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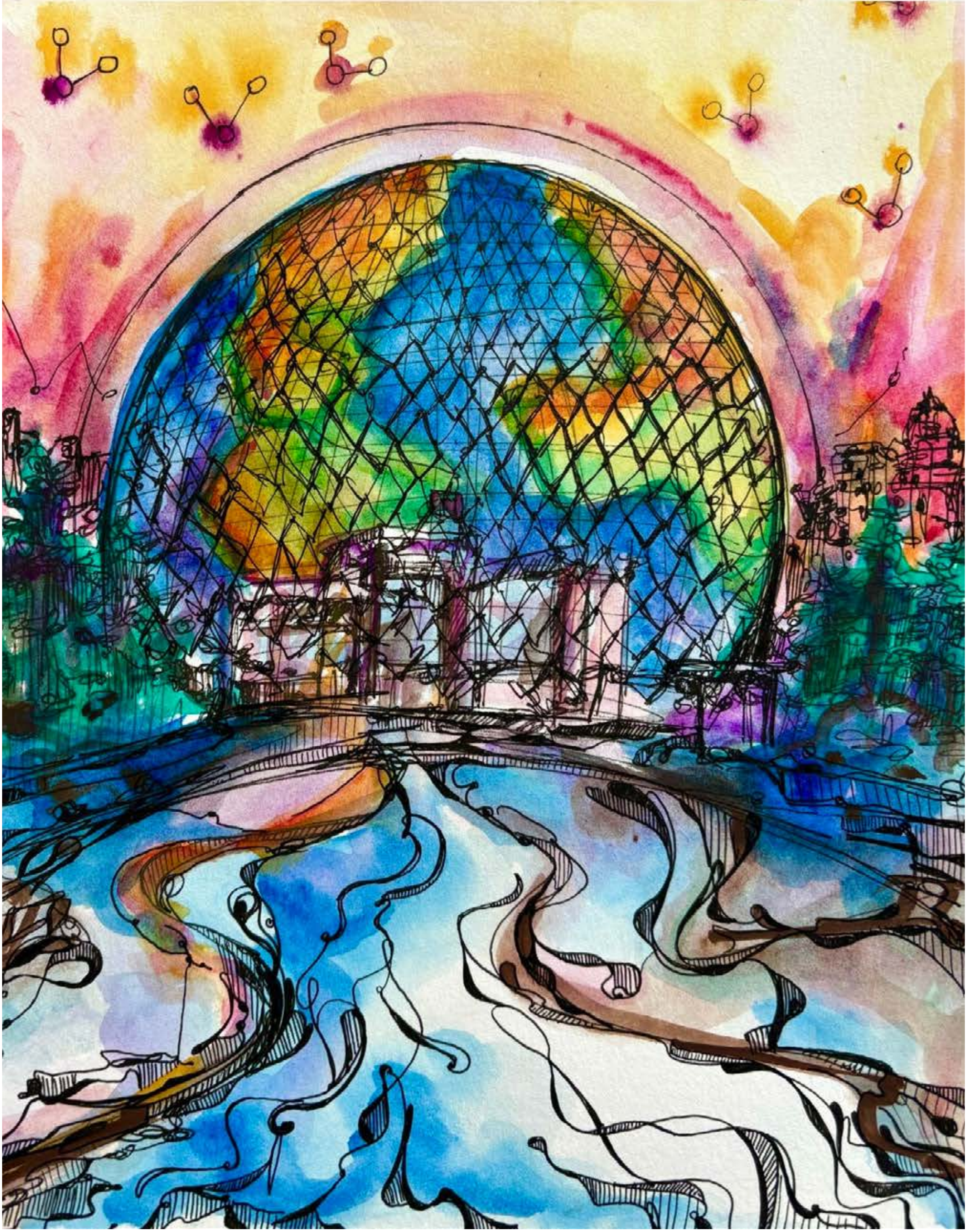

Perspective

"The Epoch of Whole Person Care": Understanding and Addressing Inequities in Palliative Care

Karen Wassef[*1]

[1]Department of Family Medicine, McGill University, Montreal, QC, Canada

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[*]**Correspondence**: Karen Wassef, Email: karen.wassef@mail.mcgill.ca

"We stand at the threshold of the third epoch of healthcare, the epoch of whole person care[1]."

