



# Ethan T. Harned

## Public Health Researcher and Consultant

- Affiliations: Global Partners and Care, University of Notre Dame
- Experienced consultant | fundraising, communications, strategic planning
- Outstanding Undergraduate Student Award | Eck Institute for Global Health, University of Notre Dame
- Fulbright-Nehru Fellow | Fulbright Program and US State Dept. | Researching Pediatric Palliative Care and Public Health in India
- I enjoy working out and remaining active. I lift weights and swim.

# More than Just the Pills: How Palliative Care Services are Addressing Social Determinants of Health in Adolescents Living with HIV (ALWH)

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**2025 PALLIATIVE CARE CONFERENCE**

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# Overview

- I. Background
- II. Method
- III. Results
- IV. Discussion
- V. Call for “Revolution”



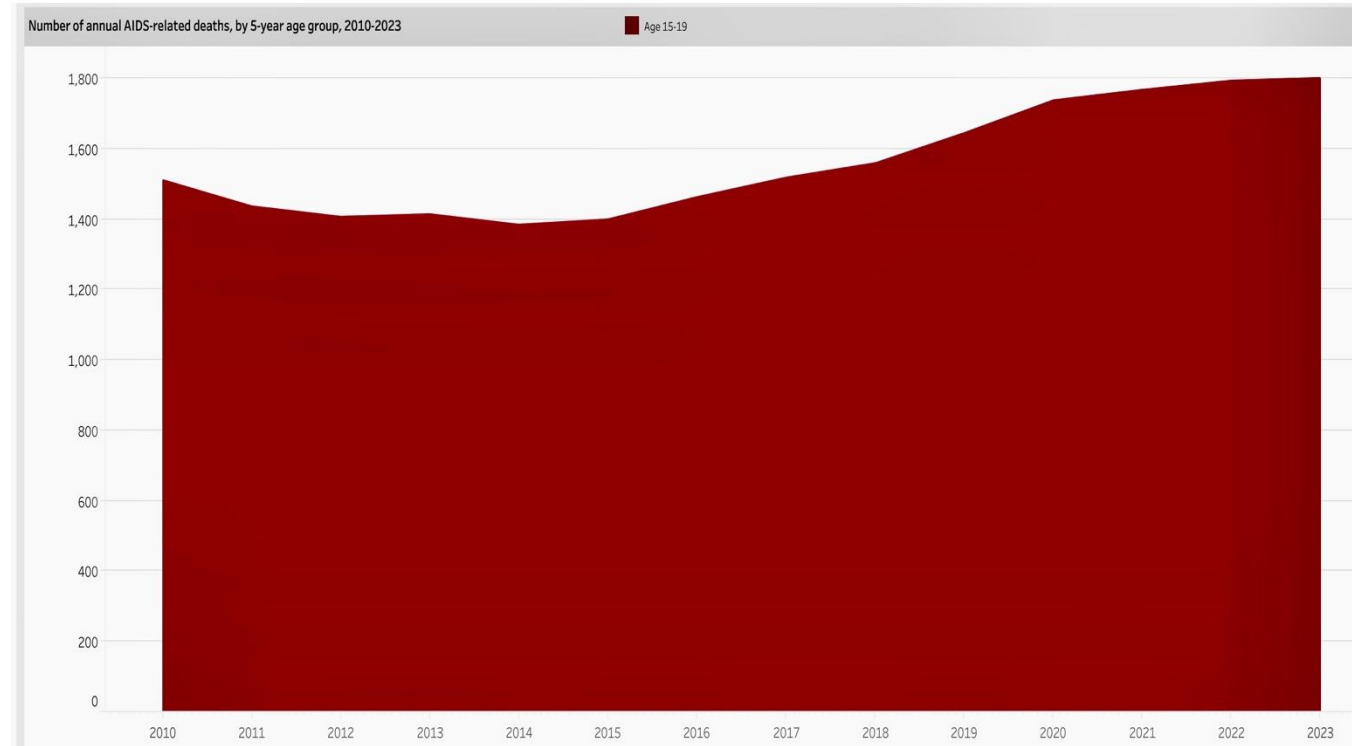
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# Background

