Aker *et al. BMC Palliative Care* (2024) 23:228
https://doi.org/10.1186/s12904-024-01555-8

BMC Palliative Care

RESEARCH **Open Access**

Experiences and access of palliative and end of life care for older people from minority ethnic groups: a scoping review

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Abstract

Background Many older people from minority ethnic groups experience inequalities towards the end of life, including barriers to accessing palliative care. With levels of international migration increasing, there is a need to understand these differences and consider the needs of minority ethnic groups in healthcare policies. This review aimed to map evidence on how older people from minority ethnic groups access and utilise palliative and end of life care, preferences for palliative and end of life care, experiences of palliative and end of life care, and how this varies between minority ethnic groups in different countries, and with different health conditions.

Methods Scoping review, following Joanna Briggs Institute (JBI) guidance. Searches of eight online databases (MEDLINE, Embase, Web of Science, CINAHL, PsycInfo, Assia, Scopus, and the Cochrane Library) and grey literature were undertaken in 2024. Qualitative sources that focused on older people from minority ethnic groups' and carers' access to and use of palliative and end of life care were included, as well as those focusing on healthcare professionals' experiences.

Results Twenty-three sources were included in the review, the majority of which were interview studies from the USA. Findings reflect a range of preferences, inequalities, facilitators and barriers to accessing palliative and end of life care, with themes relating to: (1) Knowledge of hospice and palliative care, (2) societal and structural issues, (3) language and health literacy, (4) migratory experiences, (5) trust in healthcare services and professionals, (6) religion and hope, and (7) cultural values.

Conclusions This review identified areas for healthcare providers to consider developing more culturally appropriate palliative and end of life care practice, including building trust and improving communication, sharing information, reducing language barriers, addressing stigma, and, if relevant, acknowledging the importance of culture and religion. Further qualitative research from an intersectional perspective, such as geographical location or socio-economic status, rather than race, ethnicity, and culture alone, is needed in more diverse geographical settings and on specific health conditions.

Keywords Health inequalities, Access to care, Palliative care, End of life, Older people, Ageing, Culture, Ethnicity

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Background

Minority ethnic groups, or ethnic groups of people living in a country where the main or majority ethnic group is different [1], are found in almost every country around the world in varying numbers [2]. However, there can be ethnic inequalities in access to healthcare, experiences of it, and health outcomes [3]. With levels of international migration increasing [4], there is a need to understand these differences and consider the needs of minority ethnic groups in healthcare policies across countries, who often experience health inequalities barriers to access to care [3].

Health inequalities, or inequities, are unfair and preventable differences in the health status between different groups or populations of people [5], which can be caused by the unequal distribution of health determinants [6] (non-medical factors that influence health outcomes [7]). There are many inequities that exist in palliative care and end of life care for minority ethnic groups, such as reported poorer quality of care at end of life, assumptions that family members will be able and willing to provide care at home [8], and access to pain management [9]. Reasons for these inequalities can include cultural barriers [10], discrimination [11], language and communication difficulties [12, 13], socio-economic status [14], mistrust of healthcare services [15], limited awareness of services [13], and more. People from minority ethnic groups are also often diagnosed with disease at a later stage, which can affect availability of and accessibility to care and treatment [16]. There are also differences in the preferences of care between different minority ethnic groups, including for burdensome treatment and life-sustaining therapies [17], care to be provided at home by family members [18], not discussing death or disease prognosis with the person approaching end of life [19], and for religious guidance when making care decisions [20].

Family members who are involved in the care and decision making for people receiving palliative or end of life care can be known as informal family carers. An informal carer is anyone who looks after a family member, partner or friend who needs support and is reliant on their help [21]. In some cultures, caring for an older family member is a societal expectation, which can affect healthcare decision making and support seeking on behalf of the person being cared for [22].

With populations ageing across the world [23], and increasing rates of chronic illness and multimorbidities [24], health and social care systems in all countries face challenges in ensuring that they are ready to meet the needs of these changing demographics [23]. Numbers of deaths occurring at older ages, and of older people who will need palliative care, are projected to increase over the coming decades [24]. Despite this, older people often receive less palliative care than younger people while having greater palliative care needs [25, 26]. For this reason, this review focused on older people aged over 60 years [27].

The above evidence shows that health inequalities exist towards the end of life for many older people from minority ethnic groups, as well as barriers to accessing palliative care. However, at present it is unclear how these barriers and inequalities differ across minority ethnic groups in different countries, and across health conditions within these groups, which will contribute to the greater understanding of access to palliative and end of life care for older people form minority ethnic groups. It is important to map this across countries and different contexts to shed light on the extent of inequalities in palliative and end of life care, discover insights into how different countries address (or fail to address) the needs of minority ethnic groups, and consider best practices and solutions that have been successful in different contexts. While many countries may have similar barriers and challenges, there are also unique considerations which will help inform a wealth of international research aiming to reduce inequalities in ethnic minority groups. A scoping review approach [28] was used to identify the available qualitative evidence relating to these populations, who are often underrepresented in research, highlight what the gaps in the evidence are, and identify areas for future research.