Introduction

Palliative care adopts a *whole-person* approach to support individuals affected by serious illness – a health condition that carries a high risk of mortality and negatively impacts quality of life [1,2]. People affected by serious illness often experience physical, psychological, and existential forms of suffering. Palliative care clinicians recognize patients' multidimensional needs and strive to alleviate patients' suffering and improve their quality of life [3]. However, patients from visible minority groups and other racialized and marginalized communities experience worse access to and quality of palliative care. In order to improve patient care experiences and promote whole-person care, researchers and clinicians must understand these disparities and acknowledge their biases and the behaviors that may contribute to perpetuating inequities.

I reviewed the literature on racial and ethnocultural disparities in palliative care with a specific focus on the Canadian context. I present an overview of these disparities, their root causes using a framework previously used to explore social determinants of Indigenous Peoples' health, as well as examples of existing and proposed actionable solutions in an infographic.

Determinants of Visible Minority Health in Canada

Multiculturalism characterizes Canadian heritage and identity [4-5], yet intersecting systems of oppression continue to persist and perpetuate health inequities among visible minority groups. Several social and structural determinants of health contribute to these systems [6]. An Indigenous framework for conceptualizing determinants of Indigenous Peoples' health provides a useful way to represent structural, systemic, and immediate determinants [7]. As distal determinants, medical colonialism and oppressive policies that serve to "other" visible minority patients form the deeply embedded or 'root' causes that shape more proximal determinants manifesting in everyday healthcare encounters [8-10]. These include intermediate determinants (such as systemic discrimination on the basis of race, ethnicity or culture, accent, and language) [11-14] and immediate determinants, contributing to worse health outcomes [8, 15-16].

Inequities in Palliative Care

People from visible minority groups experience greater burden of serious illness and worse access to and quality of palliative care [17-21]. Black and Hispanic patients are less likely than White patients to receive palliative care [22], and those who receive serious illness care report experiences of discrimination [23,24]. Clinician biases and discriminatory behaviors toward visible minority patients may impact the extent to which clinicians deliver care that aligns with patients' goals. Visible minority patients are less likely to receive goal-concordant care. For example, they are less likely to die at home than White patients, even though most patients prefer to die at home [25]. Patients report receiving goal-concordant care when given the opportunity to express their preferences with clinicians [26]. However, visible minority patients experience lower quality communication with their clinicians [27-29], which may contribute to disparities in overall care quality. Addressing these disparities will require a collective effort from palliative care clinicians, researchers, trainees, and policymakers to ensure equitable and tailored solutions that prioritize the needs of patients from racialized and marginalized communities.

How Can We Address Inequities in Palliative Care?

Education plays a fundamental role in fostering awareness, promoting inclusivity and social justice, and encouraging reflexivity among medical trainees and clinicians. Developing and implementing curricula that address root causes of inequities in palliative care may help students recognize and address their biases and learn how social and structural determinants impact health outcomes. Implementing programs for clinicians on anti-oppression and anti-privilege, for example, may promote the integration of culturally safe practices in institutions. Researchers can then contextually tailor these programs based on local assessments of patient-centered outcomes such as patient-provider relationship quality and satisfaction with care [30].

Two interventions in North America offer key insights into the promise of education-based initiatives: Palliative Education and Care for the Homeless (PEACH) Program and the race-conscious serious illness communication tool. PEACH, Canada's first mobile palliative care intervention for unhoused or vulnerably housed people, uses a trauma-informed and anti-oppression approach to provide symptom management, psychosocial support, and medical education

[31]. One of the program's projects, Good Wishes Project, allows clinicians to establish meaningful connections with their patients and to better understand their patients as whole persons [32]. Similarly, the race-conscious serious illness communication tool helps clinicians establish authentic relationships [33]. By explicitly acknowledging racial dynamics within the clinical encounter, the tool aims to incorporate patients' experiences with racism into care. It uses Public Health Critical Race Praxis as a framework for recommending adaptations to serious illness conversations with racialized patients. These education-based initiatives *are* interventions that hold promise in improving clinician-patient dynamics and patient care experiences.

