

Opinion Piece

Evolving Terminology in Palliative Care: Why Language Matters for Access, Integration, and Perception

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Language plays a critical role in shaping perceptions, guiding clinical practice, and influencing healthcare policy. In palliative care, terminology not only defines the scope of services but also shapes how patients, families, and healthcare providers understand and engage with care. Although significant efforts have been made to reduce stigma, improve access, and emphasise palliative care's broader role beyond end-of-life care, misunderstanding and resistance persist within both the medical community and the general public.

There has been growing interest in reconsidering palliative care nomenclature worldwide.(1,2) Proponents argue that terminology influences referral patterns, patient acceptance, and integration into routine care pathways, while critics caution against diluting professional identity and philosophical foundations. Legitimate concerns around semantic ambiguity and misplaced emphasis on language over service development have also been raised.

This opinion piece does not advocate for an immediate or universal renaming of palliative care. Instead, it critically examines the rationale for reconsidering current terminology, the potential benefits and risks of such a shift, and how language may function as either a barrier or an enabler to access, particularly within the South African context. We argue that a structured, context-sensitive process review of terminology, alongside strengthened education and policy alignment, is both timely and necessary.

BACKGROUND AND RATIONALE FOR CHANGE

Historically, palliative care has been conflated with end-of-life care, a misconception that has inadvertently restricted its scope and accessibility. While hospice care is often a

discrete end-of-life service in high-income countries, this distinction does not translate uniformly. In South Africa, hospice services are typically integrated within the broader palliative care model and may be involved throughout the illness trajectory.(3,4) Clarifying this distinction is essential to avoid reinforcing the misconceptions that palliative care equates to dying.

Internationally, several organisations have sought to address these misconceptions through reframing. In South Africa, the Association of Palliative Care Centres (APCC), formerly the Hospice Palliative Care Association (HPCA), revised its name to reflect the organisation's broader scope of care.(5) Similarly, Palliative Care for Children South Africa (PatchSA) updated its name in 2022 from Palliative Treatment for Children South Africa to emphasise its comprehensive approach beyond medical treatment alone.(6) These changes reflect broader efforts to position palliative care as an approach that supports quality of life throughout the course of serious illness.

The World Health Organisation (WHO) has long advocated for early integration of palliative care, alongside curative or disease-modifying therapies.(7) Despite such progressive transformations, the term "palliative care" continues to evoke associations with terminal illness, highlighting an age-old, persistent disconnect between evolving clinical models and public understanding.

Much of modern palliative care emerged from high-income European settings. It was designed within a biomedical framework that often emphasises individual autonomy, clinical protocols, and institutional care settings.(8) South Africa, a country very different in many respects, with diverse cultures, multilingualism, historical discrimination, and socioeconomic disparities, has found palliative care to

be unevenly implemented and poorly accepted, often due to a mismatch between contextual factors within Western models of care.(3) Research from countries like South Africa, with cultural and linguistic diversity, has shown that terminology itself can create barriers. Studies from these countries highlight how participants struggle to understand the word “palliative care,” as there is no equivalent term in several languages.(9) Although participants in a study by Kirby et al. relied on internet searches to clarify the meaning, such approaches may be less accessible in South Africa due to literacy barriers and limited access to digital resources, especially in rural areas. Additionally, in South Africa, historical inequities and cultural diversity further shape patients’ and caregivers’ expectations and experiences when engaging with palliative services.(10)

Recognising these challenges, the South African National Department of Health, in collaboration with the World Health Organisation (WHO) and palliative care experts, developed the National Policy Framework and Strategy on Palliative Care (2017).(4) In addition, the APCC, in conjunction with the Council for Health Service Accreditation of Southern Africa, developed the 5th Edition of the Standards for Palliative Healthcare Services (2025).(11) Although these initiatives aim to promote earlier integration and standardisation of care, barriers related to perception, understanding, and language persist. The South African literature further highlights persistent structural challenges, including insufficient funding, a lack of qualified healthcare workers, and inconsistent service delivery.(3) In this context, it is reasonable to consider whether terminology that is more culturally resonant and contextually appropriate could enhance understanding, acceptance, and integration of palliative care services.

EVIDENCE, PERCEPTIONS, AND LIMITATIONS OF THE CURRENT LITERATURE

Evidence suggests that terminology influences acceptance and referral. Reframing palliative care as “supportive care” has been associated with earlier referrals and reduced stigma, particularly in oncological settings.(1,2) However, much of this evidence derives from high-income countries and specialist services, limiting generalisability to primary or low-and middle-income contexts.

South African studies highlight late referrals driven by persistent associations between palliative care and terminal illness.(12–14) Whilst these studies explore clinicians’ attitudes and service integration, none explicitly examine how the term “palliative care” is perceived by patients, families, or healthcare providers. This represents a critical gap in local literature.

