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A logic model and multinational consensus definition of primary palliative care in sub-Saharan Africa

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Title: A logic model and multinational consensus definition of primary palliative care in sub-Saharan Africa

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What is already known about this topic?

- Serious health-related suffering and palliative care needs are rapidly increasing, particularly in low- and middle-income countries.
- The World Health Organization asserts that pain relief and palliative care are integral to achieving Universal Health Coverage, and that the most equitable way to achieve this is through the improvement and expansion of primary care services.
- Defining and operationalizing primary palliative care across varied health systems in sub-Saharan Africa is a major obstacle to achieving Universal Health Coverage.

What does this paper add?

- We articulate a consensus definition and logic model for implementing and evaluating of primary palliative care in sub-Saharan Africa from the perspective of experts in the field. This can be adaptable for other low- and middle-income countries.
- We conceptualize primary health care beyond setting of care to ensure primary palliative care takes a whole-of-society coordinated approach.
- We provide supporting notes and guidance on how the logic model and consensus definition can be pragmatically applied to improve and expand access to primary palliative care.

Abstract

Background: The number of people needing palliative care is rapidly increasing in sub-Saharan Africa (SSA). Healthcare systems in SSA are heterogenous, so broadly defining and operationalizing primary palliative care is a major obstacle to achieving Universal Health Coverage. We aimed to conceptualize and operationalize primary palliative care in SSA by developing an evidence-based logic model and consensus definition.

Methods: We purposively sampled expert participants in a workshop in Harare, Zimbabwe. They collaboratively developed a logic model using the Centers for Disease Control and Prevention's guide for developing and using logic models and a consensus definition using modified nominal group technique.

Results: Twenty-four primary palliative care experts comprised of researchers (70.1%), physicians (37.5%) and nurses (29.2%) from 8 countries (7 in SSA) participated. Twenty (83.3%) participants fell into multiple role categories. Primary palliative care essential resources (i.e., medications, funding, health workers), activities (i.e., clinical guidelines and referral pathway development, education), outputs (i.e., care pathways, cost-benefit ratios), and outcomes (i.e., improved quality of life, skilled primary palliative care workforce, reduced health-related suffering) relevant for countries in SSA were identified. To define primary palliative care in SSA, participants identified and ranked crucial components, including holistic care (provided by health workers with role-appropriate training), culturally congruent delivery of care, and accessibility at the entry point of healthcare systems. The definition highlights that "primary" pertains to how people access care, rather than who or where it is provided.

Conclusion: The identified essential components of primary palliative care address the region's specific context, challenges and strengths. Training the existing primary healthcare workforce in palliative care and providing necessary support and resources must be prioritized in order to improve outcomes in SSA.

Background

The prevalence of serious, life-limiting illness is rapidly increasing as populations age, with the greatest increases seen in low- and middle-income countries (LMICs). By 2060, 83% of the world's health related suffering will be in LMICs, which represents over 20 million people experiencing suffering in their last year of life.¹ Most healthcare systems, particularly those in LMICs, are poorly prepared to respond to the growing need for palliative care.² The World Health Organization (WHO) asserts that palliative care is an essential health service under Universal Health Coverage (UHC) that reduces serious health-related suffering in ageing and increasingly multimorbid populations.^{3,4}

Primary healthcare is the foundation on which strong, equitable health systems are built.⁵ Primary care utilization for chronic disease management improves patient outcomes and reduces costs.⁶ Incorporating palliative care services into primary healthcare offers a potential solution to meet patients' and families' palliative care needs effectively and efficiently.^{7,8} Primary palliative care has been defined as integrated and holistic disease and symptom management practiced by primary health care workers.⁹ However, this definition does not completely capture the bespoke adaptations to primary palliative care delivery and the unique makeup of the healthcare workforce seen in many LMICs.¹⁰ Even among LMICs, healthcare systems, primary care infrastructure, and clinical palliative care availability are heterogeneous^{11,12}, so defining and operationalizing primary palliative care across health systems is a major obstacle to achieving UHC.⁹

