Invited Editorial

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Reducing inequity in the provision of children's palliative care in low- and middle- income countries: A focus on education and research

There are over 21 million children and their families globally who need palliative care,[1] yet estimates suggest that less than 10% can access it. The greatest need for palliative care in children is in low- and middle-income countries, where 98% of the demand for palliative care in children exists, and access to services is limited. Indeed, in low-income countries there is a projected 5% increase in serious health-related suffering in children aged 5–14 years by 2060, despite a projected decrease globally in serious health-related suffering in children.[2]

Achieving equity in palliative care demands more than uniform provision of services; it necessitates a deliberate reallocation of resources to address the structural inequities that systematically disadvantage certain populations.[3] The World Health Organization (WHO)[4] defines equity as '*the absence of unfair, avoidable or remediable differences among groups*' and emphasises that health is a fundamental human right. In the context of children's palliative care, this principle requires a shift from aspirational rhetoric to concrete action, prioritising marginalised groups, dismantling barriers rooted in socioeconomic, racial and geographic disparities and embedding equity as a measurable outcome within service delivery and policy frameworks.

The imperative for children's palliative care in low- and middle-income countries is clear and undisputed. While its universality and cultural adaptability are well established, including recognition in Article 24 of the United Nations (UN) Convention on the Rights of the Child and WHO's guidance for implementation in resource-limited settings, the persistent gap lies not in acknowledging these principles, but in acting on them.[5] To improve access and quality, attention must shift towards building policy frameworks that mandate children's palliative care inclusion, securing sustainable financing mechanisms, integrating children's palliative care into primary health care and humanitarian response systems and training a culturally competent workforce capable of delivering care in diverse and often unstable environments.[6]

So how do we reduce this inequity in children's palliative care provision? Compared to high-income countries, children in low- and middle-income countries face both a need and significantly lower access to children's palliative care. Over 98% of the nearly 21 million children worldwide who could benefit from palliative care live in low- and middle-income countries,[7] yet the majority of these settings lack integrated services, trained personnel or consistent access to essential medicines.[7–9] This disparity in availability and access exemplifies the inequity we must address. To ensure a just allocation of resources and opportunities for children's palliative care development, especially in low- and middle-income countries, two core challenges must be tackled: the limited workforce trained specifically in children's palliative care, and the paucity of locally generated evidence to guide care delivery within a limited resource setting.

A scoping review of palliative care for children in low- and middle-income countries highlighted that most studies had emphasised the importance of education and training.[10] To make children's palliative care accessible, we must address the need for a trained workforce. In many low- and middle-income countries, there are not enough trained healthcare professionals with expertise in children's palliative care. Whilst the World Health Assembly (WHA) Resolution underscores the importance of integrating palliative care education across all levels of the health workforce, what is urgently needed now are scalable models such as decentralised, cascade-style training in children's palliative care, delivered by regional experts embedded within health systems, as well as digital platforms that provide modular, competency-based learning tailored to resource constraints. Embedding palliative care competencies into national accreditation standards for medical and nursing curricula, and incentivising participation through career advancement frameworks, can ensure sustainability and uptake, particularly in underserved settings.[11] Principles that have been endorsed within children's palliative care around the world along with the need for training of community health workers, volunteers and family members. Whilst community health workers exist in both high and low- and-middle income settings, training and care provision may vary. Within low- and-middle-income settings training needs to: emphasise practical palliative care skills; take into account the wide range of roles that community health workers undertake; prepare them as the first point of entry into the formal health system; and take into account the literacy skills of those being trained. The training is often of shorter duration than in high-income settings, and requires ongoing support and supervision to ensure effectiveness and sustainability.

Technology offers a powerful tool to expand access to high-quality training in children's palliative care, enabling virtual education and connection to global best practices for healthcare workers in low-resource settings. However, to translate training into meaningful care delivery, this must be accompanied by investment in supportive infrastructure, reliable digital access, ongoing mentorship and integration into national health systems, ensuring that trained providers are equipped not only with knowledge but also with the resources to act. A range of modes of delivery can be used to increase access to education on children's palliative care including, not only face-to-face training but distance learning such as online/e-learning, blended or hybrid learning and webinars/videoconferencing[12] which are accessible and affordable, and include both theory and practice. Examples include: the implementation of initiatives based on the Collaborative Online International Learning (COIL) approach, which have fostered cooperation between Brazilian academic centres and international institutions; and using Project ECHO to build children's palliative care capacity in South Asia.[13] These experiences have expanded access to up-to-date content and promoted the exchange of perspectives on culturally responsive children's palliative care practices. Such collaborations not only enhance the training of professionals to work in diverse settings but also support the development of curricula that are more attuned to both local and global realities. Too often curricula are parachuted from one setting to another, without taking into account resources, culture, health systems and local expertise, thus it is essential that curricula are adapted and/ or developed for different settings.

Strengthening training programmes is essential, but training alone is not enough. Children's palliative care must be formally recognised as a specialised service, with appropriate remuneration that reflects the complexity, time intensity and emotional demands of the work. This includes ensuring that staff are compensated at a level commensurate with other medical specialties requiring advanced training, rather than being underpaid relative to general paediatric or primary care roles. Establishing clear career pathways and professional incentives will be critical to engaging and retaining skilled providers in this field. Task-shifting has already proven to be an effective way to expand services in low- and -middle- income settings, such as increasing access to pain and symptom control through nurse prescribing.[14] At the same time, integrating palliative care into undergraduate and postgraduate medical, pharmacy and nursing education will help build a sustainable workforce, ensuring that future generations of healthcare providers are equipped to deliver high-quality care.

