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Racism and casteism: global chasms of access to palliative care and pain relief

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Minoritised racial, cultural and ethnic groups experience substandard palliative care (PC) and pain-related outcomes across all settings in absolute and relative terms.^{1–4} The suffering of Black, Indigenous and People of Colour (BIPOC) has been and continues to be frequently

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silenced through fear, intimidation, abuse, experimentation and eugenics, all of which have then been used to rationalise lack of access, shrouding both deliberate marginalisation and indifference in an argument around a lack of need for palliative care and pain relief (PCPR) based on prejudice rather than evidence.⁵ As a result, BIPOC are consistently subjugated to grave disparities of suffering through scientific racism and the clinical minimisation and distortion of their experiences, including appalling claims that they experience less pain than their White counterparts—or no pain at all—for the same ailments and injuries.⁶ Though racism is being discussed with increasing frequency, casteism is a critical factor and is defined as, ‘(a) ny action or structure that seeks to limit, hold back, or put someone in a defined ranking, (or) seeks to keep someone in their place by elevating or denigrating that person on the basis of their perceived category.’⁷ If racism is the house that shelters the privileged and excludes the marginalised, casteism is the foundation that sustains inequity from the bottom up.

Modern iterations of racism and casteism in PC settings are described in several ways and are largely resultant of structural inequities that prevent fully integrated, accessible, and tailored PC provision for many BIPOC. For instance, Black individuals at the end of life are more likely to die in acute care settings rather than at home, more frequently elect “aggressive”⁸ and potentially harmful disease-modifying interventions at end of life, have lower rates of hospice use before death, and are less likely to have completed an advance directive.^{9 10} Yet Black patients’ end-of-life care often diverges from their expressed preferences.¹¹ These may include preferences for complementary and alternative medicine (CAM) approaches, including traditional healing methods, that are often neglected and often considered inferior—despite the absence of evidence on certain CAM interventions that hold value for patients.¹²

Pain disparities in cancer and other non-cancer conditions are well noted in the literature, leaving BIPOC individuals to suffer inadequate pain assessments and management, as well as misprescribing or underprescribing of opioids and other analgesics that result in increased healthcare utilisation and poorer pain-related outcomes.³ Many minoritised cultural and ethnic groups have family-oriented and community-oriented preferences, needs, and values that must be explored, honoured, and integrated into care planning and delivery to ensure people-centred care that is goal concordant and socially inclusive.¹³ Bereaved family caregivers of minoritised racial and ethnic group decedents rate the quality of end-of-life care lower than white families, pointing to the potential impact of structural racism and overlooked needs.¹⁴

Other forms of casteism—such as colorism (the structurally reinforced preference towards lighter skin) and the marginalisation of people living in poverty and those with lower levels of education—more commonly pervade regions like Africa and the Caribbean.¹⁵ In countries like Jamaica, Barbados and Guyana, light-skinned people have historically held greater wealth, which is associated with higher education and greater power, but demographics have shifted in recent years in these island nation states where People of Color are just as likely to be fiscally and educationally empowered. In the Caribbean, however, inadequate access to PCPR stems more from poor understanding and low prioritisation of PC at the policy and decision-making levels. This, combined with a

pervasive opiophobia, means PC services opioids and other controlled essential medicines necessary for pain and symptom management are often in short supply.

In fact, of the more than 60 million people in need of PCPR worldwide each year, the overwhelming majority are in low-income and middle-income countries.² Indeed, only 1% of annually distributed opioid morphine equivalent medications—a key to relieving serious health-related suffering—are available to the poorest 50% of the world's population.² Poverty and racism are often layered onto other forms of casteist oppression due to religion, cultural or ethnic identity, tribe or community affiliation, physical or cognitive disability, homelessness, incarceration, minoritised sexual or gender identities, or other social, economic, or political qualifiers that vary by region. For example, casteism is visible worldwide through ageist barriers to integrated PC for older people¹⁶ and invalid assumptions about the suffering of younger populations, leading to vastly inadequate PCPR access for neonates, infants and children.¹⁷ These intersectional and interrelated injustices compound the travesty of the PCPR divide through sanctioned discriminatory norms, exclusive hierarchical structures and oppressive barriers, leading to dehumanising and inequitable health systems. When exacerbated by a lack of PCPR infrastructure, gaps in health professional PC, training and an absence of political will, the global pain divide remains an evolving moral threat for the poorest and sickest under the guise of caste.² Local, national and global geographical contexts all factor into the ways in which racism and casteism interact to produce higher burdens of suffering for BIPOC and deserts of PCPR access.