- Approximately 300,000 ALWH in South Africa
- Mortality rates increased by 28.6% for 15-19 age group since 2015 (UNICEF DATA, 2024)
- Social determinants of health: conditions in which people are born, grow, live, work, and age, and people's access to power, money, and resources (WHO, 2025)
- ALWH are exposed to many social determinants, including poverty, limited social support, stigma, etc. (Peterson et al., 2010)



AIDS-related Deaths for Ages 10-19 in South Africa, 2010-2023. *UNICEF DATA.*

# Study Development

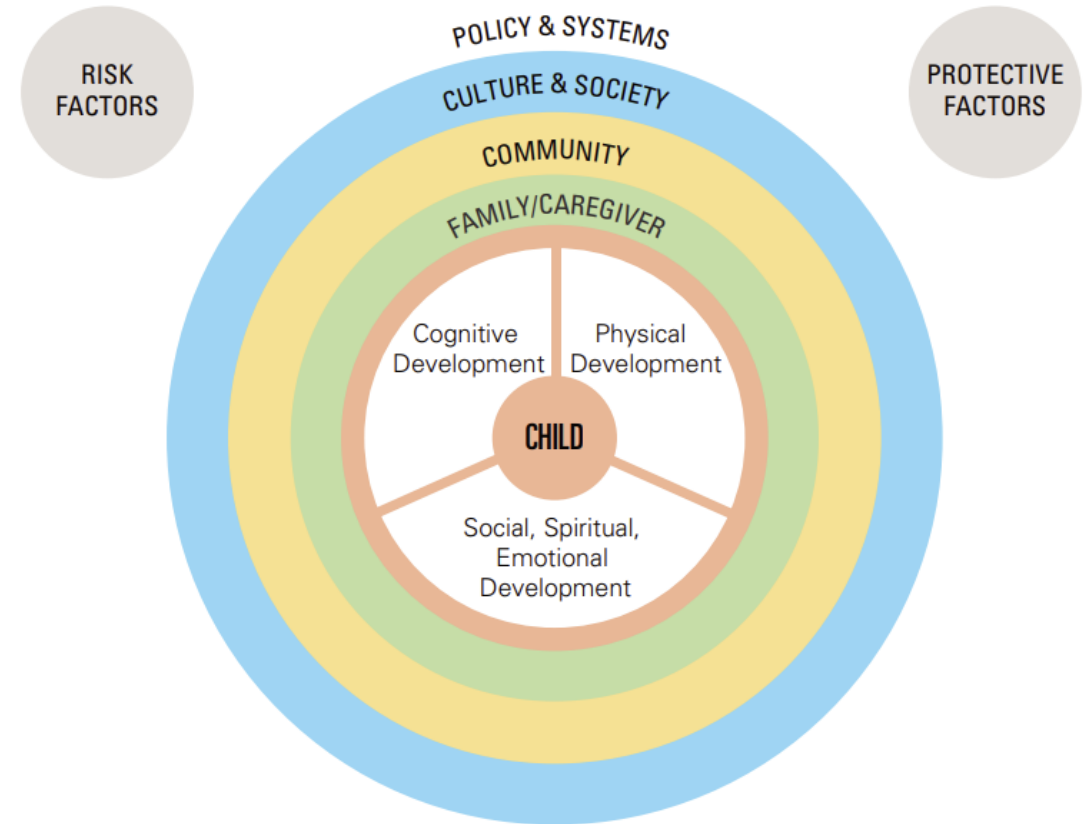
- Question: How are palliative care services addressing the social determinants of health in ALWH?
- Inspired by conversations from networking calls hosted by Global Partners in Care
- Co-designed evaluation by Sunflower Children's Hospice, University of Notre Dame, and Global Partners in Care





# Method

- Qualitative study (Exploratory Case Study approach)
- 33 semi-structured interviews and two focus groups
- 48 participants: Caregivers of ALWH, Health providers, stakeholders working at the national level (policymakers, NGOs, researchers)
- Interview guides and data analysis were conducted using UNICEF's Social Ecological Model (2024)



The Social Ecological Model. UNICEF, 2024.