Review question

How do older people from minority ethnic groups access and utilise palliative and end of life care, and how does this vary between different ethnicities, countries, and health conditions?

Objectives

The objectives are to:

- Understand the existing evidence base on palliative and end of life care for older people in the context of minority ethnic groups to identify gaps in research and understanding.
- Identify how older people of different minority ethnic groups access, engage with, and utilise specialist or generalist palliative and end of life care.
- Understand inequalities, barriers and facilitators in accessing palliative and end of life care experienced from perspectives of older people from minority ethnic groups receiving palliative or end of life care, informal carers and healthcare professionals.
- Compare how access to palliative and end of life care varies between different countries, minority ethnic groups, and health conditions.

Methods

Design

This scoping review was guided by the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis [28], and a published protocol, Health inequalities for older people from minority ethnic groups receiving palliative care and end of life care: A scoping review protocol [29]. The PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) checklist [30]. was used to guide reporting. This paper includes qualitative sources to allow an in-depth exploration of the research question.

Eligibility criteria

Population

Participants included older people from minority ethnic groups in any country, who were receiving (or had received) generalist or specialist palliative or end of life care for any health condition; informal carers; and healthcare professionals.

- Sources with a majority population (> 50%) of older people were included. Sources including both younger and older adults were included if the average age of participants was over 60, in accordance with the World Health Organisation (WHO) definition of older age as 60 years or over [27].
- A minority ethnic group is a particular ethnic group living in a country where most people are from a different ethnic group [31]. Sources including both minority and majority ethnic participants were included if data from minority ethnic participants could be extracted separately.
- Informal (unpaid) adult carers [21] for the aforementioned older people, and health and social care professionals working with these older people and carers were also included. Paid carers and young carers aged under 18 years were excluded due to the differences in their responsibilities and experiences compared to adult informal carers.

Concept

The following sources were included:

- Sources focusing on older people from minority ethnic groups' access to and use of specialist or generalist palliative care, end of life care, and care towards the end of life. This included which services were used and what enabled or prevented people accessing services.
- Sources focusing on carers' experiences accessing and using health and care services for their family member.
- Sources focusing on health and social care professionals' experiences.
- Sources exploring health inequities and inequalities experienced by older people from minority ethnic groups towards the end of life.

Sources that explored advance care planning, and healthy or not end of life/terminally ill older people's attitudes and preferences for potential future care, were excluded. Sources that did not have a focus on people from minority ethnic backgrounds, palliative/end of life care or older people were excluded. Sources that referred to older people (or used similar phrasing) but did not state the ages (individual or average) of older people included as participants were excluded. Quantitative data was excluded. For mixed methods studies, only the qualitative parts that fit the eligibility criteria were included in the analysis.

Context

Published sources were not limited by country, healthcare setting, or ethnicity of participants. Grey literature was limited to UK sources due to difficulties sourcing and accessing international grey literature.

Sources of evidence

Qualitative and mixed methods sources (where qualitative data could be extracted separately) were included. Eligible sources included primary research studies, systematic and other reviews, reports, and theses. Conference abstracts, study/review protocols, reviews of the literature, and opinion pieces were excluded.

Search strategy

Search terms were developed and refined based on preliminary search outputs and with input from authors and a research librarian. We identified key papers which we expected to be returned in our searches to check sensitivity and these were returned in our final search results. Searches of eight online databases (MEDLINE, Embase, Web of Science, CINAHL, PsycInfo, Assia, Scopus, and the Cochrane Library) were undertaken (June 2022; updated in April 2024) using the following four concepts: minority ethnic groups; older adults; palliative care and end of life care; and health inequalities, access, and utilisation. An example search strategy can be found in Appendix 1. Reference lists of included papers were searched for additional sources, and citation tracking was undertaken using Google Scholar. Full texts were requested from authors where unavailable online, which resulted in the receipt of two papers. The above concepts were used to search for grey literature using Google. The first 10 pages of Google results were searched, with the plan to search another 10 pages if sources were still identified towards the end of these, but this was not necessary.

Sources that were not in English were not excluded from consideration; however no non-English sources were identified for inclusion.

Screening and selection

Initial search results were deduplicated using EndNote X9 [32] and exported to Rayyan [33] for screening. Titles and abstracts were screened by the first reviewer (NA), with a second reviewer (PN) reviewing 10% of sources. Full text screening was undertaken by NA, with PN screening 20% due to resource limitations. Updated searches were screened by LJM, with NA screening 10% of sources. Disagreements were resolved through discussion between reviewers, and with ND, RF, NK and SG where needed.

Data extraction

Data was extracted by NA using a bespoke data charting tool. Extracted data included country of origin, participant details (including age, ethnicity, health conditions), area/aspect of palliative care being researched, and key findings relating to the research question.

