

Health promoting palliative care interventions in African low-income countries: a scoping review

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ABSTRACT

Background Palliative care (PC) has advanced rapidly since 2005, when the World Health Assembly posited it as an urgent humanitarian need. Over the same period, the principles of the Ottawa Charter for Health Promotion have been promoted to implement sustainable PC. It is not known whether the Ottawa Charter principles have been integrated into existing PC efforts in low-income African countries. The purpose of this scoping review is to determine the state of knowledge on the consequences of health promoting PC (HPPC) interventions in African low-income countries.

Methods We searched for literature published in English, French and Spanish between 2005 and 2022 in CINAHL, PubMed and PsycINFO. The inclusion criteria for studies were (1) conducted in African low-income countries and (2) evaluated the consequences of an HPPC intervention. Using Covidence, two reviewers independently carried out a two-step review process (title/abstract and full text) and data extraction.

Findings A total of 2259 articles were screened and 12 were included. Of the 22 low-income countries in Africa, 3 countries—Malawi, Uganda and Rwanda—were represented in the selected studies. The majority of studies were cross-sectional, had limited numbers of participants and were conducted in English-speaking countries. We found that volunteers and caregivers played a key role in HPPC. Interventions sought to strengthen community action by reinforcing the skills and knowledge of community health workers (usually unpaid volunteers). Only two studies were related to building health promoting policy. Changes in professional education, training and culture were addressed in a few studies.

Conclusion There is a need to increase the capacity of low-income African countries, especially French-speaking countries, to sustain HPPC interventions and to conduct and publish research on this topic. Decision-makers looking to implement HPPC measures in Africa or elsewhere may find the practical outcomes of this review helpful.

INTRODUCTION

By 2030, non-communicable diseases will make up 7 of the top 10 contributors to the global burden of disease, with the impact

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Best practice in palliative care (PC) requires integrating the principles of health promotion.
- ⇒ In low-income African countries, interventions related to PC have been implemented in recent years.
- ⇒ Our understanding of the consequences of health promoting PC (HPPC) interventions in low-income African countries is limited.

WHAT THIS STUDY ADDS

- ⇒ In low-income African countries, evidence of the consequences of HPPC is derived primarily from small qualitative or mixed-methods studies, mostly using cross-sectional designs, in only three English-speaking countries.
- ⇒ HPPC interventions have focused on either strengthening community action by reinforcing the skills and knowledge of community health workers, reorienting health services towards home-based care, or educating patients and family members.
- ⇒ Numerous concepts related to health promotion have been understudied, including empowerment, gender disparities, the creation of supportive environments and public policies.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Although the quantity and quality of evidence remains low, a few HPPC interventions have been tested and could inspire policy-makers, including the use of communication technology, provision of fundamental conditions and resources, targeting of vulnerable populations, and adoption of health policies.
- ⇒ There is an urgent need to increase sustainable funding and strengthen the capacity of researchers from low-income African countries, particularly French-speaking ones, to conduct and disseminate research on HPPC.



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being felt more in low-income countries where health systems are sometimes brittle.¹ As a result, there will be a greater need for palliative care (PC), particularly in those countries.² According to the WHO, PC is an approach that enhances the quality of life

of patients (children and adults) and their families who are facing challenges associated with life-threatening illnesses. It prevents and relieves suffering through early identification, accurate assessment and effective treatment of pain and other problems, whether physical, psychosocial or spiritual.³

PC is increasingly acknowledged as a whole-person and whole-system approach.⁴ In fact, PC can be provided in a variety of settings, including the community, as soon as a life-threatening illness is detected. PC is integrated with curative therapies, to help patients and their loved ones maintain their social roles and quality of life by addressing their medical, psychological, spiritual and social needs.⁴ Building and sustaining such a complex approach implies the mobilisation of intersectoral social actors and the recognition that health, quality of life and quality at end-of-life involve not only the healthcare system but the whole society.⁵ The concepts of health promotion can be embedded into PC models, policies and guidelines.⁶ According to the Ottawa Charter for Health Promotion,⁷ health promotion aims to enable people to maintain greater control over their health and achieve equity in health. Starting in 1999, Allan Kellehear's seminal work showed how the axes of health promotion can be applied to PC, paving the way for the development of health promoting PC (HPPC).^{5,8}