# Stakeholder Representation



health

Department:  
Health  
REPUBLIC OF SOUTH AFRICA



World Health  
Organization



GROOTE SCHUUR  
HOSPITAL



UNIVERSITY OF THE FREE STATE  
UNIVERSITEIT VAN DIE VRYSTAAT  
YUNIVESITHI YA FREISTATA



Together towards wellness



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

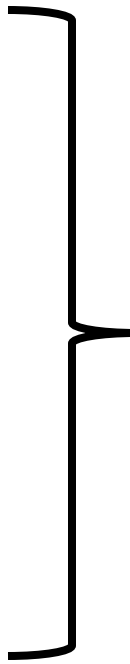


reach for a dream

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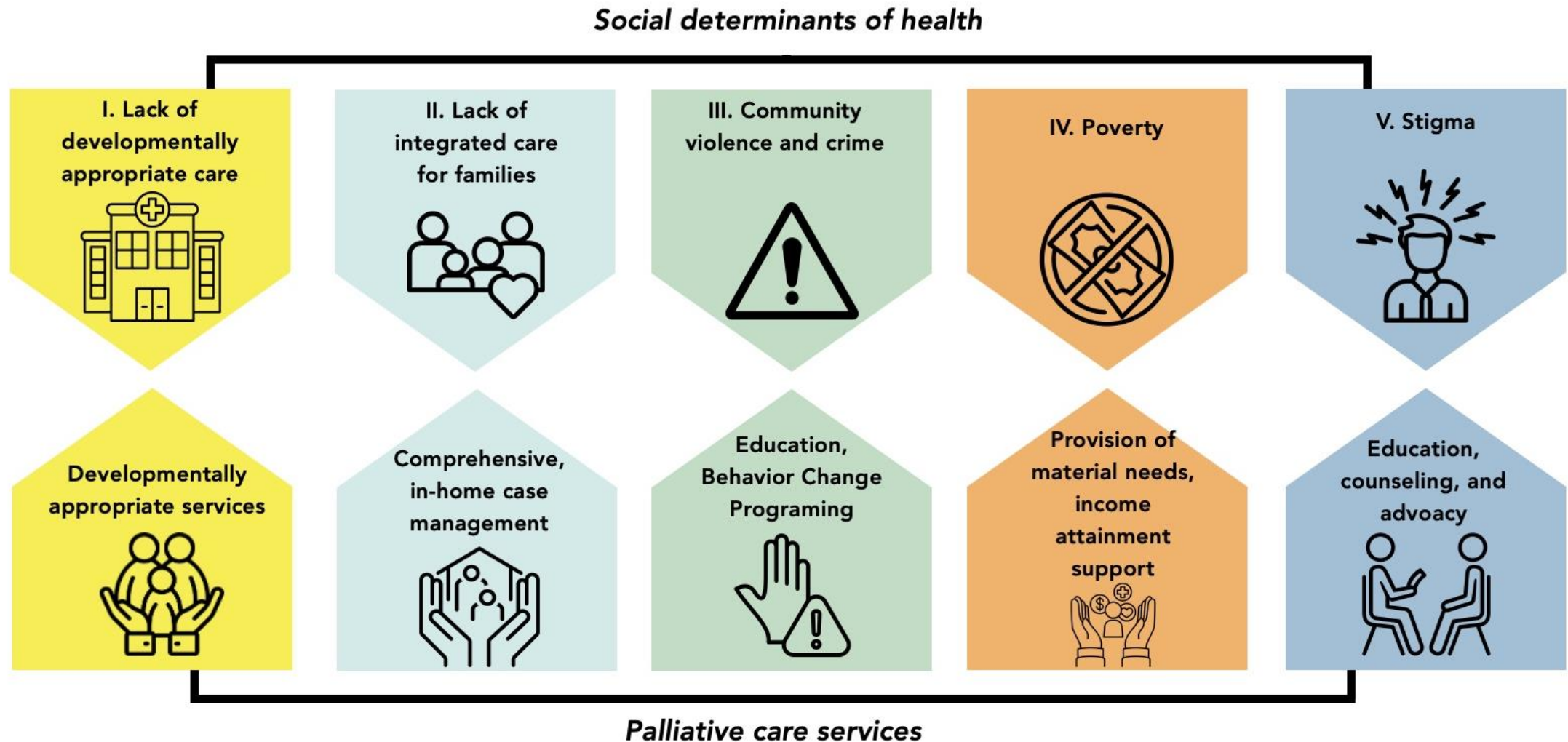
# Results