Innovations in the measurement of structural racism to achieve antiracist health policies and practices are essential to realising social justice in PC and must include attention to: (1) historical, geographical and sociocultural contexts, (2) scientific formulation by researchers from communities experiencing the impacts of racism and casteism and through community-partnered models, (3) use of novel methods to capture the multifaceted aspects of structural racism and casteist oppression, including the implications of historical trauma and (4) the importance of language (verbal and non-verbal) in conceptualising inequities, which has implications on thwarting false beliefs that shape ideology, distribution of resources and power structures.^{4 18 19} Power arrangements and policies need to be reconfigured from the clinical point of care, across educational and training milieus, in determining decision-making practices, and in the defining ethics and guiding frameworks that inform scholarly and empirical investigations (table 1).

Data must be tracked on inequitable economic appropriations for PC service development and hospice access in areas that serve or educate predominantly BIPOC. Research must integrate and account for the context of racism, casteism and the long-term impacts of structural discrimination.¹⁸ For instance, community-based participatory research approaches are essential to inform future PCPR delivery, guided by the voices of patients and families to shape emancipatory and reparatory scientific mainstays—from conceptualisation to implementation and towards sustained change.²⁰ Likewise, the community-informed and expert-guided use of critical race theory in the design, implementation and dissemination of PC research sets an important foundation to avoid white and Western norming, prioritise praxis, name racism and centre greater awareness

of the complex and often intersectional relationships of race, caste and power during serious illness, the end of life and bereavement.²¹ Critical race theory application challenges pre-existing and harmful assumptions, such as claims about racial genetic differences, race-based preferences and attributions of mistrust to account for disparities of suffering—all referenced in large proportion throughout the PC literature.²¹

Racism and casteism—and thus disparities in serious health-related suffering—are human rights violations. Although they are often expressed through overt discriminatory behaviours, they may also be veiled and deeply embedded into societal norms that vary by setting, further complicating our ability to identify and eradicate them. Global PC policy, academic, and clinical and non-clinical healthcare actors—as well as community and civil society stakeholders—must make explicit the malignancies of racism and casteism while building both formal and informal multisector coalitions to restore interpersonal, distributive and structural justice throughout the serious illness continuum. Antiracist and anticasteist principles and policies serve as essential frameworks for rehumanising healthcare and prioritising equitable, human-centred PCPR access for the systematically disenfranchised and historically marginalised. To adapt a reflection offered by the luminary Paul Farmer: If access to healthcare—and to the relief of suffering—are considered human rights, who is considered human enough to have those rights?¹

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Table 1

Action guidance on addressing racist and casteist policy and power structures that impact access to palliative care and pain relief

Aim	Action (across the serious illness continuum)
Redistribute power	<ul style="list-style-type: none"> ▶ Transform decision-making processes that drive health systems, including PC, to be inclusive of, partnered with and driven by marginalised and racialised communities ▶ Disincentivise interpersonal practices at the point of PC provision that perpetuate imbalanced power dynamics ▶ Recognise and disassemble legacy-oriented positioning of policy-makers, providers and other stakeholders who currently hold a disproportionate level of power ▶ Invest in sustainable community-based partnerships led by racially minoritised populations that honour them as the experts in their needs, preferences, goals and care delivery ▶ Support recruitment, education and inclusion of interdisciplinary PC specialists from minoritised communities to promote patient-clinician ethnic, racial and cultural concordance and to diversify the health and social care clinical workforce
Adopt antiracist and anticasteist policies	<ul style="list-style-type: none"> ▶ Prioritise training of individuals from marginalised and racialised communities in PC research and scholarship to effectively decolonise definitions of suffering and recentre its alleviation based on the lived experiences of BIPOC ▶ Develop and execute ethical, empirical, and implementation frameworks for PC grounded by antiracist and anticasteist ideas and ideals ▶ Create pathways for naming and dismantling interpersonal, institutional, systemic, and structural racism and repairing relational integrity in given contexts ▶ Ensure clinicians are equipped with training in cultural humility and competence to support the provision of culturally safe PC for BIPOC and their family caregivers during serious illness, dying and death and bereavement ▶ Fund community-based participatory approaches to enable social justice, foster long-term collaboration and mutual trust, address community-specific PC needs, and guide PC science through the lens of community values, preferences, goals and priorities

BIPOC, Black, Indigenous and People of Colour; PC, palliative care.