

Barriers to Palliative Care Uptake in Culturally and Linguistically Diverse Populations: A Systematic Review

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Abstract

Background and aim: Palliative care is essential for patients with life-limiting illnesses, as it enhances survival and quality of life. However, culturally and linguistically diverse individuals often struggle to access timely palliative care. This study investigates barriers to timely palliative care uptake in these populations.

Methodology: A systematic review was conducted in accordance with the Preferred Reporting Items for care uptake in culturally and linguistically diverse populations were included, and data were analysed using narrative synthesis. Studies were appraised based on methodological quality and quality of reporting using the assessment criteria framework proposed by Kmet, Lee and Cook.

Data sources: PubMed, Medline, Embase, PsycINFO, EBMR and Emcare (February 2022).

Results: diverse backgrounds reported barriers in four domains: negative attitudes towards palliative care, limited awareness of palliative care, poor understanding of their disease, and poor communication and collaboration with healthcare professionals (23 studies). Healthcare professionals reported barriers in four domains: lack of cultural understanding structural barriers (19 studies).

Conclusion: Barriers to palliative care delivery in culturally and linguistically diverse cohorts mainly involve the themes of poor education and communication between patients and healthcare professionals. Developing and evaluating educational interventions targeting patients, caregivers, and healthcare professionals may improve palliative care uptake in these populations.

Keywords: Palliative care; Barriers; Transients and migrants; Culturally and linguistically diverse; intervention delivery and emphasise systematic clinician training in palliative care principles to encourage early uptake.

• Early palliative care enhances survival, quality of life, and outcomes for patients and their caregivers with chronic, life-limiting illness.

• Poor palliative care uptake persists among various population groups, with limited systematic insight on culturally and linguistically diverse populations.

• This study reveals pertinent barriers experienced and endorsed by patients and healthcare professionals. Patient-perceived barriers include negative attitudes towards palliative care, limited awareness of palliative care, a poor understanding of their disease, poor communication between patients and healthcare professionals.

• Identified healthcare professional barriers span four domains: a lack of cultural understanding and awareness, a lack of palliative care-specific training, emotions related to palliative care, and healthcare system/structural barriers.

• To our knowledge, this represents the first systematic review that consolidates global migrant population data on palliative care

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Palliative care is a relatively neoteric medical speciality that serves to holistically manage the needs of patients and their families or caregivers in the context of a life-limiting illness [1]. The World Health Organisation defines palliative care as 'an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness', thus 'it prevents and relieves suffering through early identification, correct assessment and treatment of pain and other problems, physical, psychosocial and spiritual' [2,3]. It has become a fundamental aspect of best medical practice given the world's ageing population and increasing incidence rates of chronic diseases, concomitantly with improvements in treatments for these diseases [4]. The latter has meant there are more people living with chronic conditions who would benefit from palliative care support to improve their quality of life. Consequent to this, the relevance and role of palliative care is increasingly well-recognised. Evidence supports the concurrent and integrated provision of palliative care (including both specialist and generalised palliative care) into the traditional medical model of care for many chronic illnesses. Several randomised control trials have demonstrated improved patient and caregiver outcomes in terms of survival, quality of life and carer preparedness for the caregiving role when early palliative care is introduced [5-8].

International migration is increasing worldwide, and as of 2017, the number of international migrants was estimated to be 258 million comprising 3.4% of the global population - compared to 173 million in 2010 [9]. Accordingly, Western healthcare systems are serving an increasingly diverse population. While many individuals choose to migrate out of choice, migration is also necessitated by war, poverty, and persecution [10]. This population has the right to receive high-quality accessible healthcare, including the services offered by palliative care.

The culturally and linguistically diverse population is a marginalized group that is often underserved and underrepresented in palliative care uptake. Unfortunately, this results in late palliative care involvement, when patients are already suffering from severe symptom burden [11,12]. Despite the significant proportion of the community constituted by migrant patients, the barriers to palliative care uptake for this group remain ill-defined. Previous systematic reviews have explored the palliative care experiences of migrants, but they were limited by national contexts and limited inclusion of migrant groups [12-14]. In order to support the development and implementation of models of palliative care services for the culturally and linguistically diverse population, it is crucial to delineate the breadth of barriers

related to them. Therefore, this systematic review was conducted to systematically summarise and present the available published data on barriers to the uptake of palliative care among the culturally and linguistically diverse population.

This systematic review was reported based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement.