RISKS AND CONSIDERATIONS IN REBRANDING

Some clinicians have understandably expressed reservations about rebranding palliative care.(15–17) They caution that broader or alternative terminology risks diluting the

discipline’s philosophical foundation. The term “palliation” (which means “to cloak” or “to ease”) is viewed by many as accurately reflecting the core purpose of palliative care across all stages of serious illness. From this perspective, changing the name may inadvertently obscure the discipline’s focus on holistic relief of suffering.

There is also apprehension about semantic ambiguity; for instance, the term “supportive care” may overlap with other services (i.e., psychosocial or rehabilitative care), potentially leading to further misconceptions. Others advocate for the use of dual terminology, such as “Supportive and Palliative care services” as a strategy to normalise the term. From this perspective, insufficient education, rather than the terminology, is viewed as the primary driver of misunderstanding.

Finally, there is concern about a “slippery slope of terminology” where language becomes a tool to avoid discomfort around difficult but necessary conversations. While rebranding initiatives may reduce immediate stigma and facilitate earlier engagement, they do not resolve misconceptions about the nature and scope of palliative care. As such, terminology change alone should not be viewed as a standalone solution. Currently, there is no universal consensus on the optimal approach, underscoring the need for careful, context-specific deliberation.

Despite the legitimacy of these concerns, arguments in favour of rebranding are grounded in the persistent, well-documented misinterpretation of the term by the very people it is meant to serve, patients and their families. Bandieri et al. found that although participants developed a more positive view of palliative care after early exposure, many continued to perceive the term “palliative” as carrying negative connotations that did not reflect the care they were receiving.(2) Renaming palliative care as “supportive” or “integrated” care has, in some settings, reduced associations with terminal illness and encouraged earlier engagement.(1,18)

OVERCOMING THE CHALLENGES

Linguistic shifts seem to be increasingly adopted in other fields of medicine. An example is the recent rebranding of Non-Alcoholic Fatty Liver Disease (NAFLD) as Metabolic dysfunction-Associated Steatotic Liver Disease (MASLD).(19) This transition reflects a strategic effort to improve diagnostic clarity, reduce stigma, better reflect pathophysiology, recognising that metabolic and genetic factors, rather than solely alcohol consumption, contribute to the disease. As part of efforts to rename NAFLD, a Delphi survey found that 61–66% of respondents viewed the term “non-alcoholic and fatty” as potentially stigmatising.(20) Although perceptions of stigma may vary culturally and individually, the findings support avoiding such language, as any level of stigma in medical terminology is considered unacceptable.

Similarly, the term “palliative care” is deeply embedded in medical literature and institutional policies. A shift in

terminology may lead to inconsistencies in care delivery, institutional policies, documentation, and billing practices, and loss of identity within a specialty that has worked hard to establish its values and expertise.

In addition, any change in terminology would have implications for the health professions education, requiring alignment across undergraduate curricula, postgraduate training, and competency frameworks to ensure continuity of skills and professional identity.

Finally, terminology changes may have downstream effects on regulatory frameworks, service coding, benefits packages, and reimbursement structures.

These system-level considerations highlight the need for a phased and coordinated approach. It begins with extensive multinational collaborative stakeholder engagement with consulting clinicians, patients, communities, caregivers, administrators, policymakers, and advocacy groups to assess perceptions, preferences, and potential implications of a name change. Research and Delphi consensus-driven studies can be used to evaluate shortcomings of the current nomenclature, how an alternative name might influence awareness and understanding of palliative care, and its impact on clinical trials and regulatory approval processes. Most importantly, can a new name improve public acceptance, enhance clarity, and positively affect referrals and service utilisation without disrupting service delivery?

Once a suitable name is identified, implementation should occur in clearly defined phases. The first phase could involve dual use, whereby the new term is introduced in patient materials, clinical guidelines, and educational content, allowing for acclimatisation and ensuring continuity. Simultaneously, national organisations and accrediting bodies should begin updating policies and standards to reflect the new terminology. Notably, a robust communications strategy would support this transition, including training healthcare providers on strategies in communicating about the change, public awareness campaigns, and updates to documentation, websites, and insurance coding. Over time, a familiarity grows, and the old term can be phased out in favour of the new one.

CONCLUSION

Ultimately, the conversation around rebranding palliative care is not merely semantic; it reflects evolving clinical realities, ethical imperatives, and the urgent need to dismantle barriers to timely, person-centred care. While language alone cannot resolve deeply rooted barriers to access and understanding, it can be a powerful enabler when aligned with education, policy, and culturally responsive care models.

