LETTER TO EDITOR

What We Must Seek Now: Palliative Care without Borders, Race, and Ethnicity while Preserving Patient Autonomy

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DEAR EDITOR

Palliative care seeks to enhance the quality of life for patients with life-limiting illnesses and their families, transcending geographical, cultural, and socioeconomic boundaries. Recognized as a fundamental human right by the World Health Assembly 2014 resolution, access to quality palliative care and pain relief remains limited for millions, particularly in low- and middle-income countries (LMICs), marginalized groups, and minority populations. Efforts to integrate palliative care globally include specialist services in urban centers, outreach programs for home-based care in remote areas, and innovative virtual consultation models accelerated by the COVID-19 pandemic.[1] This article explores the need for universally accessible palliative care, addresses racial and ethnic disparities, and emphasizes preserving patient autonomy.

Palliative care must meet the diverse needs of society while maintaining quality standards. Globalization has increased patient mobility and enabled people with life-limiting illnesses to seek care across borders. For example, patients from LMICS often travel to countries with better facilities for specialized palliative care because of advanced facilities and lower costs. In Europe, cross-border healthcare guidelines allow access to palliative care in neighboring countries.[2]

Access to palliative care in underrepresented regions reveals stark gaps. Worldwide, the 2017 Atlas of Palliative Care reported only 1,562 specialized services, covering just 7.6% of needs, with over 3.5 million people suffering without support and more than 1 million dying annually in pain. Many countries remain at isolated provision levels, facing limited opioid availability and insufficient training. In the Middle East, palliative care is underdeveloped due to weak governmental commitments, restricted opioid access, and cultural stigma. However, initiatives like Jordan's National Palliative and Home Care Strategic Framework aim to improve integration and training. In Southeast Asia, only about 14% of those needing palliative care receive it, despite progress in Malaysia's national policies and Myanmar's capacity-building programs, as noted in the 2025 Asia Pacific Hospice Palliative Care Network Atlas.[3]

The COVID-19 pandemic accelerated virtual consultations, with platforms like Zoom enabling cross-border care delivery. A 2021 study in Kenya showed that telehealth increased access for rural patients by 40%.[2] However, in LMICs, barriers include high infrastructure costs (e.g., unreliable broadband), digital literacy gaps, regulatory hurdles like data privacy laws, and limited device access. Solutions involve partnerships with non-governmental organizations for subsidized equipment, mobile-based platforms requiring less bandwidth, and regulatory reforms to standardize telehealth guidelines.[4]

Racial and ethnic minorities face significant disparities in palliative care access, particularly in high-income countries. In the U.S., data from the Centers for Medicare & Medicaid Services (2010) shows lower hospice use among Black and Hispanic patients, who are also more likely to receive aggressive interventions in their final months, often against their preferences. Similar disparities affect Indigenous populations globally. In Canada, Indigenous peoples, including First Nations, Inuit, and Métis, face barriers rooted in colonization, such as historical trauma and geographic isolation. Inuit regions often lack palliative care, contributing to a 13-year shorter life expectancy, where cancer is a major factor. In Australia, Aboriginal and Torres Strait Islander peoples experience inequities due to cultural mismatches and access issues. The National Aboriginal and Torres Strait Islander Palliative Care Framework emphasizes culturally safe services and community involvement to enable care in preferred settings.[2, 5]

Patient autonomy, a cornerstone of palliative care ethics, ensures that decisions align with patients' values. This principle supports informed decision-making and advanced care planning (ACP), enhancing quality of life and, in some cases, survival. Physician-assisted suicide (PAS) offers control over death circumstances but is legally available in only a few regions, like the Netherlands, Belgium, and specific U.S. states (e.g., Oregon's Death with Dignity Act). Ethical debates persist: proponents highlight autonomy and compassion, aligning with principles of beneficence, while opponents cite risks of coercion, mental health influences, and potential abuse.[6]

Barriers to autonomy include legal constraints, family dynamics, and communication challenges. In collectivist cultures, such as those in East Asia, family members often dominate decision-making, sometimes overriding patients' preferences. In the U.S., legal restrictions on PAS limit options, while poor provider communication hinders informed choices. The "decision ecology" model, considering social and relational contexts, supports autonomy. For example, community-based ACP programs in India involve families and local leaders to align care with cultural norms. Innovations like AI-driven symptom management tools use machine learning to predict deterioration, optimize pain strategies, and increase referrals. Blockchain technology enables secure cross-border health records, enhancing interoperability and privacy for mobile patients.[2, 4]

In conclusion, palliative care without borders requires addressing disparities, leveraging technology, and ensuring culturally competent interventions. Preserving autonomy demands navigating legal, cultural, and systemic barriers while fostering relational decision-making. By expanding telehealth, patient navigation, workforce diversity, and incorporation of AI and blockchain, palliative care can become a universal right, respecting autonomy across all borders, races, and ethnicities.

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Declaration on the Use of AI

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