Principles of HPPC

1. Build healthy public policy: With regard to end-of-life care, building healthy public policy can mean involving community organisations and the public in developing policy that allows time off from school or work for people caring for someone who is at the end of their life.⁸
2. Create supportive environments: In supportive environments, community members take an active role in caring for people; assisting people to live comfortably in their homes; connecting people to supports; raising awareness about health, well-being and end-of-life issues and creating supportive networks to develop the capacity of others.⁹
3. Strengthen community action: This involves identifying needs, developing solutions and engaging community organisations other than those traditionally involved in PC.⁸
4. Reorient health service: This involves promoting holistic support for people at end-of-life and their families, and renormalising dying and death through various initiatives, such as death education in school curricula.⁸
5. Develop personal skills: This refers to the acquisition of personal skills as well as the development of competencies among the general public in supporting individuals at the end of life and their families.⁸
6. Reduce health inequity: Applied to PC, reducing health inequity means, for example, developing programmes intended to reach marginalised populations,

such as people living with HIV, using drugs or experiencing homelessness.¹⁰

7. Empowerment: When it comes to end of life, empowerment relies, for example, on increasing one's level of death literacy (ie, knowledge about the expected end-of-life journey and the various decisions that need to be made).¹¹
8. Gender equity: Health promotion should enable men and women equally. Men and women should become equal partners.⁷

Following Kellehear's groundbreaking work, health promotion has been incorporated into numerous PC programmes, interventions^{12,13} and frameworks intended to facilitate the adoption of PC in healthcare systems and more broadly in the social realm.^{14,15} Such interventions can include community mobilisation and participation, capacity building for community leaders and services provided by community volunteers and family caregivers. HPPC interventions have the potential to (1) provide holistic care by addressing medical and non-medical needs; (2) connect patients with organisations in their community; (3) reach populations that are less accessible; (4) reduce unnecessary admissions to healthcare facilities; (5) improve social capital through the pooling and effective use of community resources and (6) create social pressure to reorient policies.⁸

Despite the development of PC in low-income countries, there has been, to date, no synthesis of scientific knowledge on the consequences of interventions integrating HPPC in low-income African countries. Such consequences refer both to changes related to the process of care and to the effects of HPPC interventions.

State of PC development in Africa

A scoping review assessing PC development in Africa indicated that 14 countries (26%) had shown an increase in services during the period surveyed.¹⁶ Tanzania, Zimbabwe, Malawi, Mozambique, Rwanda and Swaziland have adopted PC policies. Postgraduate PC diploma programmes were offered in Kenya, South Africa, Uganda and Tanzania. Despite these expansions, the majority of African nations had little to no PC development during those years. Mozambique, Rwanda and Uganda were the only low-income countries where some growth in PC development was observed.¹⁶ An analysis of articles published from 2002 to 2018 indicated that four countries—South Africa, Uganda, Kenya and Malawi—accounted for two-thirds of African programmes to integrate PC into health systems, with South Africa hosting slightly under one-third.¹⁷ The authors noted that most studies did not describe the consequences of the interventions, although they observed an increase in publications from low-income regions.¹⁷ A report from Human Rights Watch noted that French-speaking African countries have limited access to PC and opioids in comparison to English-speaking African countries.¹⁸