Sub-Saharan Africa has 26 of the World Bank's 31 low-income countries and has seen slow but significant expansion of primary care and palliative care in recent years.^{11,13} This region is geographically, politically, and culturally diverse, resulting in contextually-specific needs for patients and families with life-limiting illness.^{14,15} There is an urgent need to define and operationalize primary palliative care across health systems in sub-Saharan Africa to implement the goals of UHC¹⁶, the World Health Assembly Resolution for evidence-informed quality, accessible palliative care¹⁷, the Disease Control Priorities (3rd edition) palliative care guidance¹⁸, the Astana Declaration to support UHC via global primary palliative care¹⁹, and the WHO guidance on integration of palliative into primary care.²⁰ As such the aims of this study were to develop an evidence-based logic model of primary palliative care and build a consensus definition of primary palliative care for sub-Saharan Africa.

Methods

Research Questions

We aimed to answer the following research questions: 1) what components are crucial to the delivery of primary palliative care in Sub-Saharan Africa, 2) what outputs signal appropriate primary palliative care delivery, 3) which outcomes are meaningful to evaluate, and 4) how is primary palliative care defined and operationalized across the heterogeneous health systems in Sub-Saharan Africa. These research questions were developed by a team of researchers from King's College London, the African Palliative Care Association, and universities in Ghana, Malawi, and Zimbabwe in a multiyear collaboration aimed at expanding access to primary palliative care in sub-Saharan Africa. This study was approved by the ethics committee of King's College London (MRA-22/23-35071).

Participant Recruitment and Selection

Clinicians and researchers with experience in primary palliative research and policy in sub-Saharan Africa were purposively sampled from institutions in seven countries: Ghana, Malawi, Nigeria, South Africa, Uganda, United Kingdom, and Zimbabwe. Participants were eligible if they had significant

experience working in primary palliative care, were 18 years or older, spoke English, and were willing and able to give informed consent. Each selected participant was invited via email to an in-person workshop in Harare, Zimbabwe and were reimbursed for their travel expenses. Participants gave written informed consent at the in-person meeting.

Logic Model Development and Data Collection

To develop a logic model of primary palliative care in Sub-Saharan Africa, we applied the Centers for Disease Control and Prevention's (CDC) methodological guidance for developing logic models.²¹ It proposes that a services can be broken down into processes, or the inputs, resources, activities, and outputs involved in delivering the service, and outcomes, or the short and long term intended effects. These components can be linked in sequence to determine how each relates to or brings about a change in another and can be useful in both planning and evaluating interventions.

During the in-person workshop, study team members highlighted existing definitions of primary care and palliative care based on a scoping review of literature,¹⁰ and expert members summarized the evidence for primary palliative care from studies they were currently conducting or had recently conducted. To construct a logic model of primary palliative care in sub-Saharan Africa, a member of the study team (OA) explained the process and divided participants into five groups. Groups were asked to consider each component (inputs, resources, activities, outputs, and short- and long-term outcomes) and develop a comprehensive list of essentials for primary palliative care components based on the social, cultural, spiritual context in Sub-Saharan Africa. Based on the CDC's guidance, inputs are defined as the resources that go into a program or intervention i.e. what is being invested in terms of financial or in-kind resources and personnel from any source. Activities are events undertaken by the program or partners to produce desired outcomes, i.e., what is being done with the resources. Outputs are the direct, tangible results of the activities, i.e. evidence of the activities' impact. Outcomes are the desired results of the program, i.e. what is achieved either immediately or over time. Each group had a scribe who wrote the essentials on sticky notes. Groups then posted their sticky notes on posters labelled with each of the components. Next, groups came together to share their lists of essentials. The larger group then discussed, and if at least three of the five groups agreed that an essential belonged, it was retained. This process lasted about 2 hours.

The logic model developed in the workshop was refined by members of the research team (OA – male, nurse researcher and AP – female, nurse researcher) in the weeks following the in-person meeting. Participants were sent the refined logic model via email, and were asked to comment, make any edits, and approve the final version.