The charting tool was refined during the data extraction process to capture all relevant information. Data extracted from three papers was checked by PN. Quality assessment of included sources was not undertaken, in line with scoping review methods [28].

Data analysis

Key information from each study was presented in a table, and characteristics of included sources were described. Findings in the context of ethnic groups accessing and utilising palliative and end of life care were narratively synthesised and discussed. Gaps in the literature were highlighted by exploring the topics studied, methods used, and populations researched.

Results

Description of included sources

Initial database searches after de-duplication identified 2059 results. From these, 254 potentially eligible studies were identified and screened as full texts (Fig. 1). Eight papers were identified for inclusion. Thirteen additional sources were identified from reference and citation searches, and one from the grey literature search. Due to the additional papers identified we discussed with an information expert our search sensitivity; however,

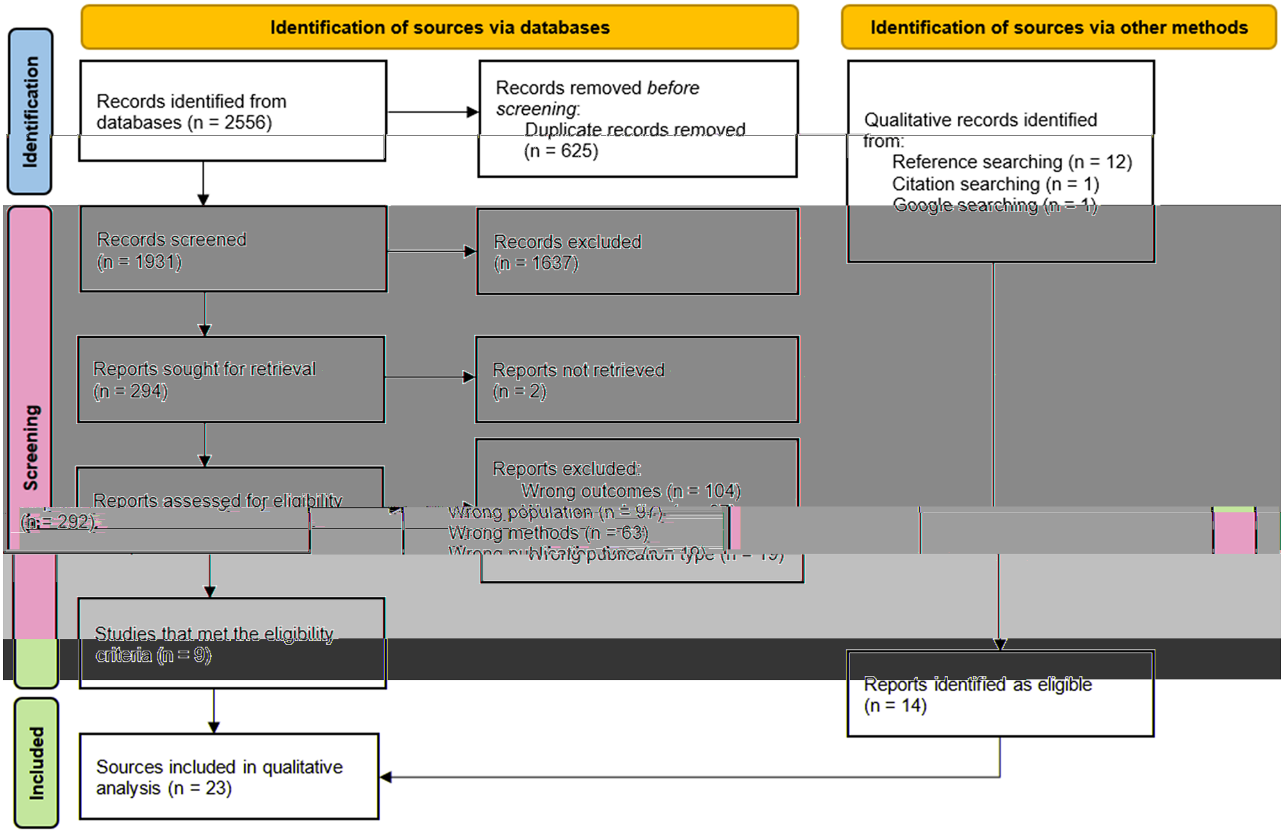

Fig. 1 PRISMA flowchart of search process

many of the additional papers were not indexed under the search terms used and would not have appeared in searches. Our search was very broad as seen in the Appendix. We discuss challenges of identifying relevant literature in the databases in the discussion. Updated searches identified 497 results, with 38 papers screened as full texts. From these, one paper was identified for inclusion. Twenty-three sources reporting on 20 different studies were included in the qualitative analysis.

The number of articles published on this topic has increased substantially over time – 18 of the 23 were published in the last 10 years, with years of publication ranging between 1995 and 2023. Nineteen papers used purely qualitative methods [11, 15, 16, 19, 20, 34–47] and four used mixed methods [48–51]. The mean number of participants recruited was 31 (range 1–100). The mean age of people receiving palliative or end of life care was 77 years. Characteristics of included papers are summarised in Table 1.