- I. Developmentally appropriate care
- II. Integrated care for ALWH and families
- III. Community violence mitigation
- IV. Poverty alleviation
- V. Stigma reduction

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- Now, we are calling for a **“revolution”** in the way palliative care is viewed.
  - To achieve this, we must ensure that our programming is presented compellingly to our policymakers, funders, community members, and researchers.



# Visual Model

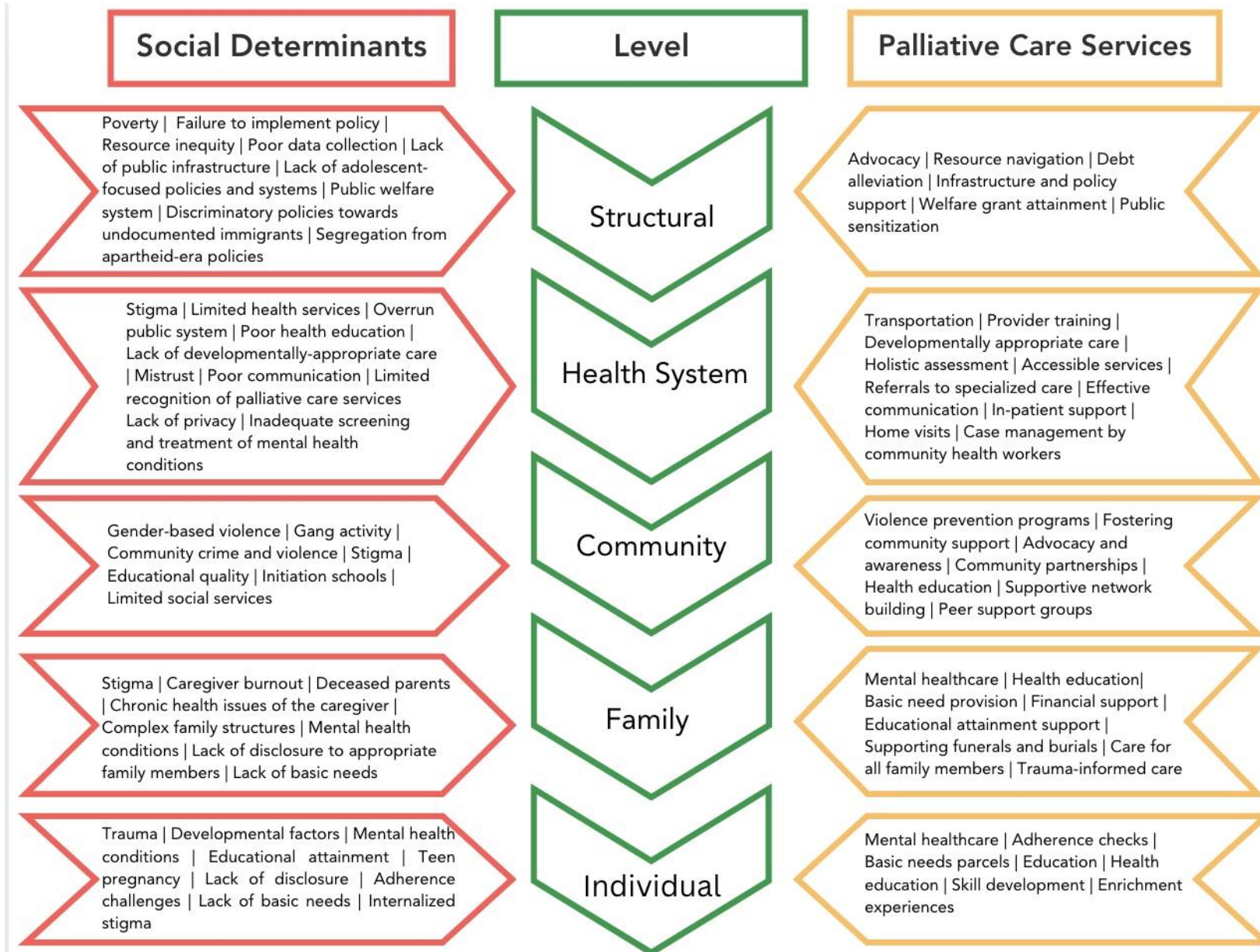


# Storytelling

- Two adolescent girls with HIV in Bloemfontein were living with undocumented parents from Lesotho
- They were living in shacks with limited access to power and water.
- They received healthcare, but could not work, attend school, or receive child support grants. The South African govt. would not issue them birth certificates.
- Sunflower's community team went to the Human Rights Commission with their cases.
- The Commission sued the South African government and won.
- Now the girls attend school, have grants, and remain in the Sunflower community program for care.

*"The family is having a problem here with the elder daughters, who don't have birth certificates. All of us mostly do advocacy, but I do most of the advocacy because I go even go to home affairs, I go to schools, I go everywhere. For these girls, I even went to the extent of going to the Human Rights Commission to report their cases. And we won, so now the girls have child support grants." (Palliative care community program manager)*

# Research Framework





# Conclusions

- This study illustrates a model of children's palliative care creating effective public health programming.
- ALWH are provided with context-specific programming to support healthy outcomes.
- The holistic approach of palliative care simultaneously addresses immediate needs while working to prevent future ones at the structural level.
