uk/insight-and-analysis/longreads/health-people-ethnic-minority-groups-england#:~:text=However%2C%20people%20from%20some%20ethnic. (Accessed: 23 July 2024).

Randhawa, G., Owens, A., Fitches, R. and Khan, Z., (2003). Communication in developing culturally competent palliative care services in the UK: a case study. *International journal of palliative nursing*, *9*(1), pp.24-31. Available at: https://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2003.9.1.11042 (Accessed: 4 August 2024).

Randolph, J., (2019). A guide to writing the dissertation literature review. *Practical assessment, research, and evaluation*, *14*(1), p.13. Available at: https://scholarworks.umass.edu/items/26e1b79b-2dfb-4f11-ad7e-c505a1ffdbaf (Accessed: 23 July 2024).

Redman, J., Higginbottom, G.M.A. and Massey, M.T., (2008). Critical review of literature on ethnicity and health in relation to cancer and palliative care in the United Kingdom. *Diversity and Equality in Health and Care*, *5*(2). Available at: https://www.proquest.com/openview/8eb2e07f8f83d49cc0c949d34c3ad2d0/1.pdf?pq-origsite=gscholar&cbl=2033334 (Accessed: 23 July 2024).

Riger, S.. and Sigurvinsdottir, R., (2016). Thematic analysis. *Handbook of methodological approaches to community-based research: Qualitative, quantitative, and mixed methods*, pp.33-41. Available at: https://books.google.com.pk/books?hl=en&lr=&id=iiTYCgAAQBAJ&oi=fnd&pg=PA33&dq=thematic+analysis+for+quantitative+data&ots=rbzq7wseoG&sig=fNfTG1olx-n5Q-NEw0SMy4WXElo&redir_esc=y#v=onepage&q=thematic%20analysis%20for%20quantitative%20data&f=false (Accessed: 16 August 2024).

Salomao, A., (2023). The Art of Interpretation: A Journey through Thematic Analysis. Available at: https://mindthegraph.com/blog/thematic-analysis/ (Accessed: 29 August 2024).

Samanta, J., Samanta, A. and Madhloom, O., (2018). A rights-based proposal for managing faith-based values and expectations of migrants at end-of-life illustrated by an empirical study involving South Asians in the UK. *Bioethics*, *32*(6), pp.368-377. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/bioe.12447 (Accessed: 4 August 2024).

Schmidt, L., Mutlu, A.N.F., Elmore, R., Olorisade, B.K., Thomas, J. and Higgins, J.P., (2021). Data extraction methods for systematic review (semi) automation: Update of a living systematic review. *F1000Research*, *10*. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8361807/ (Accessed: 05 July 2024).

Sepúlveda C., Marlin, A., Yoshida, T. and Ullrich, A., (2002). Palliative care: the World Health Organization's global perspective. *Journal of pain and symptom management*, *24*(2), pp.91-96. Available at: https://scholar.google.com/scholar?hl=en&as_sdt=0%2C5&q=Palliative+Care%3A+the+World+Health+Organization%27s+global+perspective&btnG= (Accessed: 07 August 2024).

Shabnam, J., Timm, H., Nielsen, D.S. and Raunkiaer, M., (2020). Palliative care for older South Asian migrants: A systematic review. *Palliative & supportive care*, *18*(3), pp.346-358. Available at: https://www.cambridge.org/core/services/aop-cambridge-core/content/view/262C672EE12BED8EB5A7F821D5F7E1C8/S1478951519000397a.pdf/di v-class-title-palliative-care-for-older-south-asian-migrants-a-systematic-review-div.pdf(Accessed: 20 August 2024).

Shabnam, J., Timm, H., Nielsen, D.S. and Raunkiaer, M., (2020). Palliative care for older South Asian migrants: A systematic review. *Palli///ative & supportive care*, *18*(3), pp.346-358. Available at: https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/palliative-care-for-older-south-asian-migrants-a-systematic-review/262C672EE12BED8EB5A7F821D5F7E1C8 (Accessed: 18 July 2024).

Singh, T. and Harding, R., (2015). Palliative care in South Asia: a systematic review of the evidence for care models, interventions, and outcomes. *BMC research notes, 8, pp.1-15*. Available at: https://link.springer.com/article/10.1186/s13104-015-1102-3. (Accessed: 23 August 2024).