As can be seen in the table, there were many different ways in which ethnicity was described, some of which represent the time in which the studies were undertaken. For example, CALD may now potentially viewed as outdated.

We grouped the findings across the included studies into seven overarching themes were: (1) Knowledge of hospice and palliative care, (2) societal and structural issues, (3) language and health literacy, (4) migratory experiences, (5) trust in healthcare services and professionals, (6) religion and hope, and (7) cultural values. Barriers and facilitators for accessing and utilising care were explored through each theme.

Knowledge of hospice and palliative care

Understanding of palliative and end of life care was generally limited among Black and African-Caribbean carers, migrants, and CALD (culturally and linguistically diverse) patients [35, 36, 38, 47]. Part of this may be due to there being no equivalent term for 'palliative care' in many cultures and languages [36]. A lack of understanding and limited health literacy, especially where there was limited English skills among Hispanic and Latino participants, impaired their ability to seek help, navigate the healthcare system, and make informed decisions [34, 37, 39]. Many participants learned about hospice for the first time at the time of the referral [45, 46]. Participants often had a limited understanding of hospice and the changes in goals of care (i.e., from curative to comfort care) it represented, and were not well-aware of the connection between hospice referral and disease prognosis [11, 15, 36, 46, 49]. Some participants viewed hospice as a support if their health declines further in future, despite currently receiving hospice services [46]. Others viewed hospice as a break before returning to curative treatment [41, 45]. Positive past experiences with hospice, learning about hospice care through seeing older relatives go through it, or recommendations from friends helped carers access hospice [45, 49].

Understanding the potential risks associated with life-sustaining treatments were reported to be important for Hispanic carers making end of life decisions, with carers wanting healthcare professionals to explain end of life treatment options, including purpose, goals, and limitations. Despite the discomfort surrounding the topic of hospice care, carers emphasised the importance of talking about the benefits of hospice care [15]. This was supported by families' concerns around medication use toward the end of life being dispelled through nurses providing explanations [44, 50].

Patients' and carers' insight into their own or their family member's health status also enabled them to make end of life decisions. Patients who were aware about their declining health or their conditions being unlikely to respond to medical treatment were more likely to accept recommendations to enrol in hospice, despite having little to no previous knowledge of hospice [45, 49].

Societal and structural issues

Hospice care and other end of life support held a stigma among Black African-Caribbean, African American, and Chinese American communities, seen as giving up on or not wanting to take care of someone [35, 39, 41, 43]. Stigma around dementia also resulted in later diagnosis and reluctance to seek additional support [16]. Talking about end of life, prognosis, palliative care, or hospice care was often suppressed among people from minority ethnic groups, and may cause feelings of discomfort or offence when mentioned [11, 15, 19, 20, 36, 38, 39, 50]. Healthcare professionals working with South Asian patients with kidney disease in the UK reported that not all of their colleagues agreed with discussing end of life and advance care planning with patients [37].

Institutional racism, and the risk of discrimination and mistreatment within healthcare systems was a concern for African American participants; some of whom felt that they were "second-class patients" due to experiences of differential treatment and stereotyping from healthcare professionals [43]. Structural barriers to accessing care included lack of health insurance or living in poverty [43].

Latino and Hispanic participants in the USA reported feeling uncertain about who was being billed for services received, and therefore hesitating to request more services despite needing them [46]. Carers suggested that healthcare professionals should recognise that many African American people experience substantial financial difficulties.[11] Health insurance coverage of hospice care

Table 1 Characteristics of included sources

		N **papers**	**References**
Source type	Journal article	20	[11, 15, 16, 19, 20, 35, 38–42, 44–48, 50–52]
	Thesis	3	[36, 43, 49]
Country of origin	USA (United States of America)	16	[11, 15, 19, 20, 35, 40–44, 46–50, 52]
	UK	3	[16, 36, 38]
	Australia	3	[37, 45, 51]
	Germany	1	[39]
Methods	Interviews (semi-structured and unstructured)	18 (17 and 1)	[15, 19, 20, 36–39, 41–50, 52]
	Focus groups	3	[11, 38, 52]
	Case studies	3	[16,,35, 40]
	Analysis of medical records	2	[46, 51]
	Survey	1	[52]
Participants	Carers only	8	[11, 15, 19, 20, 35, 36, 46, 48]
	Older people receiving palliative or end of life care only	7	[16, 39, 41, 49–52]
	Healthcare professionals only	1	[45]
	Carers and people receiving palliative or end of life care	6	[37, 40, 42–44, 47]
	Healthcare professionals and people receiving palliative or end of life care	1	[38]
Research setting	Hospice or hospice care	12	[15, 19, 20, 35, 39, 42–44, 46, 47, 49, 50]
	Hospital	6	[11, 37, 39, 45, 47, 51]
	Not specific	3	[36, 40, 52]
	Nursing home	3	[41, 47, 48]
	Community	2	[19, 39]
	Long-term care facility (LTCF)	1	[20]
	Admiral nursing	1	[16]
Participant groups described	Black, African American, or Black African-Caribbean	12	[11, 20, 36, 40–44, 46, 48–50]
	Hispanic	4	[15, 35, 46, 47]
	Latino	3	[19, 47, 52]
	Culturally and linguistically diverse (CALD)	2	[37, 51]
	Migrants or immigrants	2	[39, 45]
	American Indian	1	[46]
	Chinese American	1	[40]
	Italian	1	[16]
	South Asian	1	[38]
Additional languages study conducted in	Spanish	4	[15, 19, 47, 52]
	Gujarati	1	[38]
	Punjabi	1	[38]
	Urdu	1	[38]
	Bengali	1	[38]
Health conditions	Unspecified/mixed	15	[11, 15, 19, 20, 35, 39, 42–47, 49–51]
	Dementia	3	[16, 36, 48]
	Cancer	2	[37, 40]
	Kidney disease (including end-stage renal disease [ESRD])	2	[38, 52]