Conclusion

Addressing inequities in palliative care, starting by targeting medical education and clinical training programs, may contribute to transforming medical trainee and clinician perspectives and practices. Education-based interventions hold the potential to foster culturally safe communication practices among clinicians that in turn improve patient care experiences. Efforts to improve communication and relationships with visible minority patients may have implications for the quality of their care and, consequently, their health. These efforts may contribute to the advancement of broader institution-wide initiatives that seek to promote equity through *whole-person care*– a transformative approach through which clinicians holistically support and empower patients to feel like whole persons across the trajectory of a serious illness.

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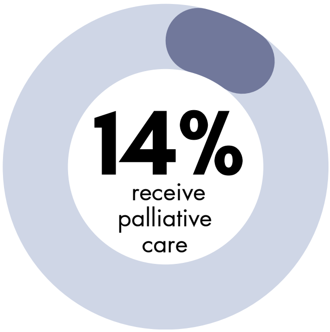
The Epoch of Whole Person Care: Addressing Inequities in Palliative Care

Karen Wassef, MJGH Associate Editor

WHAT IS PALLIATIVE CARE?

Palliative care adopts a whole-person approach to support individuals affected by **serious illness** – a health condition which carries high risk of mortality and negatively impacts quality of life [1,2]. Palliative care aims to alleviate patients' suffering and improve their quality of life [3].

Globally, only **14%** of individuals with palliative needs receives care [3]. A majority of those with needs reside in low- and middle-income countries (LMICs) where poor health infrastructure, shortage of trained professionals, poverty, stigma and culture-related ambivalence toward palliative care, and systemic oppression contribute to global unmet needs [3].

