Dying with dignity: how can we deliver values-concordant end-of-life care for immigrant patients in the United States?

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One in seven individuals in the US was born outside the country; many identify as immigrants.[1] Immigrant groups face health disparities from diagnosis to survivorship; however, less is known about disparities at end-of-life (EOL). While there exist vast heterogeneities among immigrant groups regarding their preferences in EOL care, they share barriers to meeting individual preferences at EOL.[2] In this short comment, we explore the complex barriers faced by immigrants, specifically within the behavioural, physical/built environment, sociocultural, and healthcare systems domains delineated within the National Institute of Minority Health and Health Disparities (NIMHD) framework,[3] and suggest steps forward at the levels of patient, community, and policy that promote equitable access to a good death (Table 1).

Behavioural

Much work describes how different groups' cultural and religious beliefs impact access to culturally concordant EOL care, underscoring the theme that cultural preferences are varied and should be individualised for each patient. In the US, there exists a prevailing notion that a good death entails dying at home with family. Many immigrant populations experience cultural barriers due to beliefs that diverge from those of Western cultures. For example, some groups place the family at the heart of medical decision-making and may prefer not to disclose terminal diagnoses to patients. This emphasis on collective medical decision-making may differ from individualistic approaches common in Western cultures. Perceptions of empathy and expression of existential distress can vary across cultures, with further implications for communication at EOL.

Sociocultural

Cultural mistrust may contribute to challenges in strengthening the physician-patient relationship, especially critical at EOL. Cultural mistrust is rooted in the historical experiences of minoritised patients in American medicine, including examples of serious exploitation, deception, and nonconsensual procedures. Cultural mistrust may play a role in motivating immigrant patients to insist upon aggressive, life-prolonging treatment inconsistent with EOL preferences out of fear that physicians' decisions could be influenced by economic motives.[4]

Physical/built environment

Language barriers influence access to EOL care, with 41% of immigrants having a preferred language other than English. These barriers may hinder the patient and family's ability to navigate the healthcare system by contributing to treatment delays resulting from wait times for interpreter services and cultural ambassadors, challenges in comprehending EOL care options, and difficulties in articulating preferences. Often, these barriers may contribute to levels of care non-concordant with patients' goals.[5]

Many immigrants also face financial barriers. Over 20% of Hispanic undocumented immigrants live at or below the poverty line, as do many Asian American subgroups, despite the notion of the "model minority." Many immigrants are also more likely to work in industries that do not offer employer-sponsored health coverage. Given that the final month in hospice care alone can cost $17,845 (a 2016 estimate), immigrants with financial barriers are at greater risk of being unable to use hospice care.[6] Noninsurance may also limit access to specialised palliative care physicians and facilities. Though some safety-net hospitals accept Emergency Medicaid for undocumented immigrants, they often experience palliative care staffing shortages, leaving physicians with less palliative care expertise to conduct EOL care discussions.

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	Specific barriers	Steps forward
Behavioral	• Many immigrant populations experience barriers due to cultural beliefs and preferences that diverge from those of Western cultures. • Varied perceptions of empathy and existential distress across cultures may hinder effective communication and support at EOL.	• Conduct disaggregated research on the diverse cultural preferences, coping strategies, and manifestations of existential distress for diverse immigrant groups. • Enhance cultural competency training for healthcare professionals.
Physical/built environment	• Language barriers contribute to treatment delays, misunderstanding of EOL care options, and levels of care that are incongruent with patients' goals. • Financial barriers limit access to hospice and specialized palliative care personnel and facilities	• Invest in cultural ambassadors, healthcare system navigators, and medical interpreter services who represent a broad range of languages and cultures. • Increase investment in palliative care facilities and interpreter services, particularly those that serve undocumented immigrants.
Sociocultural	• Mistrust may contribute to challenges in strengthening the patient-physician relationship • There is a dearth of culturally specific EOL support groups to help patients cope with feelings of isolation and distress at EOL.	• Collaborate with community and spiritual leaders to enhance trust and support for immigrant patients at EOL. • Conduct disaggregated research to develop and implement culturally-specific EOL support groups for immigrants.
Healthcare systems	• Undocumented immigrants remain ineligible for the Affordable Care Act and Medicaid benefits, and Emergency Medicaid funding for hospice and palliative care is also limited. • Restrictive immigration policies and deportation threats may disrupt family support networks and limit access to financial assistance programs at EOL.	• Reclassify hospice as an essential benefit mandated by in-state Medicaid programs • Expand Medicaid coverage to include undocumented immigrants. • Implement legal protections to ensure that EOL care wishes are honored, including humanitarian visas, waivers, and avenues for extended stays.