facilitated access for African American patients with low income [49].

African American patients and carers valued assistance from health and social care professionals, for instance, help from hospice staff when completing hospice enrolment paperwork [49]. Social workers also helped carers make end of life care decisions by explaining treatment options, arranging meetings with healthcare professionals, advocating for families, and supporting effective communication between family members and their dying relatives, as well as with each other.[20]

Language and health literacy

Language barriers were reported across many papers. Latino and Hispanic patients and carers highlighted a need for more Spanish-speaking healthcare professionals and materials in Spanish [19, 34, 46]. Healthcare professionals reported that South Asian patients also experienced poorer access to care due to language barriers [37]. Particular language difficulties reported by nurses and patients included adequately assessing and managing pain without interpreters [36, 50], supporting patients and families coming to terms with dying [44], and processing information about prognosis and treatment in a foreign language while suffering from distressing symptoms [38]. This can be exacerbated for people with dementia who speak English as a second language, as they may lose their English ability as well as their ability to communicate as the disease progresses [16].

Latino and Hispanic participants faced health literacy difficulties that hindered their ability to communicate with medical providers; for example, using medical terms incorrectly [46]. CALD patients with cancer had difficulties communicating with clinicians about treatment expectations [36]. Black and Hispanic carers believed that the lack of end of life communication from healthcare professionals, such as about worsening prognosis, impeded end of life care planning and decision-making; [15, 47] for example, hospice referral happening too late because the physician did not discuss hospice with carers [43]. Black and African American carers also felt they could have been better informed concerning treatments and outcomes [20, 47].

Migratory experiences

A study with Hispanic and Latino participants who had migrated to the USA found many carers were previously not exposed to issues around ageing and dying as they did not have elderly relatives nearby, limiting opportunities to learn from family members. These experiences, as well as low education levels, resulted in participants feeling limited in their ability to seek out and understand health information and services. Terminally ill Latino and Hispanic people had limited access to healthcare in their countries of origin, and once in the USA, continued to have few interactions with healthcare prior to being diagnosed with their terminal illness. This limited interaction with medical providers led to participants rarely discussing their preferences with clinicians and instead following doctors' orders [46].

Migrant patients in Germany experienced feelings of not belonging, which led to difficulties towards the end of life, such as experiencing less support from neighbours and the local community than in the country of origin, and regrets around moving.[39] These feelings of interpersonal disconnect may discourage migrant patients from seeking or using palliative care services.

Trust in healthcare services and professionals

Trustworthy information was important and acted as a facilitator to accessing care, with recommendations from friends, neighbours, and spiritual leaders being the main influence on decision making [43, 47]. There was distrust of health and care systems and physicians among Black, African American and Hispanic carers [11, 47], including refusing support from services [34] and feeling misled by doctors due to not understanding medical terminology [39]. African American patients and carers were sceptical of advice offered by healthcare professionals due to previous reports of being treated badly [43]. Carers recommended that clinicians work to establish trust while understanding their distrust of care and the medical system, and recognising the historical and social reasons for this, including slavery, racism, medical experimentation and exploitation [11].

Black and African American patients and carers are more likely to trust staff members of their community [47] and found the lack of Black hospice care workers frustrating [11, 39]. Nurses working with immigrant patients reported that trust is particularly important, and that it can be easy to lose the trust of patients and their families. They suggested building a trusting relationship by getting to know the patient and their family, and not rushing conversations about dying. Nurses reported using qualified health interpreters and having a multicultural workforce were valuable for working with immigrants [44].

Latino and Hispanic carers reported trusting doctors perceived to be knowledgeable and adept. However, those with limited health literacy had no option other than to trust doctors [46, 51]. Healthcare professionals investing time in understanding patients' beliefs about dementia resulted in a better understanding of cultural barriers and facilitators in accepting support, and promoted trust in the relationship [16].