Slort, W., Schweitzer, B.P., Blankenstein, A.H., Abarshi, E.A., Riphagen, I., Echteld, M.A., Aaronson, N.K., Der Horst, H.V. and Deliens, L., (2011). Perceived barriers and facilitators for general practitioner-patient communication in palliative care: a systematic review. Palliative medicine, 25(6), pp.613-629. Available at: https://journals.sagepub.com/doi/abs/10.1177/0269216310395987 (Accessed: 12 September 2024).

Smith, C.B. and Brawley, O.W., (2014), July. Disparities in access to palliative care. In *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform* (pp. 19-29). New York, NY: Springer New York. Available at: https://link.springer.com/chapter/10.1007/978-1-4939-0407-5_2 (Accessed: 23 July 2024).

Snyder, H., (2019). Literature review as a research methodology: An overview and guidelines. *Journal of Business Research*, *104*, pp.333-339. Available at: https://www.sciencedirect.com/science/article/pii/S0148296319304564 (Accessed: 08 July 2024).

Swedberg, R., (2020). Exploratory research. *The production of knowledge: Enhancing progress in social science*, *2*(1), pp.17-41. Available at: https://books.google.com.pk/books?hl=en&lr=&id=vlTMDwAAQBAJ&oi=fnd&pg=PA17&dq=exploratory+study&ots=lUoCg4PbZl&sig=DuKblMHm-aYtddaiPbnfCs5xfGA&redir_esc=y#v=onepage&q=exploratory%20study&f=false (Accessed: 08 July 2024).

Tod, D., Booth, A. and Smith, B., (2022). Critical appraisal. *International Review of Sport and Exercise Psychology*, *15*(1), pp.52-72. Available at: https://www.tandfonline.com/doi/full/10.1080/1750984X.2021.1952471 (Accessed: 05 July 2024).

Turner, V. and Flemming, K., (2019). Socioeconomic factors affecting access to the preferred place of death: a qualitative evidence synthesis. *Palliative Medicine*, *33*(6), pp.607-617. Available at: https://journals.sagepub.com/doi/abs/10.1177/0269216319835146 (Accessed: 4 August 2024).

UK Government. (2024). *South Asian Heritage Month 2022 | London City Hall*. Available at: www.london.gov.uk. https://www.london.gov.uk/city-hall-blog/south-asian-heritage-month-2022 (Accessed: 18 July 2024).

UK Parliament. (2024) *Palliative and end-of-life care - post parliament*. Available at: https://post.parliament.uk/research-briefings/post-pn-0675 (Accessed: 19 July 2024).

Vakil, K., Desse, T.A., Manias, E., Alzubaidi, H., Rasmussen, B., Holton, S. and Mc Namara, K.P., (2023). Patient-centered care experiences of first-generation, South Asian migrants with chronic diseases living in high-income, western countries: a systematic review.

Patient

preference and adherence, pp.281-298. Available at: https://www.tandfonline.com/doi/abs/10.2147/PPA.S391340 (Accessed: 29 August 2024).

Van Lange Paul, A.M., Liebrand, W.B. and AM, W.H., (2015). Introduction and literature review. *Social dilemmas*, pp.3-28. Available at: https://www.taylorfrancis.com/chapters/edit/10.4324/9780203769560-4/introduction-literature-review-van-lange-paul-wim-liebrand-messick-david-wilke-henk (Accessed: 08 July 2024).

Varga-Dobai, K., (2012). The Relationship of Researcher and Participant in Qualitative Inquiry: From. *Qualitative Report*, *17*, p.93. Available at: https://eric.ed.gov/?id=EJ990024 (Accessed: 08 July 2024).

Venkatasalu, M.R., Arthur, A. and Seymour, J., (2013). Talking about end-of-life care: the perspectives of older South Asians living in East London. *Journal of Research in Nursing*, *18*(5), pp.394-406. Available at: https://journals.sagepub.com/doi/abs/10.1177/1744987113490712 (Accessed: 23 July 2024).

Venkatasalu, M.R., Seymour, J.E. and Arthur, A., (2014). Dying at home: A qualitative study of the perspectives of older South Asians living in the United Kingdom. *Palliative medicine*. Available at: https://journals.sagepub.com/doi/abs/10.1177/0269216313506765*28*(3), pp.264-272. (Accessed: 4 August 2024).