Table 1: **Summary of barriers faced by immigrant patients at EOL and steps forward.**

Healthcare systems

Legal factors place many immigrants at increased risk for financial toxicity. Undocumented immigrants (over 10 million people) remain ineligible for the Affordable Care Act and Medicaid benefits. Emergency Medicaid funding for hospice and palliative care is also limited, with a survey of palliative clinicians in the US finding that hospice was limited or unavailable for over two-thirds of undocumented people in their practice.[7] The limited hospice facilities that accept undocumented immigrants are often overwhelmed with patients.

Existing barriers in access to values concordant EOL care may be exacerbated amid America's current political climate, characterized by restrictive immigration policies and uncertain health coverage. Increased deportation threats may prevent loved ones from providing essential emotional and decision-making support, performing funeral rituals in patients' home countries, and engaging with existing financial assistance programs.

Steps forward

A patient-centric approach is essential to delivering values-concordant EOL care across the care continuum. Collaborations with trusted community and spiritual leaders may help immigrant patients obtain support at EOL. A recent study of Chinese immigrants with cancer found that 80% demonstrated interest in culturally tailored EOL support groups addressing topics like healthcare system navigation.[8] Yet, there remains a dearth of culturally specific EOL support groups for many immigrants. Given the documented benefits of cultural ambassadors, healthcare system navigators, and medical interpreter services for immigrant patients, including reduced anxiety, shorter hospital stays, and fewer communication errors, hospitals should increase investment in these services, encompassing a broad variety of languages and cultures.

In the clinic, enhanced training programs for palliative care physicians, focusing on the nuances of addressing patients' cultural preferences, are beneficial. Medical school is also an important avenue through which palliative care informed by cultural humility should be taught. Didactic techniques employing case vignettes, group discussions, and role-play to simulate care for diverse patients at EOL have demonstrated positive results.[9]

Additionally, for much of EOL care, most therapeutic approaches have originated from North America and Europe, their development often limited in generalizability to more diverse groups. Thus, it is imperative to invest resources into the study of the illness experience and cultural determinants relevant to terminal conditions among immigrant populations. Qualitative research may focus on understanding value-based EOL care for immigrant patients, exploring what constitutes a "good death," and mitigating barriers faced by immigrant families when managing caregiving responsibilities.

Expansion of social and financial support services for immigrants at the EOL is necessary to bridge gaps in access to EOL care. Emergency financial assistance programs should be established to provide immediate support for immigrants facing acute EOL-related crises and travel needs. Additionally, increased investment in

the training of cultural ambassadors, medical interpreters, financial counsellors, and community health workers of diverse backgrounds can help immigrants navigate the healthcare system and access hospice and support programs.[10]

At the federal level, legal protections can ensure that EOL care wishes are honoured. In the context of immigration policy, these protections may encompass humanitarian visas, waivers, and avenues for extended stays. With regards to insurance policy, hospice should be reclassified as an essential benefit mandated by in-state Medicaid programs, and Medicaid should be expanded to include undocumented immigrants.

Conclusions

We present a patient-centered approach to address the multifaceted barriers to EOL care for immigrants. Future work should aim to amplify voices from diverse cultural backgrounds. Such work may include qualitative research into culturally specific EOL preferences, the design of EOL support groups, and policy analysis to forecast the impacts of immigration reform on EOL support access among immigrants. These efforts may galvanize the equitable delivery of values concordant EOL care for the US's diverse population.

Contributors

K.K. wrote the initial draft. All other authors contributed to literature search, writing review, and writing editing.

Declaration of interests

PN declares consulting fee from Boston Scientific, Janssen, Blue Earth, Astellas, Bayer, Novartis, Theranano, Included Health, AIQ, Grand Rounds Urology, unrelated to the topic of this work, and stocks from Nanocan, Reversal Therapeutics, Strategen Bio, Telerad Oncology. All other authors have no relevant conflicts-of-interest to declare.

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