Religion and hope

Religion was seen as a facilitator in end of life decision making. Many Black, African-Caribbean and African American carers indicated that their faith, religious beliefs, or pastoral counselling was an important resource in making end-of-life care decisions for their family member [20, 35, 47]. African American carers suggested that healthcare professionals invite their pastors to prognosis discussions and understand the role of religion and church in their lives [11]. Latino patients were similarly guided by God and religion, and end of life treatment discussions often involved a spiritual or religious leader [34, 51]. Religion also caused barriers to accessing care. For example, African American carers were reluctant to enrol their family member in hospice care because they felt that doing so reflected a lack of trust in God [43]. However, others felt that God was sending them hospice or healthcare professionals [41, 49].

One reason African American patients chose hospice care was because it allowed them to practice their spiritual and religious beliefs [49]. African American nursing home residents valued using religious activities as a source of comfort to reduce pain, including prayer, Bible reading, and laying on of hands [40]. Although psychosocial and religious support was important for Latino and Hispanic participants, many did not expect this from hospice due to their limited knowledge of hospices' philosophy of care or the range of services provided. As a result, care was sometimes not culturally appropriate [46].

For CALD patients and carers, religious faith was associated with hope, as opposed to medical futility, which was associated with death and 'giving up'. For African American carers, the decision-making process was guided by hope for recovery. Although patients' chances of recovery were small, family members accounted for this possibility in their end of life care decisions, with the belief that only God determines when someone lives or dies, and a need to make sure that everything possible was done [11, 20]. However, Latino patients expressed that they would not want any procedures to be carried out if they were diagnosed with terminal cancer, as this was considered to be futile and may increase suffering.[52] Some CALD patients with cancer also believed that returning home meant they were dying and that remaining in hospital entailed hope for recovery [36].

Cultural values

Caring for family members was an important cultural tradition in many studies. For Black, African-Caribbean and African American carers, it was reported as important to take care of their family members [35, 41]. Black African-Caribbean, African American, Chinese American and CALD families in several studies rejected the idea of residential care, expressing wishes to care for their family member at home.[36,40,51] This duty was often expected of carers, regardless of the sacrifices or personal cost, and without asking for outside help [11, 16, 34, 35]. This could cause delays in accepting care at home for patients [11].

For African American participants, there was a sense of incongruence between hospice policies and procedures, and cultural values and practices related to illness and death. Participants were critical of policies requiring patients to stop curative treatment to access hospice and felt that more African American people would consider hospice if they were able to pursue curative treatment concurrently [43]. which suggests a lack of knowledge or acceptance of the terminal nature of the condition [41].

Family involvement in end of life decision making was also important. Hospice-provided training to help family members participate in the caregiving process was of value for African American carers [41]. Where patients were unable to make their own care decisions, physicians sought family members' input to ensure that the process was cooperative and inclusive [20]. However, this could also be stressful for carers of people living with dementia, as they questioned whether their decisions would be considered correct by the person with dementia [35]. African American carers suggested that healthcare professionals emphasise that hospice staff will not 'take over' and that the family still decides what is done and how it is done [11]. For Black, African American and Latino carers, support from other family members in the decision to use hospice care and make end of life care decisions, and following family elders' wishes regarding patients' care was important [19, 47, 49]. Patients' own wishes were also taken into account, such as not going to a nursing home [11], not wishing for aggressive treatment [35, 49], dying at home [35], or continuing treatment regardless of benefits [20, 38, 51]. However, this was not always possible [34, 35].

There was also a lack of healthcare professionals' awareness and understanding of different cultures. Black African-Caribbean and African American participants believed that many healthcare professionals do not understand cultural preferences and their importance [35, 43]. CALD carers felt that the Australian medical system was not well equipped to meet their cultural or linguistic needs [36]. Nurses themselves felt they had little knowledge or understanding of what culturally responsive end of life care consists of and felt 'overwhelmed and underprepared' when encountering patients and families from diverse cultural backgrounds. Some nurses believed end of life care for patients from culturally different backgrounds was the same as for any patient [44]. Nurses suggested that working with families, learning what is important to them, determining the 'patient–family decision making model', engaging a family spokesperson, reaching compromises, and actively involving families in the patient's care were beneficial [44].

Being able to receive care at home was also important. Learning that they could receive hospice care at home was a 'relief' for African American patients as they did not want to leave their home [49]. For Black African-Caribbean carers, taking their family member living with dementia to hospital was distressing due to fears they would die there [35]. Latino and Hispanic participants' primary expectations of hospice were nursing care and receiving services in their homes, valuing their family members being cared for at home [15, 46]. Similarly, many CALD patients stated their desire to return to their home for care [50].

