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Public Health Researcher and Consultant

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- 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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Overview

- Background
- Method
- Results
- IV. Discussion
- V. Call for "Revolution"







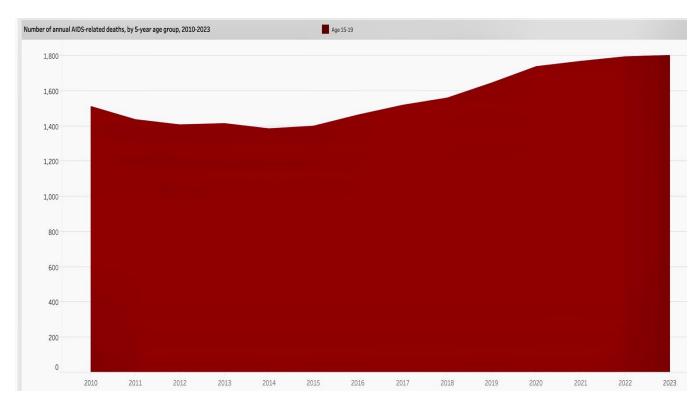
2025 PALLIATIVE CARE CONFERENCE





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.

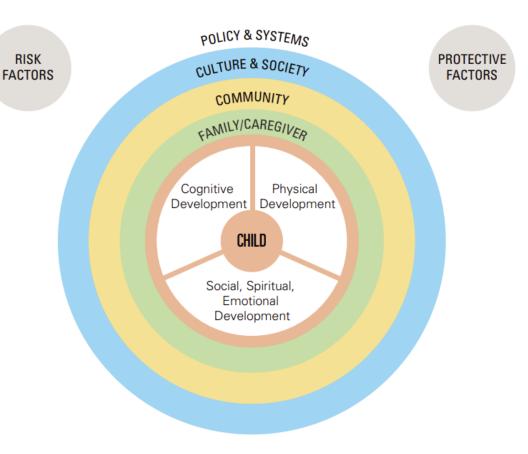
Study Development

- 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

















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Results

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

- 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

Social determinants of health



II. Lack of integrated care for families



III. Community violence and crime



IV. Poverty



V. Stigma



Developmentally appropriate services



Comprehensive, in-home case management



Education,
Behavior Change
Programing



Provision of material needs, income attainment support



Education, counseling, and advoacy



Palliative care services

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

Social Determinants

Level

Palliative Care Services

Poverty | Failure to implement policy |
Resource inequity | Poor data collection | Lack
of public infrastructure | Lack of adolescentfocused policies and systems | Public welfare
system | Discriminatory policies towards
undocumented immigrants | Segregation from
apartheid-era policies

Stigma | Limited health services | Overrun public system | Poor health education | Lack of developmentally-appropriate care | Mistrust | Poor communication | Limited recognition of palliative care services Lack of privacy | Inadequate screening and treatment of mental health conditions

Gender-based violence | Gang activity | Community crime and violence | Stigma | Educational quality | Initiation schools | Limited social services

Stigma | Caregiver burnout | Deceased parents | Chronic health issues of the caregiver | Complex family structures | Mental health conditions | Lack of disclosure to appropriate family members | Lack of basic needs

Trauma | Developmental factors | Mental health conditions | Educational attainment | Teen pregnancy | Lack of disclosure | Adherence challenges | Lack of basic needs | Internalized stigma

Structural

Health System

Community

Family

Individual

Advocacy | Resource navigation | Debt alleviation | Infrastructure and policy support | Welfare grant attainment | Public sensitization

Transportation | Provider training |
Developmentally appropriate care |
Holistic assessment | Accessible services |
Referrals to specialized care | Effective
communication | In-patient support |
Home visits | Case management by
community health workers

Violence prevention programs | Fostering community support | Advocacy and awareness | Community partnerships | Health education | Supportive network building | Peer support groups

Mental healthcare | Health education|
Basic need provision | Financial support |
Educational attainment support |
Supporting funerals and burials | Care for all family members | Trauma-informed care

Mental healthcare | Adherence checks | Basic needs parcels | Education | Health education | Skill development | Enrichment experiences

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):
 - <u>Empowering people and communities:</u> 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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