Developing and empowering children's palliative care local, national and regional leaders within resource constraint countries is also essential, and there are a range of initiatives that are enabling this effort, such as the Children's Palliative Care Leadership Institute for Southeast Asia, or the International Association of Hospice and Palliative Care's Advocacy training. Empowering children's palliative care leaders from low- and middle-income countries to have a voice, to be mentored and supported, and encouraged is essential if we are to develop services, education programmes and strengthen the evidence base.

The evidence base for children's palliative care is growing; however, much of the evidence is developed from within high-income settings. There is a continued call for the development of evidence within children's palliative care from within low- and- middle-income settings along with the 'decolonisation' of palliative care, and of research. To critically examine and transform how children's palliative care research is carried out to ensure that it is inclusive, equitable and responsive to the needs and knowledge systems of local communities. For example through: rebalancing power dynamics – ensuring the research agenda is defined by the community where it matters, involving local researchers; respecting and integrating traditional belief and values systems within the research, for example, that of ubuntu in sub-Saharan Africa; is the research defined within local ethical frameworks, values, norms and consent practices, including that of 'incentives'; demanding equitable recognition in publications, funding and career advancement; and building local capacity for children's palliative care.

A challenge for many low- and middle-income countries is the difficulty of ethically and sensitively including the child's voice in scientific studies as both children's palliative care and involving the child in research are new concepts in many countries, thus making it challenging to get ethical approval to undertake studies. This hinders a deeper understanding of their experiences, desires and needs and consequently weakens the ability to advocate effectively for their rights and interest.

However, within children's palliative care we are seeing research from low- and middle-income countries shaping research and practice within high-income settings. One such example is the development of the children's palliative outcome scale. This work started small and began across sub-Saharan Africa and is now spreading globally, across all income groups. It exemplifies how a study, through iterative refinement and inclusion over the years, has amplified the voices of children and young people from low- and middle-income countries – embedding their perspectives across all stages of research, from design and implementation to the evolution of the outcome scale. This longitudinal progress underscores the value of sustained, equitable partnerships in generating tools that transcend borders.

We have so much to learn from each other, so much to share – collaboration is key, and the field of children's palliative care research is still relatively small, so we have opportunities to work together and to develop equitable collaborations. Within the global palliative care community it is important that any additional or unique needs within our low- and- middle- income setting partners are recognised, enabling equal partnership such that all voices can be heard, and all are supported to develop services, policies, studies that meet our cultural, political, religious and economic realities. Equity requires that all voices are not only heard but centred in global children's palliative care development.

Often, research funding opportunities favour large, well-resourced departments, particularly those with established infrastructures, prior funding success and researchers with protected time for academic work. Thus, making it challenging for low and middle-income countries where children's palliative care is still a developing field, with minimal academic recognition, to build their research capacity and have access to the research training, support and mentorship that is needed. This lack of dedicated funding for children's palliative care research contributes to the slow development of a robust evidence base in low- and middle-income countries. Thus, multi-country collaborations are important but must address the research needs and gaps of low- and middle-income countries. Examples of such gaps and needs include: assessing the need for children's palliative care in different settings/ countries; interventions and models of care for children's palliative care in low- and middle-income settings; managing pain and symptoms with limited access to medicines; measuring the outcomes of care; understanding the needs of children and their families in low- and middle-income settings; evidence based methods of increasing access to essential medicines for children's palliative care including opioids; assessment of the two vs three step ladder for managing pain in children; and the validation of tools within different settings.

Collaborators can help develop the principal investigators of the future. Robust research training on children's palliative care such as Master's degrees and PhD's are a key part of doing this, but enabling students to carry out research degrees through distance learning, so they do not have to be away from friends and family for long periods of time, would also make such degrees affordable and accessible to those in low- and middle-income countries. Mentorship and support for the researchers of the future is essential, for example, for publications, particularly when writing in their second or third language. Additionally, more publishers need to enable researchers from low- and middle-income countries to publish open access articles free of charge, utilising initiatives such as Research4Life and other open access initiatives. It is essential that papers written about work done in low- and middle-income countries are available to them and their colleagues to access and initiatives such as HINARI, which provide access to non-open access journals for individuals from low- and middle-income countries need to be expanded.

Recent experience has shown us that we need to address access to conferences and research meetings on children's palliative care, ensuring that the content of 'international' conferences is truly international, with content relevant for all settings. Attendance by individuals from low- and middle-income countries can be hampered by the challenges in obtaining visas and securing funding to attend, often resulting in research from low- and middle-income countries being presented by partners from high-income countries instead of local colleagues. To address these inequities, a multi-pronged approach is needed: International conferences should be intentionally hosted more frequently in low- and middle-income countries and in different regions, in order to reduce travel barriers; hybrid models that combine in-person and virtual participation should be prioritised to enhance accessibility and inclusivity; and ensuring there is plenty of time between abstracts being accepted and the conference to enable participants to secure visas as appropriate. Furthermore, funding bodies should allocate dedicated grants to support research attendance from low- and middle-income countries, and conference organisers should embed equitable representation and participation structures into their planning process.

The commitment to children's palliative care, and to reducing the inequities in low- and middle-income countries, must be shared by everyone, and is essential for increased access to children's palliative care globally. It is only as we strengthen children's palliative care education provision and research in low- and middle-income countries that will we begin to see inequities reduce.

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