Consensus Definition Using Nominal Group Technique

With the same group of experts, we employed a modified nominal group technique (NGT) to identify key components and priorities for primary palliative care in sub-Saharan Africa with the goal of developing a consensus definition.²² We modified the NGT to include the following steps: 1) individual brainstorming sessions to answer provided questions related to key components of primary palliative care in sub-Saharan Africa, 2) small group discussions of generated ideas, 3) feedback to the larger group with discussion of what constitutes primary palliative care and what should be excluded, 4) ranking of the most important components in small groups, and 5) group consensus on the final definition (done in a remote follow-up after the in-person meeting). In total, the in-person portion lasted for about 3 hours.

Modified NGT Process, Data Collection, and Analysis

Participants were provided with written instructions, and a member of the study team (CE) gave an overview of NGT, the purpose of the exercise, the process, and introduced the guiding questions: 1) What are the important components of primary palliative care in sub-Saharan Africa? and 2) Who delivers primary palliative care in this setting? Next, participants individually generated ideas based on the research questions and wrote them on provided worksheets. Next, participants were divided into four groups and were asked to share the components they felt were most important. Each small group had a designated scribe to capture the discussion points and a facilitator from the research team tasked with prompting discussion and ensuring all group members had the opportunity to share their essential components and perspectives. Next, groups fed back to the larger group and distilled the generated ideas into a list of components of primary palliative care in sub-Saharan Africa. Once the list of components was produced, each group ranked them from highest to lowest priority. Finally, the groups came together as one larger group to compare, discuss, and identify the most important components.

Following the in-person meeting, members of the research team compiled the data written by the scribes of each group along with the rankings of priority and collated into one coherent definition of what primary palliative care entails in sub-Saharan Africa. This definition was shared with participants via email, and each commented, made edits, and agreed to the final definition. Though remote consensus is not usually included in the NGT process, this was the most feasible solution to include participants from around the world.

Results

The expert workshops were conducted in March 2023 in Harare, Zimbabwe. In total, 24 people participated in the workshops. A summary of their characteristics can be seen in Table 1, and their individual roles can be seen in Table 2. Participants represented 14 institutions from 6 countries in Africa (Ghana, Malawi, Nigeria, South Africa, Uganda, and Zimbabwe) and the United Kingdom. Most identified as researchers (n=17, 70.1%), physicians (n=9, 37.5%), nurses (n=7, 29.2%), allied health professionals (n=6, 25%), and policy makers (n=2, 8.3%). These categories were not exclusive, so participants could be both a nurse and a researcher, for example. Twenty (83.3%) participants fell into multiple role categories. The median years of experience working in palliative and end-of-life care was 16 (range 4–32 years), and the median years of experience working in primary care was 18 (range 7–37 years).

Table 1. Demographics

[Insert Table 1]

Table 2. Roles of Participants

[Insert Table 2]

Logic Model Workshop

Participants identified 35 potential inputs and resources that relate to primary palliative care delivery in sub-Saharan Africa, 23 of which were retained in the final logic model based on our threshold of three out of five groups agreeing each was essential (seen in Figure 1). These include inputs such as available medications, public and private funding, treatment algorithms, evidence-based education, a well-trained multidisciplinary workforce, and relevant national policies. Nineteen of the 35 activities

needed to reform primary palliative care were incorporated into the logic model, including development of evidence-based care pathways, economic evaluation, holistic care, training and mentorship for healthcare workers, and national monitoring and evaluation of services. Participants prioritized 18 of the 36 outputs, such as equipment availability, improved quality of life for patients and families, appropriate and timely referrals to higher levels of care, and the number of trained and competent staff. Ten of the 13 short term outcomes were retained, including improved quality of life for patients and families, clear care pathways and guidelines for delivering care, and reduced out of pocket expenditures. Finally, 6 of the 14 long term outcomes were incorporated into the final logic model, including reduced health related suffering, a robust healthcare workforce trained to deliver primary palliative care, sustainable government funding, and improved access to essential medicines.