Discussion

Main findings

Results from 23 papers identified a broad range of factors affecting how palliative care is accessed and utilised by older people from minority ethnic groups and their carers. All included papers originated from high-income, Western countries (mostly from the USA, with others from the UK, Australia, and Germany), all of which are in the top 10 countries with the highest numbers of foreign-born residents [52]. The majority of challenges and experiences could be applied across different countries, contexts, health and care systems; for example, language and communication, migration and feelings of responsibility. However, the main difference that required specific contextual consideration was financial implications in the USA. It is important to note that the health system, lived experiences, and composition of minority ethnic groups are particularly different in the USA compared to European countries and cannot be generalised to other countries, which should be considered in the context of the findings. As quality appraisal was not formally undertaken for included sources in line with scoping review guidelines [28], any potential impact of possible difference in the methodological quality of the studies was not considered in the context of the findings, however, the limitations of the included studies are acknowledged within the discussion.

Findings from this review generally align with previous quantitative research. For example, greater numbers of older people from minority ethnic groups die in hospital, or have more hospital stays towards the end of life [12], which could be attributed to the preference for curative treatment over the idea of 'giving up'. Previous research also showed these populations were more likely to remain in the community despite serious physical and cognitive impairment, with family members expected to provide care at home [18]. Current review findings supported this, but also identified further factors such as social stigma, cultural values, and mistrust.

Previous research importantly identified intersectional differences such as lower rates of education and greater financial difficulties [53], with a more positive view of intensive procedures such as mechanical ventilation [54], higher levels of spirituality [55], less pain assessments [56], and less awareness of hospice care [57] among participants from minority ethnic groups compared to those from majority ethnic groups. Findings from this review also identified many of these issues.

Gaps in the literature and implications for future research

While all included papers focused on minority ethnic experiences, with many reporting language barriers, most studies were conducted in English. While it may be the case that this was provided without being documented in publications, inclusivity and accessibility should be strived for in research as well as healthcare. Many studies provided limited information on participants' ethnicities, despite the research focusing on ethnic differences, for instance using general regional terms such as 'South Asian', or overarching terms such as 'CALD' or 'migrants' without specifying ethnicity in the results. This may result in findings with reduced context. Although people's experiences cannot be reduced to their ethnicity (for example the intersection between migration and ethnicity can lead to health inequalities due to differences in environment, culture, and biology [58]), reporting ethnic differences and inequalities will add valuable context. There was a lack of consideration of findings from an intersectionality perspective, such as geographical location or socio-economic status, rather than race, ethnicity, and culture alone.

The majority of research did not focus on particular health conditions, however the end of life stage can differ based on illness and comorbidity [59, 60]. For example, dementia is the leading cause of death in countries such as England and Wales [61], and often poses different complications to other health conditions, such as unpredictable prognosis, loss of mental capacity and reduced ability to communicate [62]. Only three papers explored care towards the end of life for people of minority ethnic groups with dementia, even though rising rates of dementia is leading to increased palliative care needs for older people [63, 64]. Christianity was the only religion mentioned in the included sources, which suggests that more research is needed to understand palliative and end of life care from the perspectives of people following other religions, and also those who are spiritual rather than religious.

More studies are needed on healthcare professionals' views, as few were found in this review. More research exploring this topic from the perspective of countries in addition to the USA, where there may be different populations of minority ethnic groups, would also be valuable.

Practice and policy

There are many recommendations that can be made for making steps towards providing more inclusive and accessible care. Focusing on improving patient-clinician communication can be helpful, including through providing translated documents and access to interpreters for patients and carers who may be experiencing language barriers. In addition, sharing information on palliative care, end of life, and available support can enable people to access the help they need and enable better communication and understanding between patients, carers, and professionals. Supporting carers providing care at home, offering individualised care as needed, and building trusting relationships (including through exploring and addressing potential stigma and institutional racism), can facilitate better access to care. Acknowledging the importance of religion and culture at the end of life, if relevant to the individual, can also allow for more culturally sensitive care.

Strengths and limitations

This scoping review followed rigorous processes to scope the existing literature on this topic and highlighted important gaps in the literature. Study populations (ethnicities and health conditions) were not restricted for this review to include as much relevant data as possible.

However, it is important to note that while this review included older people using the WHO definition of older age (60 years and over) [27], older people from minority ethnic groups, including from Black and Hispanic backgrounds, are often younger and sicker at the end of life, and can access palliative and end of life care at a younger age [65, 66]. Because of this age limitation, this review may have excluded potentially relevant sources.

Variation in classifications of older age caused difficulties when identifying and screening sources. Other papers did not clearly define terms used to describe participants such as 'older' or 'seriously ill', and so were excluded. This highlights the need for describing and defining terms such as these in research.

Although a systematic process was used to undertake a thorough search, it is possible that evidence may still have been missed, as a large number of studies were found through reference and citation tracking. We conducted extensive preliminary searches guided by a research librarian (information expert), conducted to improve the sensitivity and specificity of the searches before carrying out the final searches. In our final search we identified key papers we expected to be returned which assured us our search was sensitive and specific to the topic. As we received a large number of studies through additional forward and backward citation tracking, we explored why these papers were returned in our searches. We identified high inconsistent indexing of papers where relevant papers were not indexed using appropriate terms or failed to assign terms which would have been relevant to the topic they discuss. For example, inequalities or access to care was often categorised and associated key words/MeSH (Medical Subject Headings) terms were not used to index these studies. This in itself is an important finding and raises further questions about how we ensure work on inequalities is not further subject to inequalities in itself with poor indexing limiting the opportunity to share and discover such important work.

