



Commentary

Denied the right to comfort: Racial inequities in palliative care provision

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People who are racialized often exist in the margins of our health systems. Inequitable health care is experienced from the moment of birth and continues throughout life, extending into end of life and palliative care. This occurs even though the United Nations acknowledges palliative care as a human right [1], and the World Health Organization (WHO) mandates that all states provide it [2]. As we strive for health systems where all people are treated equitably, palliative care must be included. To begin, it is important to collate what is known, and then to chart a way forward. This piece will focus on palliative care in the US and Canada but similar concepts may apply more broadly.

It is known that *race* is a subjective, social construct—with no genetic basis—initially created to facilitate dehumanization and abuse of those living outside of Europe starting in the 1500s. The effects of colonialism are still felt in many realms. For example, a false belief that people who are Black feel less pain was created as a tool of oppression and slavery. Its legacy continues, and Black adults and children still endure inadequate treatment of their pain [3,4]. Later, in Canada, the reserve system was devised to assist with committing cultural genocide against Indigenous peoples. Today, those living on reserves have inadequate access to many medical necessities [5], including several WHO essential medications for symptom management; violating the United Nations Declaration on the Rights of Indigenous Peoples.

When navigating our end of life journeys, most individuals would benefit from receiving culturally safe palliative care. In a landmark study by Temel et al., patients with advanced lung cancer who received early palliative care had statistically significant improvements in their quality of life, mood, and lived 30% longer [6]. However, the benefits of palliative care are not experienced equitably. Many racialized people have suffered discrimination at the hands of the health system and are affected by intergenerational racial trauma. Racialized individuals have less utilization of palliative care services, experience worse symptom control, and are less likely to have their

end of life wishes documented or respected [7]. If one's preferred language is not the most commonly spoken language, professional interpretation is frequently denied, resulting in inadequate communication and poorer symptom management [8].

Racism manifests in multiple forms. On the individual level, health care providers bring assumptions about race, ethnicity and culture which may have immense impacts on the care received [6]. These prejudices are frequently unconscious and unrecognized. Furthermore, within the health care workforce many racialized groups remain under-represented, despite mounting evidence of the benefits of racial inclusion. For example, a recent study showed that the mortality of Black newborns was halved if their doctor was also Black [9].

Medical research can further exacerbate health inequities for racialized people, with many disparities being attributed erroneously to other factors, ignoring the predominant cause: systemic racism [10]. Furthermore, racialized participants are underrepresented in most palliative care studies and there is limited research examining racial inequalities.

Palliative care for racialized people is in a state of crisis, and urgent action is needed. Looking forward, we must:

- (1) Acknowledge systemic racism and its effects: Everyone working within the palliative care system must receive education on colonialism, cultural safety and anti-racism; and must advocate for anti-racist policies in all areas where we have influence.
- (2) Make palliative care systems racially representative of the people served: Initiatives to recruit under-represented groups into the health professions, into program staffing, and into leadership positions must be supported.
- (3) Collect race-based data and tie it to meaningful action: Utilization or outcome differences based on race should be recognized as health disparities and remediated. Cultural safety must be ensured, and community stakeholders must be engaged at all steps.
- (4) Prioritize representation in palliative research: Racialized participants must be included in studies. Research that is funded and published must represent work produced from racially diverse investigators and increased racial representation is needed within the publishing industry, including on editorial boards.

Palliative care in many countries has its roots in policies, beliefs and practices that were determined by its almost unanimously White founders. It is time to critically examine palliative care provision

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through a lens grounded in anti-racism and the protection of human rights. We, as a palliative care community, must move from a system of exclusion and marginalization to one of inclusion and empowerment. We must use our collective power to build up a society where all individuals can receive high quality palliative care that acknowledges their individual worth and dignity. The time for action is now.

Declaration of Competing Interest

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