During the larger group discussion, participants agreed that conceptually, the identified essentials could be categorized into themes, physical, financial, process, educational, human and policy. The physical theme encompasses essentials that relate to tangible materials and resources required to deliver primary palliative services. The financial theme relates to any resource, activity or output that reflects monetary need or benefit. The process theme contains essentials related to the actual methods of delivering services, while the education theme includes those that reflect the workforce's development of knowledge and skills in primary palliative care. The human theme concerns workforce availability and community assets. Finally, the policy domain includes essentials that relate to government codification of palliative care priorities, funding, or service guarantees on a national or sub-national level. Each identified essential was categorized into one theme, though in some cases, there was significant overlap between themes. Here, the study team reached consensus about the "best fit." For this reason, the components are color coded by theme across components.

[insert Figure 1]

Consensus Definition Workshop

In step 1 of the modified NGT process, participants generated a median of 8 items (range 3 – 12) during the individual brainstorming session. In step 2, groups of six shared their items with each other and developed a list to feedback to the larger group. In step 3, small groups presented their lists to the larger group, and the generated ideas were consolidated into 24 components. In step 4, the small groups ranked these components by how important they felt it was for them to be included in the definition of primary palliative care in sub-Saharan Africa. The highest ranked components indicated that primary palliative care should: 1) focus on holistic care, including quality of life and physical, psychosocial, and spiritual well-being; 2) be provided by health workers, including community health workers, traditional practitioners, and volunteers, with holistic training appropriate to their role; 3) be delivered with cultural sensitivity, empathy and dignity; 4) be accessed at the entry point of the healthcare system; and 5) involve patients, families and communities. These five priority components were combined to create a preliminary definition that was sent to participants via email in Step 5. This definition was refined and confirmed with input from participants.

Consensus Definition of Primary Palliative Care in Sub-Saharan Africa

Primary palliative care in sub-Saharan Africa is defined as integrated palliative and end-of-life care²³ provided by trained health workers (i.e., practitioners with a registered qualification, community health workers who meet the training requirements in the country in which they practice²⁴, traditional

and complementary medicine practitioners²⁵) at the first point of entry where people access healthcare services. The goal of primary palliative care is to provide people and their families with culturally congruent, empathetic care that upholds dignity and focuses on quality of life and physical, psychosocial, and spiritual well-being in the setting of life-limiting, life-threatening, or chronic illness. Importantly, 'primary' is not defined by place of care, but by how people access it. Primary palliative care may be provided by generalist healthcare workers at the first point of entry (i.e., general outpatient clinics, community- or home-based care) or in secondary or tertiary healthcare facilities where people access preventative or generalist services.

Based on feedback during step 5 and identification of the need for a comprehensive definition of primary palliative care in sub-Saharan Africa, supporting notes and guidance were developed and agreed (using the same process) that further delineate essential components and recommendations for governments to implement to achieve and improve palliative care integration in their countries' health system.

Supporting Notes and Guidance on the Definition

Primary palliative care involves person-centred communication, holistic assessment of physical, psychological, social, and spiritual concerns and symptom identification and management as illness progresses, through end-of-life care, dying, death and beyond into bereavement. Teamwork and communication within and between members of the multidisciplinary team, patients, and families facilitates optimal quality-of-life, including the development of personalized goals of care where appropriate. It can be delivered as part of integrated optimal disease management or as stand-alone support to be accessed as needed. Criteria for and referral pathways to and from specialist services (i.e., respiratory, gerontology, oncology, palliative care) should be available.

The delivery of such care requires context specific training at all levels (i.e., pre-licensure, in-service, and post-graduate) in palliative and holistic care for multidisciplinary healthcare workers, traditional and complementary medicine practitioners, and community volunteers, referral pathways to specialist palliative care services when available for those with complex needs, community engagement and partnerships to foster palliative care networks, and availability of appropriate medications. Primary palliative care should be subject to audit and quality improvement utilising WHO quality indicators and should be responsive to findings from high quality, locally driven research.²⁶ Furthermore, primary palliative care delivery should be supported through central and local government funding mechanisms (including taxation and/or insurance) utilising national health financing platforms.

