

# REFUGEES & ADVANCE CARE PLANNING OR SHARED DECISION-MAKING

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Please find following a summary of a literature search and relevant results. All articles can be provided in full - email [library@monashhealth.org](mailto:library@monashhealth.org) for a list of the articles you require.

## QUESTION

What is the available evidence for advance care planning, end-of-life care, and shared decision-making in refugee cohorts?

## RESULTS

### ONLINE RESOURCES

### AUSTRALIAN GUIDELINES & REPORTS

Australian Government Department of Health, Disability, and Ageing. (2020). **Exploratory Analysis of Barriers to Palliative Care – Issues Report on People from Culturally and Linguistically Diverse Backgrounds.** [Web link.](#)

- Includes information on barriers to palliative care access for CALD populations (including refugees), culturally appropriate palliative care models, advance care planning considerations., language barriers and health literacy, cultural differences around death and decision-making, need for interpreters, culturally appropriate resources, and community education.

Victorian Foundation for Survivors of Torture. (2026). **Australian refugee health practice guide.** [Web link.](#)

- Includes sections on trauma informed care, patient-centred consultation approaches, communication and interpreter use, and mental health and psychosocial care.
- Recommends a “universal precautions” trauma-informed approach, assuming many patients may have experienced trauma

### STATE GUIDELINES & REPORTS

Victorian Department of Health. (2019). **Refugee and asylum seeker health services: Guidelines for the community health program.** [Web link.](#)

- Includes sections on culturally responsive care, service coordination, trauma-informed service delivery, and improving access and equity for refugee populations.

NSW Health. (2021). **Refugee health plan 2022-2027.** [Web link.](#)

- Includes sections on culturally responsive and trauma-informed care models strengthening mainstream health services for refugees and improving access and equity in health services.

### PEER-REVIEWED JOURNAL ARTICLES – MOST RECENT FIRST

Articles are grouped by theme:

- Advance Care Planning
- End-Of-Life Care
- Shared Decision-Making

Each article summary contains excerpts from the abstract and an online link.

### ADVANCE CARE PLANNING

McKeith, A., et al. (2025). **Advanced Care Planning in Refugee Patients.** *The American journal of hospice & palliative care*, 10499091251348463. Advance online publication. [Request full-text.](#)

Our results suggest that the percentage of refugees who have ACPs in place is very low. With the large number of refugees that have entered the US each year, more and more clinicians will be seeing refugees in their practice. They should consider including discussions about ACP in their care of these patients.

### END-OF-LIFE CARE

Batumalai, V., et al. (2026). **Cancer Control in Refugee and Asylum Seeker Populations: A Scoping Review.** *JCO global oncology*, 12, e2500307. [Click for full-text.](#)

Refugees and asylum seekers face persistent and multifaceted inequities in cancer care, shaped by both individual and systemic factors. Although some high-performing models and interventions exist, large gaps remain in research and service delivery. The findings emphasize the urgent need for an integrated strategy that incorporates the comprehensive cancer care needs of refugees and asylum seekers into national and international health policies.

Doyon, K., et al. (2026). **Healing with Humility: Palliative Care for Refugee Communities.** *The American journal of nursing*, 126(3), 31–35. [Click for full-text.](#)

This article offers a practical framework grounded in holistic, person-centered values for delivering palliative nursing care to refugee communities. It outlines the complex resettlement journey and highlights how structural inequities, institutional racism, and communication barriers can undermine trust and care delivery. Cultural humility is defined and proposed as a guiding principle. Through real-world examples, communication strategies, and evidence-based insights, the authors demonstrate how care grounded in this principle can promote dignity, build trust, and improve outcomes. Special attention is given to interpreter use, social integration, and the importance of recognizing both cultural differences and individual strengths.

Nakajima, M., et al (2026). **Experiencing Cultural Safety in Nursing Care: A Focused Ethnography With Refugees.** *Nursing & health sciences*, 28(1), e70311. [Click for full-text.](#)

Five major themes were identified: Having a place of spiritual sanctuary, culturally congruent care, hopes for holistic care within the Japanese healthcare system (body-mind-spirit), recognition, and equality from Japanese society, and receiving culturally respectful end-of-life care. Themes revealed how spiritual, cultural, and social continuity shape refugees' health experiences, highlighting both resilience and vulnerability. Nurses can foster culturally safe care by supporting spiritual and

community spaces, integrating bicultural practices, addressing systemic inequities, and collaborating with families and community leaders in end-of-life planning.