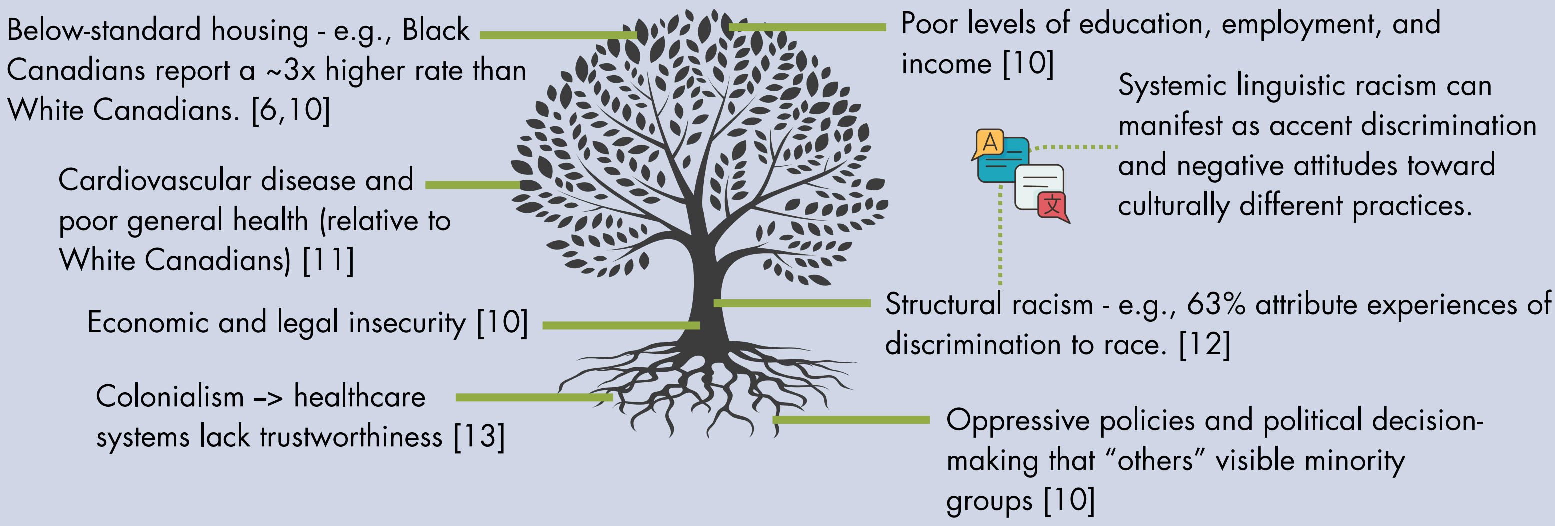


Inequities in palliative care are not exclusive to LMICs. In Canada and USA, **visible minority groups** experience inequitable access to and quality of palliative care [4-6].

Social and structural barriers, such as systemic discrimination, compound patients' suffering and impede their access to healing-oriented care [1,7].

"Visible minority groups" in Canada consist of these groups: South Asian, Chinese, Black, Filipino, Arab, Latin American, Southeast Asian, West Asian, Korean, and Japanese [8].

DETERMINANTS OF VISIBLE MINORITY HEALTH *based on NCCIH framework [9]*



Below-standard housing - e.g., Black Canadians report a ~3x higher rate than White Canadians. [6,10]

Cardiovascular disease and poor general health (relative to White Canadians) [11]

Economic and legal insecurity [10]

Colonialism –> healthcare systems lack trustworthiness [13]

Poor levels of education, employment, and income [10]

Systemic linguistic racism can manifest as accent discrimination and negative attitudes toward culturally different practices.

Structural racism - e.g., 63% attribute experiences of discrimination to race. [12]

Oppressive policies and political decision-making that "others" visible minority groups [10]

Figure I. Distal, intermediate, and proximal determinants of visible minority health as respectively represented by roots, trunk, and leaves of the 'tree'

INEQUITIES IN PALLIATIVE CARE - WHAT DO THEY LOOK LIKE?

Current palliative care practices are predominantly Western-informed [6]. By design, these exclusively target Western populations. Cultural barriers for visible minority groups contribute to suffering and perpetuate systemic oppression as seen across these care aspects:

USE OF CARE

- Black and Hispanic patients are less likely to receive services than non-Hispanic White patients. [13,14]

INTENSIVENESS OF CARE

- Black, Hispanic, Chinese, and South Asian patients report higher rates of aggressive end-of-life care. [6,15]

GOAL-CONSISTENT AND RESPECTFUL CARE

- Black patients experience incongruence between preferred and actual care goals/practices. [15]

QUALITY OF COMMUNICATION & RELATIONSHIPS

- Black patients disproportionately report poor clinical communication than White patients, and this is pronounced in racially discordant patient-provider relationships. [15]

WHAT ACTIONS ARE BEING TAKEN TO ADDRESS INEQUITIES?

Palliative Education And Care for the Homeless (PEACH) Program [6]

- A street and shelter-based palliative care program that adopts an anti-racist, anti-oppressive, and low-barrier approach to care for homeless people

Living My Culture [6]

- An online platform where culturally diverse communities share their perspectives, values, and beliefs around serious illness

Race-conscious serious illness communication (SIC) tool [17]

- A tool for training providers in delivering SIC that acknowledges patients' lived experiences with racism, and other intersectional experiences of oppression, to reduce implicit/explicit biases

DID YOU KNOW?

In 2018, Health Canada developed a framework for delivering palliative care, with equity integrated as a key goal [16]. Yet, unjust disparities related to visible minority status continue to persist in Canada.

HOW CAN WE FURTHER ADDRESS INEQUITIES IN PALLIATIVE CARE?