Walshe, C., Todd, C., Caress, A. and Chew-Graham, C., (2009). Patterns of access to community palliative care services: a literature review. *Journal of pain and symptom management*, *37*(5), pp.884-912. Available at: https://www.sciencedirect.com/science/article/pii/S0885392408004442 (Accessed: 23 July 2024).

Wilkinson, E., Randhawa, G., Brown, E., Da Silva Gane, M., Stoves, J., Warwick, G., Akhtar, T., Magee, R., Sharman, S. and Farrington, K., (2016). Exploring access to end of life care for ethnic minorities with end stage kidney disease through recruitment in action research. *BMC palliative care*, *15*, pp.1-9. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940835/ (Accessed: 23 July 2024).

Wilkinson, E., Randhawa, G., Brown, E., Da Silva Gane, M., Stoves, J., Warwick, G., Akhtar, T., Magee, R., Sharman, S. and Farrington, K. (2016) ‘Exploring access to end of life care for ethnic minorities with end stage kidney disease through recruitment in action research’, *BMC Palliative Care*, 15, pp. 1-9. Available at: https://link.springer.com/content/pdf/10.1186/s12904-016-0128-1.pdf (Accessed: 20 August 2024).

Wilkinson, E., Randhawa, G., Brown, E.A., Da Silva Gane, M., Stoves, J., Warwick, G., Akhtar, T., Magee, R., Sharman, S. and Farrington, K., (2014). Communication As Care At End Of Life: An Emerging Issue From An Exploratory Action Research Study Of Renal End-Of-Life Care For Ethnic Minorities In The UK. *Journal of renal care*, *40*(S1), pp.23-29. Available at: https://onlinelibrary.wiley.com/doi/full/10.1111/jorc.12084 (Accessed: 23 July 2024).

Wilson, C., Alam, R., Latif, S., Knighting, K., Williamson, S. and Beaver, K. (2012) ‘Patient access to healthcare services and optimisation of self-management for ethnic minority populations living with diabetes: a systematic review’, *Health & Social Care in the Community*, 20(1), pp. 1-19. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2524.2011.01017 (Accessed: 20 July 2024).

Worth, A., Irshad, T., Bhopal, R., Brown, D., Lawton, J., Grant, E., Murray, S., Kendall, M., Adam, J., Gardee, R. and Sheikh, A., (2009). Vulnerability and access to care for South Asian

Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *Bmj*, *338*. Available at: https://www.bmj.com/content/338/bmj.b183.abstract (Accessed: 23 July 2024).

Wright, M., Wood, J., Lynch, T. and Clark, D., (2008). Mapping levels of palliative care development: a global view. *Journal of pain and symptom management, 35(5), pp.469-485.* Available at: https://www.sciencedirect.com/science/article/pii/S0885392407007294 (Accessed: 23 August 2024).

Young, J.M. and Solomon, M.J., (2009). 'How to critically appraise an article', *Nature Clinical Practice Gastroenterology & Hepatology*, 6(2), pp. 82-91. Available at: https://www.nature.com/articles/ncpgasthep1331 (Accessed: 05 July 2024).

Appendix A: Data Extraction Table

Study	Location	Study Aims	Design and Methods	Participants	Key Findings	Limitations	CASP score
Clarke et al. (2023)	UK	To use narratives to explore participants' own stories about their access to palliative care	Narrative Inquiry with in-depth qualitative interviews.	Total 27 South Asian participants.	Key themes included: Places in the healthcare system where people get lost, such as circular referrals, lack of continuity of care and system politics. Issues with treatments and decision-making. and culturally sensitive healthcare issues such as language barriers preferences for healthcare provider ethnicity, experiences of racism, the role of faith and religion and issues relating to personal care, respect and dignity.	Limited sample size.	10/10
Venkatalasu, Arthur, and Seymour (2013)	UK	The study focuses on the perspectives of older South Asians living in East London towards talking about death and dying.	Constructivist grounded theory approach. Focus groups and in-depth interviews.	55 older adults between the age range of 52 to 78.	Two key themes emerged: The theme 'avoidance as a cultural norm' relates to the relative absence of discussions around death and dying experienced by participants. Participants were neither expected to have discussions about their death and dying within their family nor to assume any involvement in decision-making. The second theme 'avoidance as protection' relates to beliefs and experiences about the delegation of decision-making to family members.	Inexperienced qualitative interviewer, the ethnic subgroup identity of the interviewer may have influenced the participants' responses, and gender difference between the interviewer and participant.	9/10