Study no.	Author/Year/Country	Aim	Design	Participants	Data collection method	Outcomes related to barriers of Palliative Care uptake

10	Dhingra et al., 2020, USA	To describe attitudes and beliefs concerning advanced care planning in older, non-English-speaking Chinese Americans in a medically underserved urban region	Qualitative	179 Chinese American older adults (mean age 68.2 years)	interviews	Cultural beliefs impeded palliative care discussions: 1/3rd of participants believed that talking about death in the presence of a dying person
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19	McGrath et al., 2021, Australia	from non-English speaking backgrounds	Qualitative	33 caregivers of patients Indian <i>n</i> =4, Filipino <i>n</i> =5, Chinese <i>n</i> =7, and Italian <i>n</i> =10 backgrounds	Focus groups	Poor awareness of palliative care and hospice services. Patients from cultural groups indicated that talking about death or dying was a cultural taboo. There was also a language barrier.
20	Morris et al., 2005, USA	To improve understanding of how to approach discussions between language-discordant patients and clinicians about terminal or life-threatening illness	Qualitative	68 professional medical interpreters (Asian <i>n</i> =32, North American <i>n</i> =18, South/Central American <i>n</i> =11, European <i>n</i> =5, African <i>n</i> =2)	Focus groups	Health professionals had poor understanding of cultural rituals surrounding death. There was poor coordination with other providers, and interpreters struggled to provide education to patients about death and dying.
21	Nielsen et al., 2015, Canada	home and negotiations of care between Chinese immigrants receiving palliative home care, their family caregivers, and home healthcare practitioners	Qualitative	20 participants (Chinese patients with terminal cancer <i>n</i> =4, their caregivers <i>n</i> =5, and health care providers <i>n</i> =11)	Semi-structured interviews	Poor understanding of palliative care services available. Cultural taboo of death along with language barriers, and poor health professional understanding of patients' cultures.
22	Paal et al., 2017, Germany	life preferences of patients with a migration history in Germany and to identify migration a theoretical hypothesis for further research and clinical applications	Qualitative	37 patients (Non-migrant German patients <i>n</i> =19, Migrant patients from Europe, US, Israel, Turkey, Indonesia <i>n</i> =18) with advanced/life-limiting disease (Cancer <i>n</i> =28, Chronic, non-malignant disease <i>n</i> =9) receiving palliative care in	Semi-structured interviews	Patients denied the need for palliative care and often did not understand what it was. Talking about the end-of-life was linguistically and culturally suppressed.
23	Papadopoulos et al., 2007, United Kingdom	Chinese people in London	Qualitative	35 participants of Chinese background (Health professionals <i>n</i> =5, Asylum seekers		

29	Watts et al., 2017, Australia	To identify oncology nurses' and oncologists' individual communicating with patients from minority backgrounds	Qualitative	38 oncology health practitioners (Oncology nurses n=21, Medical oncologists n=12, Radiation oncologists n=5)	Individual interviews or focus groups	professionals to work with diverse patients; overall lack of cultural competency. There was a lack of awareness of the support services available to minority patients and their families. (available to tim Re017) (Australia) -1.2 TD(Australia) fm71SQq 1 0 0p, reTjTjedT(available to timRe017) Oltj litativeava>60j(Quaauper7Tfvidual)T726.sts

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ree identi ed studies found that patients and their caregivers occasionally demonstrated limited understanding of their disease processes [28,35,40]. In two of these studies, participants did not completely understand the implications of their initial diagnosis, translating to continuing uncertainty regarding disease course, treatment, and prognostication [28,40]. is restricted the ability of patients and carers to engage in advance care planning and explore the option of palliative care. In addition, carers' poor understanding of

Another key theme identified among the patient and carer cohorts was poor communication among healthcare practitioners, patients, and carers. Chiefly, language barriers led to the delayed introduction of palliative care in multiple studies, a theme recurrent in the literature that has been demonstrated to reduce patient satisfaction and the quality of healthcare delivered [61]. In palliative care specifically, several studies have found that limited-English proficiency patients receive worse quality end-of-life care and goals of care discussion than English-proficient patients [62], and that this can be improved with the use of professional interpreters [63,64]. However, in our review, patients were sometimes reluctant to utilise interpreter services due to privacy concerns and variability in the quality of the interpreter used [19,42,43]. In addition, a review of the literature reported that poor clinical outcomes in interpreting are found with the use of untrained or ad hoc interpreters, defined as “an untrained person called upon to interpret, such as a family member, a bilingual staff member, or a self-declared bilingual in a hospital waiting room” [64]. This contrasts with professional interpreters, who have been shown to improve clinical outcomes substantively [64]. Therefore, to improve palliative care uptake, communication should be prioritised by increasing the availability of professional interpreters in the hospital and clinic setting.