Rather than advocating for an immediate renaming of palliative care, we support a nationally coordinated, evidence-informed, and consultative process to critically examine terminology within the South African context. If this process is approached thoughtfully and implemented

in parallel with education, policy alignment, and public engagement, it may be possible to enhance the acceptance and integration of palliative care services while preserving the discipline's philosophical core and professional integrity.

REFERENCES

1. Dalal S, Palla S, Hui D, et al. Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *Oncologist*. 2011; 16(1):105–111. doi: 10.1634/theoncologist.2010-0161
2. Bandieri E, Borelli E, Gilioli F, et al. Stigma of palliative care among patients with advanced cancer and their caregivers on early palliative care. *Cancers (Basel)*. 2023; 15(14):3656. doi: 10.3390/cancers15143656
3. Drenth C, Sithole Z, Pudule E, et al. Palliative care in South Africa. *J Pain Symptom Manage*. 2018; 55(2 Suppl):S170–S177. doi: 10.1016/j.jpainsymman.2017.04.024
4. National Department of Health, South Africa. National policy framework and strategy on palliative care 2017–2022 [Internet]. Pretoria: National Department of Health; 2017 [cited 2025 Apr 17]. Available from: <https://www.health.gov.za/wp-content/uploads/2020/11/NationalPolicyFrameworkandStrategyonPalliativeCare20172022.pdf>
5. Association of Palliative Care Centres. Hospice Palliative Care Association rebrands as the Association of Palliative Care Centres [Internet]. 2024 Feb 7 [cited 2025 Apr 17]. Available from: <https://apcc.org.za/press-releases/hospice-palliative-care-association-rebrands-as-the-association-of-palliative-care-centres/>
6. Palliative Care for Children South Africa. We've changed our name to Palliative Care for Children South Africa. 5 Jan 2022. Available from: <https://patchsa.org/weve-changed-our-name-to-palliative-care-for-children-south-africa/>
7. World Health Organization. Palliative care [Internet]. Geneva: World Health Organization; 2020 [cited 2025 Apr 19]. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
8. Clark D. From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncol*. 2007; 8(5):430–438. doi: 10.1016/S1470-2045(07)70138-9
9. Kirby E. "It doesn't exist...": negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliat Care*. 2018; 17:90. doi:10.1186/s12904-018-0343-z
10. Gwyther L, et al. Spiritual care practices in hospices in the Western Cape, South Africa: the challenge of diversity. *Palliat Med*. 2021;35(3):573–580. doi:10.1177/0269216320977756
11. Association of Palliative Care Centres, Council for Health Service Accreditation of Southern Africa. Standards for palliative healthcare services, 5th ed. 2025 [cited 2025 Apr 17]. Available from: <https://apcc.org.za/standards-for-palliative-healthcare-services/>
12. McMillan TA, Hutton L, Jenkins L. Doctors' knowledge, attitudes and practices of palliative care in two South African districts. *Afr J Prm Health Care Fam Med*. 2024; 16(1):a4503. doi:10.4102/phcfm.v16i1.4503

13. Gage CH, Gwyther L, Stassen W. South African palliative care provider perspectives on emergency medical services in palliative situations. *Afr J Emerg Med.* 2024; 14(4):231–239. doi:10.1016/j.afem.2024.08.007
14. Balbadhur R, Gwyther E. Understanding the dignity experience of South African patients in primary palliative care. *S Afr Fam Pract.* 2025; 67(1):a6047. doi:10.4102/safp.v67i1.6047
15. Milne D, Jefford M, Schofield P, Aranda S. Appropriate, timely referral to palliative care services: A name change will not help. *J Clin Oncol.* 2013;31(17):2055. doi:10.1200/JCO.2012.48.4493.
16. Boyd K, Moine S, Murray SA, Bowman D, Brun N. Should palliative care be rebranded? *BMJ.* 2019; 364:l881. doi:10.1136/bmj.l881
17. Fadul N, Elsayem A, Palmer JL, et al. Supportive versus palliative care: what's in a name? A survey of medical oncologists and midlevel providers at a comprehensive cancer center. *Cancer.* 2009; 115(9):2013–2021. doi: 10.1002/cncr.24206
18. Rao R, Chambers SK, Paul CL, et al. Does it matter what you call it? A randomized trial of language used to describe palliative care services. *Support Care Cancer.* 2013; 21(12): 3411–3419. doi:10.1007/s00520-013-1919-z
19. World Health Organization. National cancer control programmes: policies and managerial guidelines. Geneva: World Health Organization; 2002. <https://www.who.int/publications/i/item/national-cancer-control-programmes>
20. Rinella ME. Examining the nomenclature change from NAFLD and NASH to MASLD and MASH. *Gastroenterol Hepatol (NY).* 2023; 19(11):697–699.