Primary palliative care must include:

- Care at the entry point of the healthcare system that is accessible, continuous, comprehensive, coordinated and person-focused⁵
- Support for both people with life-limiting, chronic, or serious illness and their family
- Evidence-based models of care that are effective in the context of sub-Saharan Africa
- Identification and screening of patients for palliative care needs¹⁵
- Holistic assessment (includes physical, psychological, social, and spiritual needs)
- Symptom identification and management
- Drug availability at the point of care

- Targeted communication between patients, families, and healthcare team focused on quality-of-life concerns and goals of care
- Culturally competent, empathetic care that upholds dignity
- Shared decision-making, goal setting and advance care planning
- Interdisciplinary collaboration
- Referral pathways for patients or families with complex needs
- Guidelines and operational procedures taking into consideration care providers' competencies
- Continuity of care in the primary care setting, the community, and at home

Discussion

To our knowledge, this paper reports the first logic model and consensus definition of primary palliative care as it is delivered in sub-Saharan Africa from the perspective of experts in the field. Together, the definition and logic model define and operationalize the concept of primary palliative care in sub-Saharan Africa. Our diverse and interdisciplinary sample of researchers, clinicians, policy makers, and key stakeholders from throughout sub-Saharan Africa offer unique insights into the contextual elements that impact the delivery of primary palliative care here. We have taken a rigorous approach with clear methodological grounding drawing on high-quality, recent evidence. Given the lack of prior attention to how optimal primary palliative care can be achieved within different contexts and resources within sub-Saharan Africa, our original approach has driven forward the potential to achieve policy goals.

In both workshops, there was strong agreement among participants about the core tenets of palliative care, including holistic assessment, symptom identification and management, cultural congruence and empathy, and family and community involvement when possible. These are reflected in the inputs, resources, activities, and outcomes in the logic model and in the final consensus definition and supporting notes. However, participants found that defining and operationalizing what makes care 'primary' was more challenging than what makes care 'palliative'. In previous efforts to define and operationalize primary palliative care, experts have disagreed on whether or not to include palliative care provided by acute care generalists, such as intensivists or hospitalists, or other specialists without specific palliative care training, such as cardiologists or oncologists.^{9,27} Other attempts to define what makes care 'primary' used a three factor framework based on who is providing the care (providers), what type of care is being provided (services) and where the care is being delivered (setting).²⁸ However, the discussions in these workshops centered around primary care being defined by how people access services as the first point of entry, rather than who is providing the services. Participants articulated that people should access palliative care at an entry point into the healthcare system or in the community in order for it to be considered 'primary palliative care.'

While to our knowledge there are no other published logic models of primary palliative care, this definition shares some commonalities with other definitions of primary palliative care in different settings. A 2019 panel definition from Munday and colleagues states that primary palliative care "includes early identification and triggering of palliative care as part of integrated and holistic chronic disease management, collaborating with specialist palliative care services where they exist, and strengthening underlying professional capabilities in primary care."⁹ Another from Weissman and Meier states that primary palliative care the "basic skills and competencies required of all physicians and other health care professionals."²⁹ All share a focus on holistic disease management and communication and highlight that it is provided by primary care providers or in a primary care setting. The unique context of

sub-Saharan Africa warranted a bespoke logic model and consensus definition that acknowledge the distinct strengths and needs of African communities and health systems. For example, the definition from Munday and colleagues excludes patients with non-chronic or infectious diseases who could benefit from integrated primary palliative care, a group with large numbers in sub-Saharan Africa and LMICs more widely. Similarly, Weissman and Meier's definition only mentions healthcare professionals, which overlooks the potential asset in community health workers, volunteers, or traditional and complementary medicine practitioners that make up a large segment of the health workforce in the region and in other LMICs.³⁰ As the majority of primary palliative care development and research takes place in high-income countries^{11,24}, the needs of people and health systems in LMICs are underrepresented or overlooked in the development of global statements or definitions.