Conclusions

Key barriers and facilitators for older people from ethnic minority groups accessing care include knowledge about palliative care services, language, migratory experience, trust in services, religion, culture, and societal and structural issues. Many of the issues outlined in the results were common regardless of country, condition and specific contexts. Gaps were identified in condition-specific studies, healthcare professional studies and studies in countries outside the USA and in non-Christian religions. Further qualitative research needs to explore these gaps, so that more relevant and appropriate tools for supporting particular groups may be developed. Research should also be conducted through an intersectional lens to help understand inequalities more comprehensively.

Appendix 1

CINAHL search strategy

S1	ethnic minorit*
S2	minority ethnic
S3	(MH "Ethnic Groups+")
S4	racial minorit*
S5	minority rac*
S6	(MH “Racial Equality”)
S7	racial
S8	minorit*
S9	bme
S10	bame
S11	black*
S12	black british
S13	british black*
S14	asian*
S15	asian british
S16	british asian*
S17	black american*
S18	african american*
S19	asian american*
S20	american asian*
S21	american african*
S22	latin*
S23	hispanic*
S24	pacific island*
S25	middle east*
S26	south america*
S27	central america*
S28	indigenous people*
S29	indigenous
S30	ethnic*
S31	ethnic group*
S32	foreign*
S33	(MH “Cultural Diversity”)
S34	(MH “Cultural Values”)
S35	cross-cultural comparison
S36	cross cultur*
S37	(MH “Transcultural Care”)
S38	(MH "Transients and Migrants")
S39	migrant*
S40	immigrant*

S41	transient*
S42	transcultur*
S43	(MH “Refugees”)
S44	(MH "Immigrants+")
S45	(MH "Emigration and Immigration")
S46	(MH “Relocation”)
S47	refugee*
S48	asylum seeker*
S49	seek* asylum
S50	displaced people
S51	displaced person*
S52	chinese
S53	india*
S54	china
S55	pakistan*
S56	bangladesh*
S57	african*
S58	caribbean*
S59	arab*
S60	traveller*
S61	roma
S62	gyps*
S63	jew*
S64	muslim*
S65	sikh*
S66	buddhis*
S67	hindu*
S68	old* adult*
S69	old* people*
S70	old* person*
S71	(MH “Dementia”)
S72	dementia*
S73	(MH "Hospitalization of Older Persons")
S74	(MH “Frail Elderly”)
S75	(MH "Health Services for Older Persons")
S76	(MH "Health Services, Indigenous")
S77	elder*
S78	frail*
S79	(MH “Palliative Care”)
S80	(MH "Hospice and Palliative Nursing")
S81	(MH “Palliative Medicine”)
S82	(MH "Terminal Care+")
S83	palliative
S84	hospice*
S85	(MH “Hospices”)
S86	(MH “Death”)
S87	death*
S88	dying
S89	died
S90	terminal*
S91	end of life
S92	life limiting
S93	(MH "Advance Care Planning")
S94	(MH "Advance Directives+")
S95	(MH “Health Inequities”)
S96	(MH “Healthcare Disparities”)
S97	health* inequalit*
S98	health* inequit*
S99	health* equalit*
S100	health* equit*
S101	health* disparit*
S102	(MH "Health Services Accessibility")
S103	ethnic minorit*
S104	minority ethnic
S105	(MH "Ethnic Groups+")
S106	racial minorit*
S107	minority rac*
S108	(MH “Racial Equality”)
S109	racial
S110	minorit*
S111	bme
S112	bame
S113	black*
S114	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S76
S115	seniors
S116	senior citizen*
S117	geriatric*
S118	S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S77 OR S78 OR S115 OR S116 OR S117
S119	S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94
S120	S95 OR S96 OR S97 OR S98 OR S99 OR S100 OR S101 OR S102
S121	S114 AND S118 AND S119 AND S120

Abbreviations

CALD	Culturally and linguistically diverse
ESRD	End-stage renal disease
JBI	Joanna Briggs Institute
LTCF	Long-term care facility
MeSH	Medical Subject Headings
PRISMA-ScR	Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Acknowledgements
Not applicable.

Author contributions
NA designed and conducted the review, analysed the findings, and drafted the article. ND, RF, SG and NK supervised the review, and KW advised the review. PN was second reviewer, and LJM reviewed the updated searches. All authors read and critically revised the article, and approved it to be published.

Funding
The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project is funded by the National Institute for Health and Care Research (NIHR) School

for Primary Care Research (project reference C009) as part of NA's PhD studentship.
The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 25 June 2024 / Accepted: 3 September 2024

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