In their rapid systematic review, Agom *et al* examined the state of knowledge regarding barriers to the provision

and use of adult PC in Africa.¹⁹ Those authors found that patients lacked access to PC due to its unavailability, isolated services, poor funding, lack of or inadequate policy and inadequate referral practices.¹⁹ More recently, Maree *et al* looked at research output published by African nurses in the field of palliative cancer care from 2012 to 2021.²⁰ Those authors found that existing studies focused on the family and caregivers. Pain was the only symptom investigated.²⁰ Since these reviews, evidence has been published related to HPPC in Africa, but it has not been synthesised.^{21 22} It is also not clear whether these PC interventions have been funded through external donors or local resources, which may influence their sustainability and local capacity building.²³

HPPC, which aims to empower both individuals and communities, is crucial in low-income settings, where access to high-quality PC services is limited. A better understanding of HPPC interventions in low-income African countries could be useful to identify service gaps and guide the development of these essential services. Our objective was to conduct a scoping review of the consequences of HPPC in low-income African countries.

METHODS

Protocol and registration

We conducted a scoping review to map the core ideas behind our topic of interest as well as the primary sources and types of evidence available.²⁴ We adhered to Arksey and O'Malley's widely used methodological approach to ensure accuracy and replication.²⁵ We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA) guideline to guide the reporting of the research process and results.²⁶ The initial protocol was not registered.

Eligibility criteria

Inclusion criteria

We included articles published in French, English and Spanish between 2005 and 2022. The start year was 2005, which is when the World Health Assembly identified PC as an urgent humanitarian need, sparking advancements in the field.²⁷ Included studies had to be conducted in low-income African countries, as defined by the World Bank. These 22 countries are Burkina Faso, Burundi, the Central African Republic, Chad, the Democratic Republic of the Congo, Eritrea, Ethiopia, The Gambia, Guinea-Bissau, Liberia, Madagascar, Malawi, Mali, Mozambique, Niger, Rwanda, Sierra Leone, Somalia, South Sudan, Sudan, Togo and Uganda.²⁸

The studies had to assess the consequences of an HPPC intervention. Thus, interventions had to relate to PC and at least one principle of the Ottawa Charter for Health Promotion.⁷ PC has been defined as 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment

and treatment of pain and other problems, physical, psychosocial and spiritual'.²⁹ HPPC interventions were defined as PC interventions related to at least one of the main goals or axes of the Ottawa Charter for Health Promotion: (1) build healthy public policy; (2) create supportive environments; (3) strengthen community action; (4) develop personal skills; (5) reorient health services; (6) reduce health inequity; (7) empower (for more details, see principles of HPPC above). The content of the articles was analysed by experts in health promotion and PC to identify the articles related to the field of HPPC.

Interventions were defined as organised systems of action that aim, in a given environment and given time period, to modify the foreseeable course of a phenomenon in order to correct a problematic situation.³⁰ In light of this definition, interventions could be, for example, a care model (eg, community-based PC provided by volunteers) or a short-term programme aimed at strengthening the care model (eg, a training programme). Consequences were defined as positive or negative changes that occur in a social system as a result of adopting and implementing an intervention.³¹ These changes triggered by the intervention could affect various types of actors involved in developing, providing and using PC (eg, patients, informal caregivers, healthcare managers, community health workers (CHWs), providers or other professionals). Peer-reviewed articles presenting empirical evidence collected through studies using either qualitative, quantitative or mixed methods were included.

During the selection process, the research team members applied these definitions to determine whether an article met the inclusion criteria related to HPPC interventions. At least two members of the team reviewed and verified all articles. The team included an expert trained in health promotion and the Ottawa Charter for Health Promotion. This researcher guided and trained the team throughout the process to ensure that all team members had a comprehensive understanding of the Ottawa Charter. Weekly meetings were conducted to discuss the definitions of the Charter and their applications in this context.

Exclusion criteria

We excluded studies conducted in middle-income or high-income countries in Africa, as defined by the World Bank.²⁸ We also excluded publications that (1) were not peer-reviewed; (2) did not provide empirical evidence collected through studies using either qualitative, quantitative or mixed methods; (3) only described an intervention or (4) were not evaluating an HPPC intervention.