Implications for Research, Policy, and Practice

The majority of multinational guidance on primary palliative care development and delivery lacks specificity for health systems and cultures in LMICs. Often times, assumptions that guidelines are based on that implicitly apply in high-income countries do not hold true in LMICs. These include:

1. **A functional primary healthcare system:** For many LMICs, primary healthcare systems can be fractured, informal, stretched thin and/or underdeveloped.¹² Recommendations for primary palliative care development and delivery often fail to acknowledge how to tailor processes for systems that are not already fully functional.
2. **A strong focus on physical and psychological palliative needs:** Often times, guidelines place a heavy emphasis on physical and psychological support and lack attention to social and spiritual needs that can be of paramount importance to patients and families in LMICs.³¹
3. **The evidence base is generalizable and reflects all healthcare systems:** The vast majority of palliative care research has been conducted in developed countries without the resource limitations seen in most LMICs.²⁴ Primary palliative care research in LMICs is emergent, and it is not guaranteed that the same models of care seen in high-income countries will be feasible or acceptable in LMICs.¹⁰
4. **Recommendations inevitably translate to change in practice:** Evidence has shown that just providing recommendations rarely leads to change within healthcare systems, particularly in LMICs.³² Recommendations need to outline specifically how involved parties should respond, required resources (physical, financial, human and educational) and how interventions can be sustained long term.³³
5. **Primary care providers view palliative care as within their scope of practice:** Evidence has shown that primary care providers in LMICs are often not trained in palliative or end-of-life care and thus feel unprepared to deliver services.³⁴ Often, they can feel the palliative care is out of the scope of practice which could limit uptake of multinational guidelines.

For these reasons, we chose to focus solely on the unique context of sub-Saharan Africa when defining and operationalizing primary palliative care, although we recognize heterogeneity between sub-Saharan countries. The logic model and consensus definition developed in these two workshops address each assumption and provide novel insight into how to acknowledge and reduce their collective negative impact on primary palliative care development and delivery. They are designed to be used to inform service development to capitalize on strengths of the current system in sub-Saharan Africa and fill existing gaps in care. Therefore, our conceptualization and operationalization of primary palliative care

in sub-Saharan Africa can guide policy and service development, implementation and evaluation on a population level.

We hope this work will also help shape future research related to the development and delivery of primary palliative care in sub-Saharan Africa and potentially in LMICs more broadly. As this research focuses on the specific needs and context of sub-Saharan Africa, future research should determine whether or not this definition and logic model are generalizable to other low resource settings. Additionally, the developed logic model is theoretical, so it should be evaluated as used in service development to illuminate mechanisms of change to achieve the desired outcomes.

Limitations

This study has a few limitations to consider alongside the results. First, our panel of experts was purposively sampled from institutions which we have collaborated with on previous research projects. As such, researchers were more likely to be invited to attend, though most also engaged in clinical work as well as research. Furthermore, while they represent 14 institutions from 7 countries, not all countries or health systems in the region were represented. Secondly, we modified the NGT process to include follow-up via email. While this is not traditionally part of the NGT process, we felt we needed more time to write a clear definition and achieve consensus and following up via email shortly after the in-person workshops was most pragmatic. This modification is justified in the NGT literature.³⁶

Conclusion

There is great potential for the model of primary palliative care to meet the needs of the growing number of people living with life-limiting illness. The populations, cultural context, and healthcare systems of sub-Saharan Africa have unique strengths and challenges that impact the development and delivery of primary palliative care. Together, this logic model and consensus definition provide comprehensive, evidence-based detail to conceptualize and operationalize current practice in this setting and identify priority areas for care delivery. This will not only inform service development, but also local, national and international policies to improve and expand access to primary palliative care for those who need it.