Markham, Islam, and Faull (2014)	UK	This paper describes a project in Leicester to discover what members of the BAME communities knew about palliative care and the providers of hospice services; what they thought the barriers were to their use of these services; and how they would like to find out about them.	Informal discussion groups.	A total of 134 participants; 89 females and 45 males	Findings suggested that knowledge about palliative care was scant, though much valued when understood. Cultural and religious strictures on using palliative care services or a palliative care approach were not demonstrated, though others, including considerable concerns about food when an in the patient was deemed of importance.	Lack of verbatim transcripts, some sections of the population remained elusive.	9/10
Moss et al. (2023)	UK	To use the Community Readiness Model to identify the barriers that influence how South Asian communities’ access and use two new palliative care services.	Questionnaires and focus group discussions.	Ten key stakeholders.	The South Asian communities were found to be at the ‘pre-planning’ stage of readiness, despite initiatives to improve awareness. The readiness of the health system was found to be limited, with a narrow medical focus during advance care planning, poor integration of voluntary and community services and limited understanding of what people consider a ‘good’ death.	Small sample size.	10/10
Philips and Taylor (2011)	UK	This article outlines a hospice apprentice program that aims to promote and expand the use of specialist palliative and end-of-life care services for a South Asian community.	Narrative inquiry using interviews and discussions.	12 district nurses.	The project improved referrals to palliative care, reduced barriers, improved awareness of specialist palliative care services, and reduced stigma associated with the use of palliative care services.	Much of the positive reported outcomes of the project are anticipated or unanticipated. Limited evidence supporting arguments.	9/10
Worth et al. (2009)	UK	To examine the care experiences of South Asian Sikh and Muslim patients in Scotland with life	Prospective, longitudinal, qualitative design using in-depth interviews.	25 South Asian Sikh and Muslim patients, 18 family carers, and 20 key health professionals.	Most services struggled to deliver responsive, culturally appropriate care. Barriers to accessing effective end-of-life care included resource-constrained services; institutional and,	Some of the participants recruited were not in the last year of their lives.	10/10

		limiting illness and their families and to understand the reasons for any difficulties with access to services and how these might be overcome.			occasionally, personal racial and religious discrimination; limited awareness and understanding among South Asian people of the role of hospices; and difficulty discussing death.		
Ventakalasu, Seymour, and Arthur (2014)	UK	To explore beliefs, attitudes and expectations expressed by older South Asians living in East London about dying at home.	Qualitative study using focus groups and semi-structured interviews.	55 older adults (24 men and 31 women) aged between 52 and 78 years.	Two key themes were identified. The theme of 'reconsidering the homeland' draws on the notion of 'diaspora' to help understand why for many participants, the physical place of death was perceived as less important than the opportunity to carry out cultural and religious practices surrounding death. The second theme 'home as a haven' describes participants' accounts of how their home is a place in which it is possible to perform various cultural and religious rituals.	Inexperienced qualitative interviewer, the ethnic subgroup identity of the interviewer may have influenced the participants' responses.	9/10
Owens and Randhawa (2004)	UK	To conduct an exploratory investigation into how professionals address the difficulties, problems and ambiguities of culturally competent practice.	A phenomenological methodology. Semi-structured in-depth interviews.	10 professionals who work in the palliative care field.	Five key themes emerged: definitions of palliative care; ideas of cultural differences; South Asians' access to palliative care services; meeting the needs of South Asian patients; and devising culturally competent care services.	Restricted sample size, low generalizability.	10/10
Samanta, Samanta, and Madhloom (2017)	UK	To argue for the accommodation of faith-based values of migrants at end-of-life within normative structures of receiving countries.	Qualitative study. Focus groups.	Total 12 participants; six males and six females, seven of Hindu and five of Muslim faith.	The faith-based and cultural values of migrants regarding end-of-life care expectations should be accepted and accommodated as part of the receiving country's societal norms.	Limited sample size purposefully selected, limited data to be used a "verbatim quotation"	9/10

