Literature Review: People living with life-limiting illness who are culturally diverse

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Description of population

The literature emphasised the experiences of non-White immigrant populations in Western nations. Individuals belonging to this group face significant barriers to accessing care, some of which are mitigated based on age at time of immigration, language proficiency, and financial resources.

Search criteria and methods

The review was conducted in February 2025, and began with key-word Boolean searches on Google Scholar using "palliative care," "access," "hospice care," "culturally diverse," "immigrant," "barriers to palliative care," "language," "life-limiting illness," and "systematic review." For relevant articles found, hand-searching of references was conducted.

Lived experiences of inequitable access to palliative and end of life care

The literature highlighted several common experiences that are shared across cultural groups:

- Compared to patients with limited English proficiency are more likely to experience the following when compared to those without English proficiency limitations (Bigger et al., 2024):
    - Inadequate assessment of pain and diagnostics
    - Misunderstanding their prognosis
    - Higher likelihood of medical errors leading to harm
    - Longer hospital stays, higher rates of 30-day readmission
    - Smaller chances of being referred to hospice
    - Confusion after discharge
- Members of culturally diverse groups may be more likely to distrust providers and to seek additional information from lay community members and religious leaders (Herbstsomer & Stahl, 2021).
- Visible minorities may experience financial and insurance challenges, and care preferences are guided by cultural and religious preferences (e.g., shared decision making, refusal to end life-saving treatments, and viewing pain as divine will) (Gardner et. al., 2018).
- Culturally diverse groups are may have a shared desire for family members to care for the sick and dying and, and members may experience backlash from communities for enrolling in palliative/hospice care (Herbstsomer & Stahl, 2021; Shabnam et al., 2022). Families are likely to take on prominent roles in caregiving driven by cultural expectations (Phiri et. al., 2023; Shabnam et al., 2022).

- Under-represented groups are more likely to receive aggressive treatments and interventions than hospice care, which is associated with higher costs and lower quality of life (Jones et al., 2021).
- Family members often receive limited information about support services available, institutional delay, medical paternalism, discriminatory approach, challenges practicing cultural and religious beliefs, and feelings of being ignored (Iluno et al., 2024).

The literature described several specific population groups who experience unique challenges:

- **Forced migrants** may experience difficulties building rapport, medical misinterpretation, and lack of information leading to feelings of powerlessness, and distress (Clancy et. al., 2024).
- **Chinese immigrants** may place a strong emphasis on family values including family caregiving, believing death to be a private affair, and a reluctance to seek external help (Kwok et al., 2020).
- **Undocumented immigrants** may face delayed access to care, causing them to present with higher symptom burden. This often leads to aggressive treatments and admissions to the ICU (Seto et al., 2019). Mental distress may be experienced due to loss of income while seeking care, discrimination, and challenges accessing medical care (Seto et. al., 2019).
- **South-Asian migrants and relatives** may have preference to die at home and fear of hospital stays due to cultural factors such as (cleanliness, privacy, ability to perform rituals and presence of family). Family caregivers are considered as preferred option to maintain dignity and comfort (Shabnam et al., 2020). Female caregivers specifically are more prevalent and struggle with managing caregiving and other responsibilities (Shabnam et al., 2020).

Barriers and facilitators to access palliative and end of life care

Barriers described in the literature can be loosely grouped into three groups: language and communication barriers; barriers arising from cultural and personal beliefs; and knowledge and accessibility barriers.

Language and communication barriers:

- Language barriers due to linguistic diversity (Bigger et al 2024; Phiri et al., 2023; Shabnam et al., 2022).
- A reluctance to speak through a third party (Herbstsomer & Stahl, 2021).
- Information sharing defects, complex medical communication, and need for interpreter (Iluno et al., 2024).
- Overreliance on families for interpretation which raises concerns for disclosure and accuracy of information (Clancy et al., 2020; Shabnam et al., 2020; 2022).
- Lack of resources to provide interpreters and psychosocial support (Shabnam et al., 2022).
- Families desire to withhold prognosis from patients (Phiri et al., 2023).
- No direct translation to some of the concepts of palliative care into minority languages (Shabnam et al., 2020).

Barriers arising from personal or cultural beliefs:

- HCP barrier: Non acceptance of treatment and emphasis on traditional methods of healing (Clancy et al., 2020).
- HCP barrier: Spiritual and religious beliefs become a barrier when leading patients/families to request futile treatments and prevent end-of-life care discussions (Clancy et al., 2024).

- The belief that palliative care conversations hastens death (Kwok et al., 2020).
- Reluctance of caregivers to seek external support (Kwok et al., 2020).
- Preference for collective decision making (Kwok et al., 2020, Phiri et al., 2023).
- Limited resource for practitioners to learn and address complex minority needs (Shabnam et al., 2023).

Knowledge and accessibility related barriers:

- Poor availability and accessibility of care and navigation of health care system (Clancy et al., 2024).
- Cost of care and leaving work to provide care (Clancy et al., 2024; Seto et al., 2019).
- Misconceptions, mistrust, and lack of information and misunderstanding about palliative care (Gardner et al., 2018; Herbstsomer & Stahl, 2021; Shabnam et al., 2022).
- Low uptake of healthcare services by Chinese migrant populations are connected to cultural differences between chicness and the host community (i.e., filial piety and collective decision making) and their experiences of palliative care in their country of origin (high costs and lack of services) (Kwok et al., 2020).
- Limited health literacy among family members, including advanced care planning (Phiri et al., 2023; Seto et al., 2019).
- Fear of deportation (Seto et al., 2019).

Facilitators

- Interpreters: Medical interpreters to reduce the risk of miscommunication and poor health outcomes (Bigger et al 2024; Shabnam et al., 2020).
- Preference for discussing end of life matters with someone who understood their language and culture (Gardner et al., 2024).
- Increasing cultural competence among healthcare professionals (Shabnam et al., 2020).
- Minority representation at the policy level to address needs (Shabnam et al., 2022).

Promising interventions and practices

- Training clinicians on how to incorporate professional interpreters into the care team and training interpreters in palliative care (Bigger et. al., 2024; Herbstsomer & Stahl, 2021).
- The most studied intervention in a systematic review is in education, whereas community support interventions and effectiveness of clinical home-based care were less addressed in the literature (Jones et al., 2021).
- A recent and promising interventions to increase support includes education and training for healthcare providers; consultations between HCP and patients/families; and coordination of care between organizations (Shabnam et al., 2023).

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