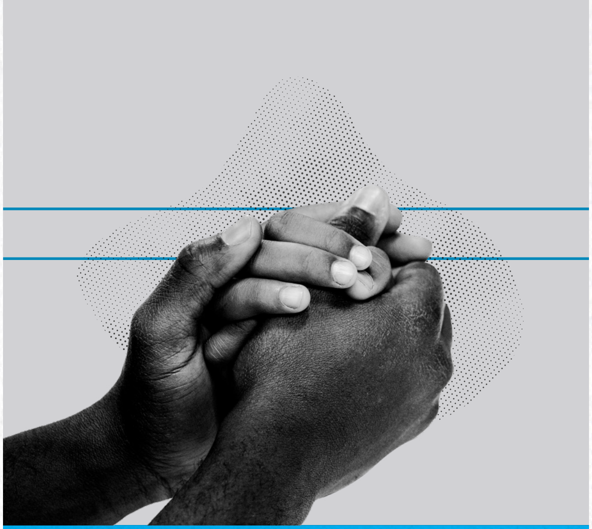
the aha! moment
Key research insights



Project facts

Key words
Caregivers, Hope, Palliative care, Stigma, Support

Behavioral themes
Delayed referral to palliative care, Emotional and psychological burden on caregivers, Lack of empathy and patient-centered care, Need for integrated and continuous medical support

Research design
Human centered design

Scope
Start date: January 2024
End date: May 2024
Sample size: n=8

Location
Nairobi, Kenya

Partner
KEHPCA (Kenya Hospice and Palliative Care Association)

Ethics approval
N/A

No. 23
August 2025
Busara

Is palliative care only for the dying—or is there more to it?

This research was undertaken to develop two behaviour change communication (BCC) materials on children's palliative care (CPC) in Kenya, aiming to address common barriers and misconceptions while increasing public awareness and demand for CPC services.

Background: Palliative care in Kenya

Pillar 2 (Information, Education and Awareness), is a strategic guiding pillar of KEHPCA that aims to transform public understanding of palliative care. This is achieved by providing accurate information, capacity building of communities and health workers, and creating awareness campaigns that challenge the myths and stigma around palliative care. It ensures that families, caregivers, and communities are equipped with the knowledge to seek and support timely palliative care services. KEHPCA is further implementing a project—WAWA (WAna WAtunzwe) with the goal of improving access to sustainable children's palliative care (CPC) services in Kenya for children living with cancer and other palliative care needs.

According to the Kenya Palliative Care Policy 2021-2030, less than 5% of children living with palliative care needs have access to CPC.. This project sought to increase the demand for palliative care and early diagnosis through behavior change communication and programming.

The project developed materials that influence the public conversation regarding the barriers and myths surrounding CPC for children with palliative care needs in an innovative way and thus increase demand for children's palliative care.

Conducting the research

Our approach was divided into the following workstreams:

- Formative research: Literature review; conducted key informant interviews with caregivers and children suffering from terminal illness.
- Stakeholder design workshop and prototype development: Developed along with the KEHPCA team, healthcare providers, and caregivers.
- Testing, prioritising and refining prototypes: Brainstorming in collaboration with KEHPCA and healthcare providers.
- Development of the final prototype.

the aha! moment

Key research insights

- Majority of Kenyans including health care providers have limited knowledge of children palliative care, and most caregivers erroneously associate palliative care with end of life care.
- Cultural beliefs, common misconceptions, and financial limitations often act as invisible barriers to accessing palliative care, shaping perceptions and influencing decisions at both the caregiver and community levels. As a result, caregivers often experience heightened emotional strain, with many developing symptoms of depression. In some cases, they lack access to any form of psychosocial support, leaving them to cope alone with the heavy burden of care.

Implications

For policy makers:
The findings of this study highlight the need for guidelines and policies that mandate early integration of palliative care into treatment plans, rather than limiting it to end-of-life care.

There is a need to invest in training programs for healthcare providers to increase awareness and understanding of palliative care. Equipping providers with this knowledge is essential, as their understanding and attitudes influence timely identification of patient needs, appropriate referrals, and integration of palliative care into standard treatment pathways.

For practitioners:
Actors focused on terminal illness can use this research to foster collaboration between oncologists, general physicians, and palliative care teams to improve holistic patient management.

Recognize caregivers as key stakeholders in a patient's journey and provide them counseling and peer support groups.

Recommendations for future research

Future studies should explore strategies for early integration of palliative care across diverse illnesses, assess the impact of provider training on referral patterns, and examine models of interdisciplinary collaboration. Research should also investigate caregiver support mechanisms to enhance holistic care and identify effective policies for system-wide implementation.

Further reading

SNOW, R. W., ARMSTRONG, M., FORSTER, D., MUNG'ALA, V. O., & MARSH, K. (1994b). Factors Influencing Admission to Hospital during Terminal Childhood Illnesses in Kenya. *International Journal of Epidemiology, 23*(5), 1013–1019. https://doi.org/10.1093/ije/23.5.1013

Esmaili, B. E., Stewart, K. A., Masalu, N. A., & Schroeder, K. M. (2018). Qualitative Analysis of Palliative Care for Pediatric Patients With Cancer at Bugando Medical Center: An Evaluation of Barriers to Providing End-of-Life Care in a Resource-Limited Setting. *Journal of Global Oncology, 4*, 1–10. https://doi.org/10.1200/jgo.17.00047

Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C., Amidi-Nouri, A., & Kramer, R. F. (2008). Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers. *PEDIATRICS, 121*(2), 282–288. https://doi.org/10.1542/peds.2006-3153

Study team

KEHPCA team: Roselyne Omolo, Miriam Igobwa, Dr. Beryl Okose
Busara team: Lynette Gow, Mellan Lilumbi, Fiona Mahiani

To cite:
Busara. 2025. *Is palliative care only for the dying—or is there more to it? (The aha! moment No. 23)*. Nairobi: Busara. DOI: doi.org/10.62372/GEXR2678

The aha! moment summarises key facts and insights from Busara's research projects.

38 Apple Cross Road, Nairobi, Kenya **www.busara.global**