Randhawa et al. (2015)	UK	This study specifically set out to try and understand why palliative care services were seemingly underused by minority ethnic groups and to propose changes to working practices and modes of service the provision that would improve the uptake of care.	Exploratory study. Semi-structured interviews.	Total 10 participants.	It was found that the services provided are, in most cases, valued and seen as being effective. The main issues were found to be the need to inform South Asian populations of the availability of palliative care services and the need to improve communication between patients and service providers.	Limited generalisability, statistically unrepresentative sample.	10/10
Brown et al. (2013)	UK	To explore the interface between South Asian cultures and the experience of palliative care services of children, young people, and families.	Literature Review	-	The findings reveal that how families understand concepts such as health and disease arise from the complex interaction between personal experience and cultural lifestyle including language, family values, and faith.	Probability of selection bias.	9/10
Turner and Flemming (2019)	UK	To systematically synthesize the existing qualitative evidence for socioeconomic factors affecting access to preferred places of death in the United Kingdom.	A thematic synthesis of qualitative research.	-	Two overarching themes were identified: ‘Human factors’ represent support networks, interactions between people and decision-making and ‘Environmental factors’, included issues around locations and resources. Few studies directly referenced socioeconomic deprivation.	The focus on a single health system limited the generalizability of the findings.	10/10
Clarke et al. (2022)	UK	To recommend five key considerations for researching ethnicity and palliative care.	Literature Review	-	The five key considerations include improvement of ethnic group categories, sensitive, proportionate, and timely data collection, support for staff collecting ethnicity data, responsible and contextualized use of data, and building public trust.	Limited generalizability.	10/10
Fang et al. (2016)	UK	To explore attitudes, behaviours and patterns	Scoping Review.	-	Primary barriers include cultural differences between	Inclusion criteria are too broad.	9/10

to the utilization of EOL care by culturally and spiritually diverse groups and identify gaps in EOL care practice and delivery methods.

healthcare providers; persons approaching EOL care and family members; under-utilization of culturally sensitive models designed to improve EOL care; language barriers; lack of awareness of cultural and religious diversity issues; exclusion of families in the decision-making process; personal racial and religious discrimination; and lack of culturally tailored EOL information to facilitate decision-making

Appendix B: CASP Table

Checklist Questions	**Clarke et al. (2023)**	**Venkatalasu, Arthur, and Seymour (2013)**	**Markham, Islam, and Faull (2014)**	**Moss et al. (2023)**	**Philips and Taylor (2011)**	**Worth et al. (2009)**	**Ventakalasu, Seymour, and Arthur (2014)**	**Owens and Randhawa (2004)**	**Samanta, Samanta, and Madhloom (2017)**	**Randhawa et al. (2015)**	**Brown et al. (2013)**	**Turner and Flemming (2019)**	**Clarke et al. (2022)**	**Fang et al. (2016)**
1. **Was there a clear statement of the aims of the research?**	Yes “To use narratives to explore participants’ own stories about their access to palliative care.”	Yes “To explore the perspectives of older South Asians living in East London towards talking about death and dying.”	Yes “To discover what members of the BAME communities knew about palliative care and the providers of hospice services; what they thought the barriers were to their use of these services; and how they	Yes “To use the Community Readiness Model to identify the barriers that influence how South Asian communities’ access and use two new palliative care services.”	Yes “To outline a hospice apprentice program that aims to promote and expand the use of specialist palliative and end-of-life care services for a South Asian community.”	Yes “To examine the care experiences of South. Asian Sikh and Muslim patients in Scotland with life limiting illness and their families and to understand the reasons for any difficulties with access to	Yes “To explore beliefs, attitudes and expectations expressed by older South Asians living in East London about dying at home”	Yes “To conduct an exploratory investigation into how professionals address the difficulties, problems and ambiguities of culturally competent practice.”	Yes “To argue for the accommodation of faith-based values of migrants at end-of-life within normative structures of receiving countries.”	Yes “To try and understand why palliative care services were seemingly underused by minority ethnic groups and to propose changes to working practices and modes of service the provision that would	Yes “To explore the interface between South Asian cultures and the experience of palliative. care services of children, young peoples, and families.”	Yes “To systematically synthesize the existing qualitative evidence for socioeconomic factors affecting access to the preferred place of death in the United Kingdom.”	Yes “To recommend five key considerations for researching ethnicity and palliative care”	Yes “To explore attitudes, behaviours and patterns to the utilization of Eol care by culturally and spiritually diverse groups and identify gaps in EoL care practice and delivery methods.”