Information sources

The search strategy was developed with the help of a professional librarian with experience in health. First, we manually searched the Cochrane Library, Campbell Collaboration, International Prospective Register of Systematic Reviews and the grey literature looking for

Table 1 Inclusion and exclusion criteria

| | Inclusion criteria | Exclusion criteria |
|----------------------|---|---|
| Language | French, English or Spanish | Other languages |
| Dates | 2005–2022 | Before 2005 |
| Country | Low-income countries in Africa | Other countries |
| Publication type | Peer-reviewed articles presenting empirical data | Protocols, editorials, guidelines, intervention descriptions and interviews |
| Study type | Experimental or observational studies, including qualitative, quantitative or mixed methods | Articles that did not present a design or methods. Articles that did not present empirical evidence. |
| Intervention type | Health promotion interventions in PC as presented in the Ottawa Charter targeting any age or illness (eg, HIV, cancers). | Interventions in PC not related to the field of health promotion as presented in the Ottawa Charter. |
| Targeted entity | Interventions targeting actors involved in PC, such as patients, informal caregivers, healthcare managers, community health workers, providers or other professionals | None |
| Outcomes | Any changes measured | Studies looking only at outcomes related to pain reduction or number of admissions |
| PC, palliative care. | | |

a review on the identified topic, but we were unable to locate any existing or forthcoming reviews. Then, we searched CINAHL, PubMed and PsycINFO in March 2023.

Search

With the help of the professional librarian, we developed a list of keywords and MeSH terms for concepts related to “health promotion,” “palliative care” and “low-income African countries”. Online supplemental file 1 features the full electronic search strategy for the three databases, including search terms, so that our strategy could be replicated.

Selection of evidence sources

The results were imported into Covidence, a software program for managing literature reviews.³² Two reviewers independently carried out a two-step review process (title/abstract and full text). They judged the titles and abstracts of potentially relevant studies based on the inclusion and exclusion criteria (table 1). They also looked for relevant publications in the reference lists of included papers. Disagreements between reviewers were resolved via discussion. When disagreements persisted, a third researcher was brought into the discussion.

Data charting process and data items

Once the articles were selected, one researcher extracted the relevant data using a data extraction form custom-designed in Excel. The following information was extracted to summarise the articles: name of the scientific journal, year of publication, authors' countries of academic affiliation, source and type of funding, language, study country, aims, design, setting, targeted illness, participants, number of participants, outcomes measured, general results and study results linked to

health promotion. We considered where the authors' institutional affiliations were based (local vs abroad). If an article assessed multiple interventions in multiple countries, we only included the data emerging from the low-income African countries. A second researcher validated the data extracted by the first, and disagreements were settled through discussion to reach a consensus. When the disagreements persisted, they involved a third researcher.

Synthesis of results

General and specific information was described and summarised to chart the available literature. We conducted a thematic analysis using themes based on the principles of the Ottawa Charter for Health Promotion. The results section of this paper aims to answer the questions:

- ▶ What are the characteristics of the included articles?
- ▶ Which populations and illnesses were targeted in the studies?
- ▶ What are the links between the interventions studied and the concepts of the Ottawa Charter for Health Promotion?
- ▶ What are the consequences of the HPPC interventions studied?
- ▶ What are the sources of funding for the HPPC interventions studied?

Patient and public involvement

Neither patients nor the general public were involved in the planning, execution, analysis or reporting phases of this literature review.