Conflict of interest: None

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Table 1. Demographics

	Total N=24
	N (%)
Gender	
Male	11 (45.6)
Female	13 (54.4)
Role	
Researcher	17 (70.1)
Physician	9 (37.5)
Nurse	7 (29.2)
Allied Health Professional	6 (25)
Policy Maker	2 (8.3)
Median years of palliative care experience (range)	16 (4–32)
Median years of primary care experience (range)	18 (7–37)

Table 2. Participants' Roles

Participant	Professional Role
Participant 1	Primary care nurse; primary and palliative care researcher
Participant 2	Acute care nurse; primary and palliative care researcher
Participant 3	Primary care nurse; primary and palliative care researcher
Participant 4	Professor; community health nurse; primary and palliative care researcher
Participant 5	Professor; social worker; primary and palliative care researcher
Participant 6	Epidemiologist; primary and palliative care researcher
Participant 7	Palliative care nurse; primary and palliative care researcher
Participant 8	Primary care physician; health economist; primary and palliative care researcher
Participant 9	Public health worker
Participant 10	Palliative care nurse; primary and palliative care researcher
Participant 11	Family physician; primary and palliative care researcher
Participant 12	Family physician; palliative care specialist physician
Participant 13	Palliative care specialist physician; primary and palliative care researcher
Participant 14	Primary care, community health, and palliative care researcher
Participant 15	Family physician; primary and palliative care researcher
Participant 16	Family physician; primary and palliative care researcher
Participant 17	Palliative care nurse; primary and palliative care researcher
Participant 18	Behavioral scientist; primary and palliative care researcher
Participant 19	Oncologist; policy maker
Participant 20	Family physician
Participant 21	Palliative care specialist physician
Participant 22	Primary care nurse; primary and palliative care researcher

Participant 23 Public health worker; policy maker

Participant 24 Palliative care counsellor

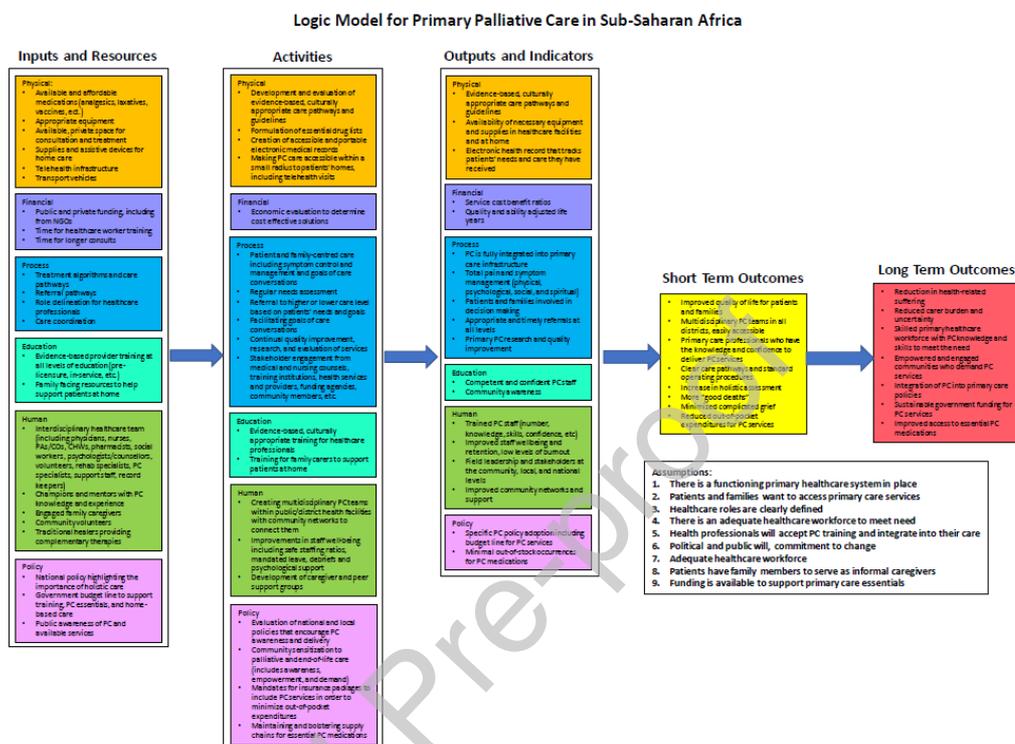


Figure 1. A logic model of primary palliative care in sub-Saharan Africa.