Sasie, S. D., et al. (2026). **Community health assets and refugee wellbeing: Qualitative evidence across mental health, disability inclusion, end-of-life care, and women's health - A global scoping review.** *PLOS global public health*, 6(2), e0005459. [Click for full-text.](#)

Common barriers included stigma, gender-based violence, legal insecurity, cultural and language discordance, and limited access to specialized services. Effective strategies included peer-led psychosocial support, culturally concordant providers, integrated community-based care models, and safe spaces for women and marginalized groups.

Clancy, M., J. (2025). **Exploring the experiences of children's palliative care for forced migrant families in the United Kingdom: an interpretative phenomenological study.** *Frontiers in pediatrics*, 12, 1494938. [Click for full-text.](#)

Four overarching themes were identified related to experiences of loss and grief, communication, faith and coping strategies and alienation and discrimination. Compassionate, empathetic, family-centred care which valued family belief systems and coping strategies, optimised care. Learning with and from families was described by all participants, which enhanced understanding and fostered mutual respect. However, barriers included poor access to services and resources, protocol-led care, limited time with families, communication barriers and staff burnout.

H, M., et al. (2025). **Enhancing the wellbeing of refugees living with advanced life-limiting illness in high-income resettlement countries: A systematic review.** *Palliative medicine*, 39(7), 750–764. [Click for full-text.](#)

We identified 17 assets that enhanced refugees' wellbeing: resilience, religion, spirituality, sense of identity, belonging, community connections, health and death literacy, acculturation, family and social support, social capital, community structures, access to funeral information, access to services, palliative care service approaches, and workforce capacity. Resilience was linked to identity and belonging, connections within cultural and religious networks, social capital and creating meaningful funeral rituals in resettlement. Palliative care workforce capacity, death literacy, acculturation, refugees' grief experiences and willingness to discuss and plan for death, influenced refugees' attitudes to palliative care, communication with staff about treatment, prognosis and spiritual care, and care outcomes.

Njue, C., et al. (2022). **Models of Maternal Healthcare for African refugee women in High-Income Countries: A Systematic Review.** *Midwifery*, 104, 103187. [Click for full-text.](#)

The lack of evidence regarding the impact of care models on the maternal healthcare outcomes of African refugees highlights the need to improve care evaluations. These results reinforce the importance of education and interventions to build refugee women's health literacy and strength-based communication approaches supported by multidisciplinary, multilingual and highly trained teams of health professionals. There is also a need to involve African refugee women in shared decision making.

Guo, P., et al. (2021). **Compounded trauma: A qualitative study of the challenges for refugees living with advanced cancer.** *Palliative medicine*, 35(5), 916–926. [Click for full-text.](#)

This study reveals the impact of fractured families and networks on social support in advanced cancer, and the compounding trauma of the disease for refugees. Detailed person-centred assessment and emphasis on psychosocial support is essential, and home-based care should not presume community support for patients to remain at home.

Clancy, M., et al. (2020). **A systematic review exploring palliative care for families who are forced migrants.** *Journal of advanced nursing*, 76(11), 2872–2884. [Click for full-text.](#)

Forced migrant families have multiple needs including physical and emotional support and help in navigating complex systems. Professional interpreters can ease communication barriers when resourced appropriately. Individualized care is crucial to addressing the intricate mosaic of culture such families present. A cultural sensitivity/insensitivity framework is presented that may help guide future interactions and priorities for those working in children's palliative care.

Najjar, S. N., et al. (2020). **Challenges in the Provision of End-of-Life and Palliative Care to Ethnic Nepali Refugees.** *Journal of pain and symptom management*, 60(2), 476–486. [Click for full-text.](#)

The refugee experience and culturally specific factors affect the end-of-life care of this population. Challenges in the end-of-life care of Nepali refugees include challenges related to social and health inequities, such as significant chronic respiratory disease burden; lack of protocols for deferral of illness disclosure; lack of support for group decision making; unfamiliarity with spiritual, religious, and traditional health practices; and difficulty with cross-cultural communication. Culturally competent care of ethnic Nepali refugees can be accomplished through respectful exploration of patients' and families' preferences regarding the challenges identified.

O'Connor, M., et al. (2020). **Palliative care for asylum seekers living in the community in Australia.** *Progress in Palliative Care*, 28(6), 362-365. [Click for full-text.](#)

Drawing on a story of one asylum seeker, this paper describes some of the key considerations required in caring for an asylum seeker who is facing the end of their life, making recommendations for addressing their often-complex care needs

Madi, F., et al. (2019). **Death, Dying, and End-of-Life Experiences Among Refugees: A Scoping Review.** *Journal of palliative care*, 34(2), 139–144. [Request full-text.](#)

Research on end-of-life experiences among refugees is sorely lacking. This study raises awareness of the need for empirical data on end-of-life challenges and palliative care among refugees, thus equipping humanitarian agencies with a more explicit and culturally sensitive lens targeting those with life-limiting conditions.