RESULTS

Selection of sources of evidence

The search strategy led to a total of 2259 articles. After duplicates were eliminated, 1640 articles were left for

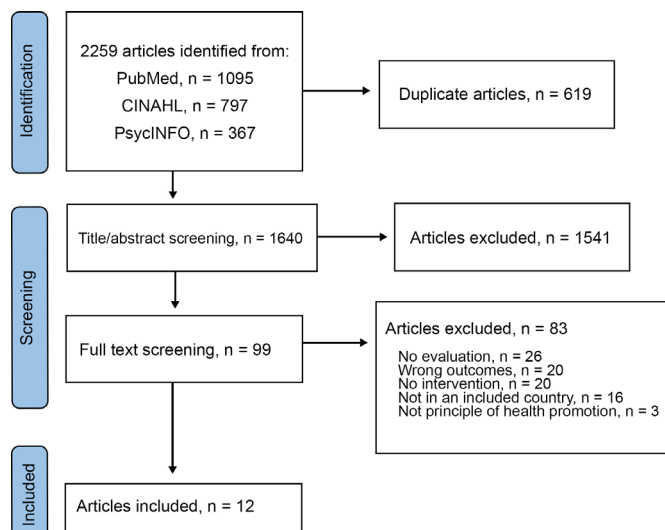


Figure 1 PRISMA diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

title/abstract screening. We discarded 1541 articles during the initial screening because they did not meet the inclusion/exclusion criteria. Thus, 99 full texts were screened. Of these, 12 articles met our inclusion/exclusion criteria and were included in the analysis. [Figure 1](#) presents the PRISMA diagram. It provides the number of articles screened, assessed for eligibility and included in the review, along with reasons for exclusions at each stage.

What are the characteristics of the included articles?

All the studies were published after 2009 and in English. Seven studies reported using mixed methods.^{22 33–37} Four used qualitative methods, including photovoice.^{38–41} More than half of the studies were cross-sectional. One study reported using rapid evaluation techniques.⁴² Four used pretraining and post-training knowledge tests.^{22 34 35 37} Jane Bates *et al* conducted a prospective observational study.²¹ All but three had a sample size below 70 participants, despite the reported use of mixed-methods designs ([table 2](#)).

For the majority of the articles, the first author's academic affiliation was not based in the local country where the study was conducted. Six articles had a first author based in the UK and three had a first author based in the USA. Three articles had a first author with an academic affiliation in the country where the study was conducted. Two articles did not include any authors from the country where the study was conducted. See online supplemental file 2 for more specific information on authorship.

The studies were conducted in a narrow range of settings. Of the 22 low-income countries in Africa, we found studies from only three countries: Malawi, Rwanda and Uganda (see [figure 2](#)). Of the six studies conducted in Malawi, three examined the same programme, that is, the St. Gabriel's Hospital Community PC, based in a rural referral hospital in the city of Namitete.^{22 33 34} Of

the seven studies conducted in Uganda, three emerged from Hospice Africa Uganda in the Kampala region^{39 40 43} and one from Mulago Hospital, also in Kampala.³⁵ The multicountry study partly conducted in Rwanda included 3 of that country's 47 hospitals.³⁷ This was the only study that included a francophone setting. None of the studies were conducted in West Africa.

Which populations and illnesses were targeted in the studies?

The majority of the included studies assessed interventions targeting all types of life-threatening illnesses. Two interventions targeted people living with HIV who also had cancer.^{39 40} One intervention targeted people with HIV only⁴¹ while another was implemented in one of the areas hardest hit by the AIDS pandemic.^{42 43} Two interventions targeted adults who had received a diagnosis of advanced cancer^{21 38} and one was about the development of children-specific PC.⁴³

The majority of the articles did not clarify whether and how the programmes under study addressed sex and gender issues. Mburu *et al*⁴¹ highlighted the limited involvement of men in PC; initially, community-based PC was provided only by women, but men were increasingly involved in physically demanding tasks.

What are the links between the interventions studied and the concepts of the Ottawa Charter for Health Promotion?