Several studies identified healthcare professional barriers to the uptake of palliative care in culturally and linguistically diverse populations. Providers’ lack of cultural understanding was identified as the most pertinent barrier to palliative care uptake. Palliative care delivery must consider the shifting and culturally diverse setting in which healthcare is delivered in multicultural societies. Therefore, healthcare practitioners must consider, respect, and become sensitive to the various cultures and cultural norms encountered, especially when dealing with the sensitivities surrounding death and end-of-life [65].

The literature outside this review documents the subjectivity of pain, detailing its dependence on the particular context of a patient, including their cultural background [66], highlighting the necessity of providing culturally-appropriate healthcare. Several randomised controlled trials have demonstrated the benefit of utilising culturally sensitive material and training for healthcare practitioners [65,67]. A study by Hölzel et al. randomised 435 adult primary cancer migrant patients to receive either standard translated or culturally sensitive adapted material, measuring the patient-rated usefulness of provided information. Usefulness was significantly higher in the intervention group, suggesting that culturally-sensitive material can improve patient-practitioner communication and health outcomes [67]. Another randomised control trial found that cultural sensitivity training in healthcare practitioners increased open-mindedness, cultural awareness, and the ability to communicate with people from minority backgrounds [65]. In this study, after one year, patients who received care from trained providers demonstrated improvement in utilising social resources and overall functional capacity [65]. Accordingly, healthcare practitioners training in cultural awareness and palliative care principles must be indicated. Studies delineating educational initiatives that combine cultural training with palliative care training should be conducted to improve palliative care uptake in the culturally and linguistically diverse population.

Moreover, providers’ lack of palliative care-specific training was reported as a barrier in multiple studies. This finding is consistent with other studies that found a lack of palliative care inclusion in medical school curricula in the US, Australia, and the UK [68,69]. Where palliative care education has been included, it is often delivered inconsistently, with significant variation between different medical

schools [70,71]. Additionally, this teaching is often presented within the classroom, with many students completing medical school without clinical exposure to death or dying patients [69]. This largely contributes to the feelings of under-preparedness and inadequacy frequently reported by medical students and junior physicians alike, resulting in healthcare professionals often lacking the skills to convey emotional support to patients and explain the principles of palliative care sensitively and effectively to culturally and linguistically diverse recipients. With an ever-ageing population that will exhibit a longer chronic phase before death, almost all healthcare professionals will encounter patients with palliative care needs.

Furthermore, an undertrained medical workforce has implications for patient outcomes. For example, a randomised control trial by Coonsen et al. found that General Practitioners trained with a palliative care education programme could identify more patients suitable for palliative care than the control group (median 3 vs. 2, $p=0.046$) and more often provided multidimensional care than the group of untrained GPs ($p=0.024$) [72]. It can be argued that an unskilled workforce will fall short in identifying and addressing the complex supportive care needs of patients with life-limiting illnesses. Therefore, it is imperative to introduce and standardise palliative care education and training in medical school and post-graduate speciality curricula to improve palliative care delivery.

While rigorously conducted, this systematic review has several limitations. First, while we performed a comprehensive search, it is possible that articles were missed or overlooked. Second, the studies were heterogeneous regarding palliative care providers (general practitioners, oncologists, interpreters, specialist palliative care physicians) and the type of palliative care provided (general, specialist, home). Third, most of the included studies were qualitative and suffered from limited sample sizes, restricting the generalisability of the results to other populations. However, this was addressed by including studies from diverse ethnographic populations and countries (including developed and developing nations), allowing for a universal exploration into migrant-perceived barriers to palliative care. Given the exponentially increasing rate of migration worldwide coupled with an ever-ageing population, healthcare systems will see a rise in culturally and linguistically diverse patients needing palliative care services over the coming years.

Palliative care can significantly benefit patients from culturally and linguistically diverse backgrounds who have unmet supportive care needs. However, our systematic review has identified several barriers that impede the provision of streamlined palliative care services to this population group. These barriers can be primarily attributed to poor education and communication between patients, their carers, and healthcare professionals, as well as inadequate training of healthcare professionals in palliative care. To improve access, utilisation, and delivery of palliative care to this traditionally underserved population, it is essential to develop interventions and educational initiatives targeting these themes. By identifying these barriers, we hope to guide the development of initiatives that will effectively address the challenges faced by patients from culturally and linguistically diverse backgrounds and ensure that they receive the palliative care they need and deserve.

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