Ben-Arye, E., et al. (2018). **Refugees in Conflict: Creating a Bridge Between Traditional and Conventional Health Belief Models.** *The oncologist*, 23(6), 693–696. [Click for full-text.](#)

European oncologists face a communication gap with refugee patients who have recently immigrated from Middle Eastern and northern African countries, with their different health belief models and affinity for traditional and herbal medicine. A culturally sensitive approach to care will foster doctor-refugee communication, through the integration of evidence-based medicine within a nonjudgmental, bio-psycho-social-cultural-spiritual agenda, addressing patients' expectation within a supportive and palliative care context. Integrative physicians, who are conventional doctors trained in traditional/complementary medicine, can mediate between conventional and traditional/herbal paradigms of care, facilitating doctor-patient communication through education

and by providing clinical consultations within conventional oncology centers.

## SHARED DECISION-MAKING

Pitta, A., et al. (2026). **Bridging the Language Gap in Healthcare: A Narrative Review of Interpretation Services and Access to Care for Immigrants and Refugees in Greece and Europe.** *Healthcare (Basel, Switzerland)*, 14(2), 215. [Click for full-text.](#)

The use of trained medical interpreters and intercultural mediators improves comprehension, shared decision-making, patient satisfaction, and clinical outcomes.

Viksveen, P., et al. (2026). **Mental Health Services for Adolescents With Status as Asylum Seekers or Refugees: A Qualitative Study of Healthcare Professionals' Perspectives.** *Transcultural psychiatry*, 63(1), 70–83. [Click for full-text.](#)

Four themes were developed through the study: (a) culturally sensitive and adapted services; (b) low threshold and outreach services; (c) building a trusting relationship; and (d) user involvement. Some of the recommendations include an ongoing collaboration with youth and their families to better understand their culture; healthcare professionals who acquire cultural competence, practice cultural humility and are mindful of their own cultural backgrounds. There should be comprehensive education and training programmes for healthcare professionals. Services should be easily accessible with simplified referral procedures and arena flexibility. Skilled interpreters should be used, including cultural interpreters. Shared decision-making should be used to actively engage youth in their treatment.

Dotta-Celio, J., et al. (2025). **Medication Adherence and Perceptions According to the Presence or Absence of a Migration Background in a Dialysis Unit (DIANA Qualitative Study).** *Patient preference and adherence*, 19, 2107–2118. [Click for full-text.](#)

More studies are needed to understand how shared decision-making can be established between health professionals and patients, taking into account their migration status. To provide tailored education, it is essential to evaluate patients' health literacy and to use the teach-back method to find the best way to convey health messages. The acquisition of transcultural clinical skills by health professionals is necessary to support medication adherence.

Son, C., et al. (2025). **Person-centred care for migrants: a narrative review of healthcare literature.** *Frontiers in health services*, 5, 1573813. [Click for full-text.](#)

The review led to three main practices: (a) enhancing migrants' ability to participate in their healthcare, (b) building intercultural partnerships, and (c) promoting cultural education of healthcare providers. These practices underscore the significance of respecting diverse cultural beliefs about shared decision-making and understanding how PCC practice is perceived in different cultural contexts. The results also indicate a need for educational programs that equip healthcare providers with intercultural communication skills and knowledge to provide culturally sensitive PCC.

Lionis, C., et al. (2018). **Assessing refugee healthcare needs in Europe and implementing educational interventions in primary care: a focus on methods.** *BMC international health and human rights*, 18(1), 11. [Click for full-text.](#)

Evidence-based interventions, encompassing elements of patient-centredness, shared decision-making and compassionate care, could contribute to the assessment of refugee healthcare needs

and to the development and the implementation of training programmes for rapid capacity-building for the needs of these vulnerable groups and in the context of integrated PHC care. This article reports on methods used for enhancing PHC for refugees through rapid capacity-building actions in the context of a structured European project.

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**APPENDIX****SEARCH METHODOLOGY**

A systematic search was conducted for literature. The results were screened by librarians using [Covidence](#).