- Develop **curricula** that address root causes of inequity and dismantles power structures
- Implement **clinical training programs** on anti-oppression, anti-privilege, and cultural safety
- Set & measure **targets** toward patient-centered, healing-oriented care
- Improve reach by **upscaling services** in primary & home-based care
- Ensure **equitable representation** on care teams & center patient voices in research

IMPLICATIONS

For achieving Sustainable Development Goals [18]:

3 GOOD HEALTH AND WELL-BEING

10 REDUCED INEQUALITIES

For patient outcomes:

- Higher quality patient-provider relationships
- Positive healthcare encounters –> trust-building –> healthcare-seeking behavior –> better health outcomes and quality of life
- Culturally safe and healing-oriented care –> adaptive coping with suffering

> **We stand at the threshold of the 3rd epoch of healthcare, the epoch of whole person care [1].**
>
> *Dr. Balfour Mount, father of palliative care in Canada*

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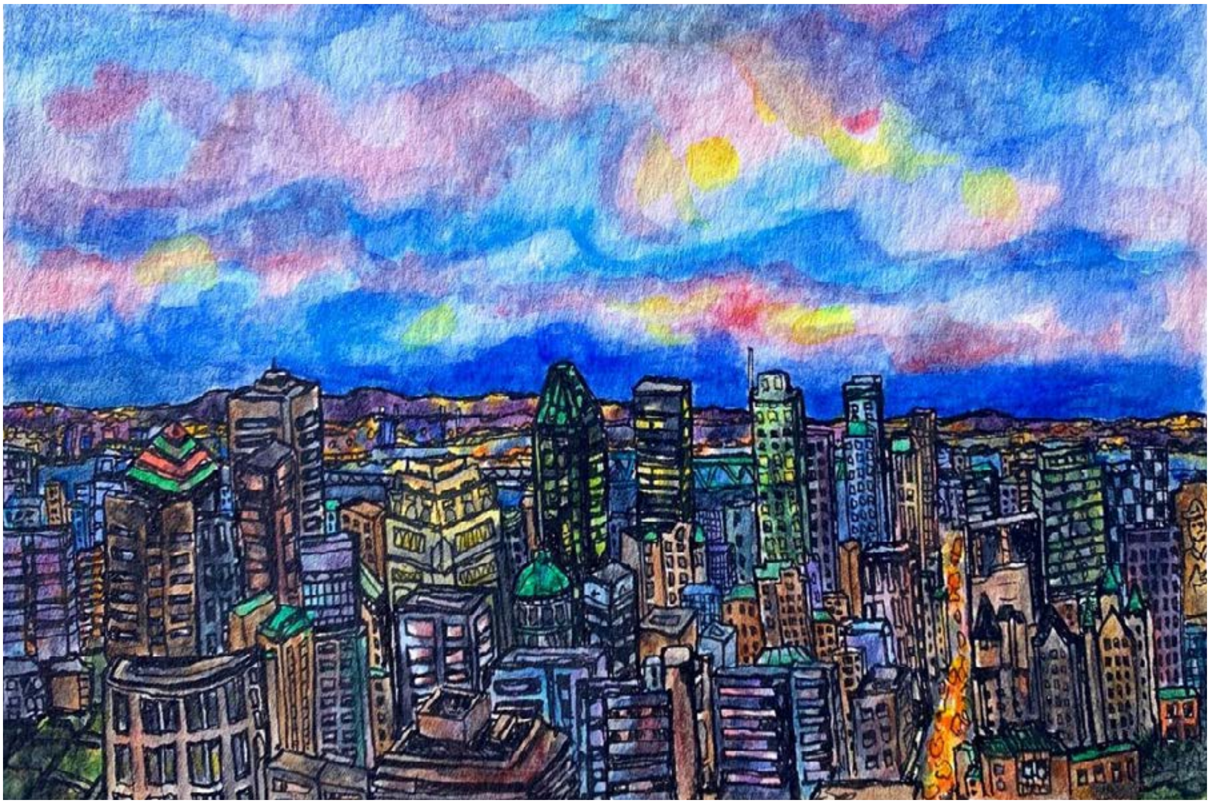

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