- Palliative care is filling a gap for a population often neglected by the wider health system.



# The Call for "Revolution"

- Children's palliative care is an invaluable tool in public health.
  - Its holistic model designs context-specific interventions that respond to the needs of communities.
  - It fills gaps in health systems that policymakers and implementers fail to recognize as gaps from the very beginning.
- The challenge now lies in justifying the work of children's palliative care across sectors to ensure it is seen for all it can truly be.
- By utilizing broader global mechanisms to define the evidence for children's palliative care, this study demonstrates how to effectively represent palliative care to a wider global audience.

# The Call for "Revolution"

- This research also falls in line with global recommendations from the WISH Report (2024):
  - Empowering people and communities: The model evaluated was based on the work of a community programme run by community health workers living in the communities they support. Using a human-centered approach, programs have been designed based on community needs.
  - Research: This research was informed by all major recommended stakeholders and was context-specific. It was developed in partnership between academia and community-based services. Furthermore, it used the UNICEF Social Ecological Model (2024) as a framework, a human-centered model of evaluation.



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## Acknowledgements

- Co-authors: Joan Marston, Lacey Ahern, and Marie Donahue
- Collaborators: Global Partners in Care, University of Notre Dame, Sunflower Children's Hospice
- My informants
- Olga Molahole, Tshegofatso Taunyane, and Thomas Selebe at Sunflower Children's Hospice