			would like to find out about them.”			services and how these might be overcome.”				improve the uptake. of care.”				
2. Is a qualitative methodology appropriate?	Yes “To understand the experiences of participants, it is appropriate.”	Yes “To explore the perspectives of participants, it is appropriate”	Yes “Discussion groups are appropriate for identifying barriers and determining how they can be mitigated from the point of view of participants.”	Yes “To identify the barriers that influence participants’ access, it is appropriate”	No “To establish the effectiveness of a program a quantitative methodology would have been more appropriate”	Yes “To understand the experiences of participants, it is appropriate.”	Yes “To explore the perspectives of participants, it is appropriate”	Yes “To explore the perspectives of participants, it is appropriate”	Yes “The methodology is appropriate for the presentation of an argument”	Yes “To understand the experiences of participants, it is appropriate.”	Yes “To explore a situation, it is appropriate”	Yes “To explore the impact of one variable on the other, this methodology is appropriate”	Yes “It is appropriate to provide recommendations for improvement”	Yes “To explore the attitudes, behaviours, and patterns of participants about something, it is appropriate”
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment	Yes “In-depth	Yes “Focus groups	Yes “Informal	“Yes, questionnaires	Yes “Narrative	Yes “in-depth	Yes “Focus group	Yes “Semi-structur	Yes “Focus groups	Yes “Semi-structu	No The literatur	Yes the literature	Yes Literature review	Yes Scoping review

strategy appropriate to the aims of the research?	qualitative interviews were appropriate for understanding of participants’ perspectives.	were appropriate for exploring perspectives of participants.”	discussion groups were appropriate for this research	and focus groups were appropriate to establish the effectiveness of a model”	inquiries were appropriate for the research”	qualitative interviews were appropriate for examining and exploring experiences”	discussions were appropriate for exploring beliefs, attitudes and expectations of participants”	ed in-depth interviews were appropriate for instigating the difficulties, problems and ambiguities”	were appropriate for this study”	red in-depth interviews were appropriate for understanding participants’ experiences”	e review was not appropriate for this study according to the research aim”	review was appropriate for this study”	was appropriate for this study”	was appropriate for this study”
5. **Was the data collected in a way that addressed the research issue?**	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. **Has the relationship between the researcher and participants been adequately considered?**	Yes	No	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No
7. **Have ethical issues been taken into consideration**	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
8. **Was the data analysis sufficiently rigorous?**	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Is there a clear statement of findings?														
10. **How valuable is the research**?	This study is valuable because it allowed us to understand first-hand experiences of the South Asian community when accessing palliative care services.	This study helped understand the perspectives of older South Asians living in East London towards talking about death and dying.	It strengthens our knowledge of what members of the BAME communities know about palliative care and what barriers they encounter.	This study is valuable because it established the role and effectiveness of the Community Readiness Program in improving the condition of palliative care services for the South Asian population.	This study supported the argument of improving support for healthcare staff to **provide** culturally tailored palliative care services for the South Asian community using a hospital apprenticeship program.	This study used the first-hand experiences of participants to better identify the barriers faced by the South Asian community in accessing palliative care services.	This study established why the South Asian community prefer to die at home rather than hospital.	This study presented the challenges faced by professionals in providing quality palliative care for the South Asian population	This study is the first to argue for faith-based palliative care services for ethnic minorities.	This study helps understand how palliative care services might be different for ethnic minorities and the barriers they experience followed by recommendations on how they could be improved	This study allowed us to understand how South Asian culture may impact the experiences of palliative care services for children, young people, and families.	This study established socioeconomic factors' impact on access to preferred places of death in the United Kingdom.	This literature review provided key recommendations supported by scientific evidence for researching ethnicity and palliative care.	This study allowed to understand the behaviours, attitudes, and patterns of EoL care by culturally and spiritually diverse groups and identify gaps in EoL care practice and delivery methods.