**SEARCH LIMITS**

- English-language
- Published within the last 10 years

**DATABASES SEARCHED**

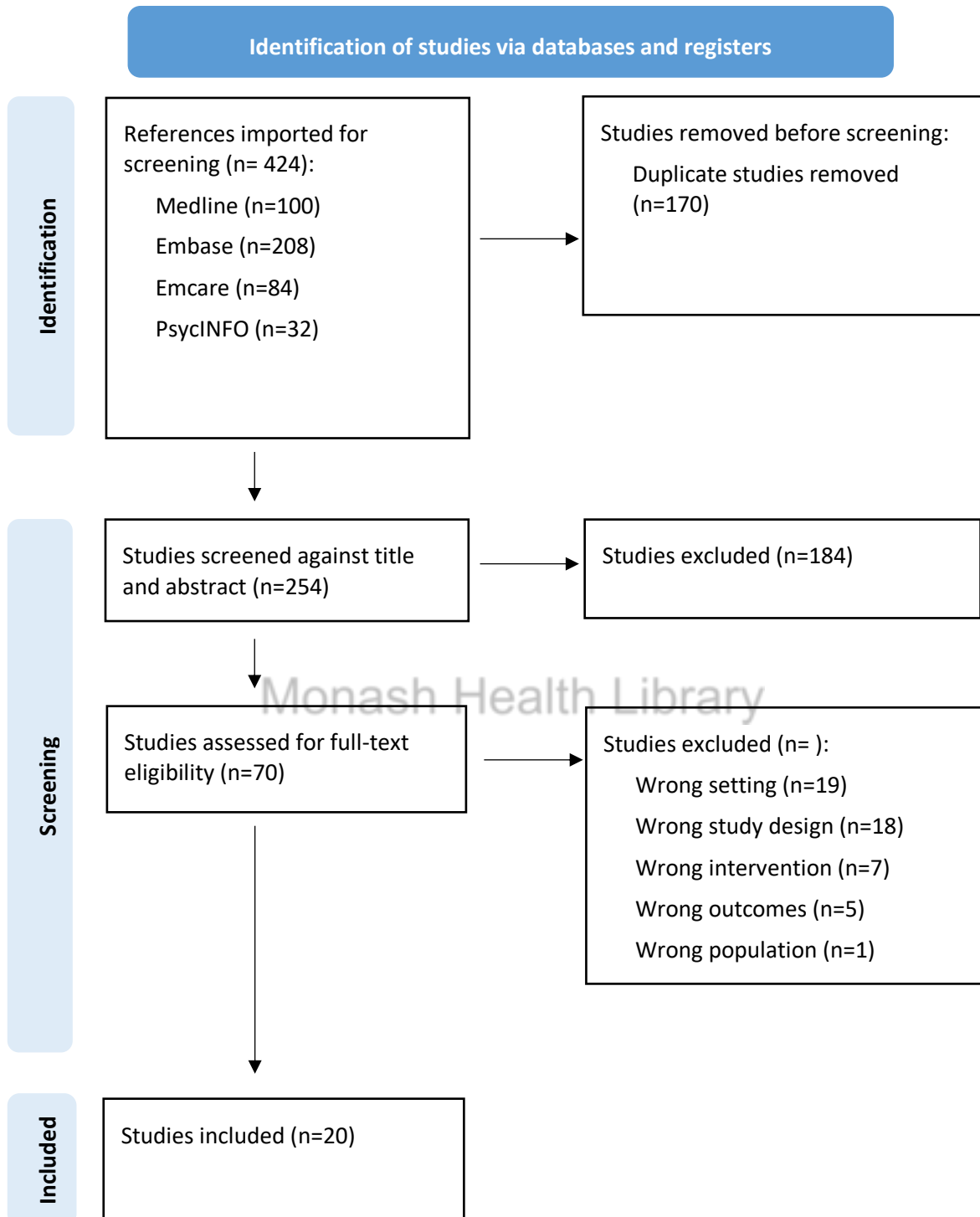
- Medline – index of peer reviewed articles across health sciences and medicine.
- Embase – index of biomed and pharmacological peer reviewed journal articles.
- Emcare – index of nursing, allied health, critical-care medicine and more.
- PsycINFO – index of psychology and psychiatry peer review journal articles and book chapters.
- UpToDate & BMJ Best Practice – synthesised evidence for patient care.
- Grey literature – Google, Google Scholar, Trip database, Biomed Central Proceedings.

**MEDLINE SEARCH STRATEGY**

This search strategy was conducted on 12/03/2026 and translated to other databases, as relevant. Searches in each database were conducted on the same day.

- 1 (refugee\* or asylum\* or asylee\*).tw,kf.
- 2 ((people\* or person\* or population\* or wom?n or man or men or child\* or patient\* or individual\*) adj3 displace\*).tw,kf.
- 3 (migrant\* adj2 (humanitarian or forced)).tw,kf.
- 4 Refugees/
- 5 1 or 2 or 3 or 4
- 6 (advance care plan\* or advance care directive\* or advance directive\* or "end of life" or end-of-life or palliative or shared decision\* or supportive care or comfort care or hospice or terminal care or living will or living wills).tw,kf.
- 7 Advance Care Planning/ or Advance Directives/ or exp Terminal Care/ or Palliative Care/ or Decision Making, Shared/
- 8 6 or 7
- 9 5 and 8
- 10 limit 9 to last 10 years

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