The studies touched on between one and five of the health promotion concepts identified in the Ottawa Charter for Health Promotion (online supplemental file 3). Across the studies, we found that volunteers and caregivers played a key role in HPPC. Interventions seeking to strengthen community action by reinforcing the skills and knowledge of CHWs (usually unpaid volunteers) recommended by village leaders were more frequent. In this sense, the interventions drew on existing human resources in the community to enhance self-help and social support. However, unlike what is recommended in the Ottawa Charter for Health Promotion, their involvement did not translate into community action in setting priorities, making decisions and planning strategies to achieve better health at the system level.

About half of the interventions were aimed at developing personal skills through patient and family education. Only two studies were related to health promotion policy (eg, legislation, fiscal measures, taxation and organisational change).^{37 41}

Interventions seeking to reorient health services mostly did so by strengthening home-based care. Changes in professional education, training and culture were addressed in two studies.^{35 37} For instance, in Grant's study, complex beliefs in the efficacy of traditional medicine, negative views about morphine and ideas that curses are actual causes of disease were addressed and included in training and awareness sessions.³⁷ In Downing *et al*'s study,³⁵ a significant improvement was seen in nurses' confidence after receiving training that addressed

Table 2 Characteristics of included studies

| First author (year) | Low-income countries | Setting | Study aim | Methods | Study participants |
|--------------------------------|----------------------------|---|---|---------------|--|
| Nesbit, 2015 ³³ | Malawi | St. Gabriel's Hospital Community PC, Namitete | Evaluate a PC training programme for CHWs | Mixed methods | 20 CHWs |
| Nesbit, 2019 ³⁴ | Malawi | St. Gabriel's Hospital Community PC, Namitete | Evaluate the effectiveness of a training programme over a 5-year period | Mixed methods | 60 CHWs |
| Wilson, 2020 ²² | Malawi | St. Gabriel's Hospital Community PC, Namitete | Evaluate a training programme integrating technology into rehabilitation care delivery | Mixed methods | 60 CHWs |
| Bates, 2018 ³⁸ | Malawi | Tiyanjane Community PC team in Blantyre | Explore participants' perspectives of well-being and the contribution of PC following a diagnosis of advanced cancer | Qualitative | 13 (patients with advanced cancer, family caregivers) |
| Jane Bates, 2021 ²¹ | Malawi | Queen Elizabeth Centre Hospital in Blantyre | Investigate total household costs of cancer-related healthcare after a diagnosis of advanced cancer, with and without receipt of PC | Quantitative | 150 households, comprising patients and caregivers |
| Amery, 2009 ⁴³ | Uganda | Children's PC service at Hospice Africa Uganda in Kampala | Evaluate a children's PC service designed specifically for a resource-poor sub-Saharan African setting. | Mixed methods | 33 (children using services, parents/legal caregivers, staff) |
| Jack, 2011 ³⁹ | Uganda | Community Volunteer Worker programme at Hospice Africa Uganda in Kampala | Evaluate the impact of a PC CHW programme | Qualitative | 64 (patients, staff, CHWs) |
| Jack, 2012 ⁴⁰ | Uganda | Community Volunteer Worker programme at Hospice Africa Uganda in Kampala | Evaluate the motivation for and the personal impact of being a CHW | Qualitative | 43 (CHWs, staff) |
| Mburu, 2013 ⁴¹ | Uganda | Networks Project and other community-based care initiatives in Mbale and Jinja districts | Identify community system elements that facilitate the provision of community-based PC to people living with HIV | Qualitative | 65 (people living with HIV, family, providers) |
| Downing, 2016 ³⁵ | Uganda | Mulago Hospital, Kampala | Evaluate the impact of the PC link nurse programme | Mixed methods | 21 (nurses and other healthcare staff) |
| Grant, 2011 ⁴² | Uganda, Malawi (and Kenya) | Home Based Care Charitable Trust in Blantyre, Malawi Kitovu Mobile PC service in Masaka, Uganda | Describe the perspectives of patients, families and the local community on the impact of three community-based PC interventions | Mixed methods | 150 participants (patients, caregivers, providers, volunteers and community leaders) |

Continued

Table 2 Continued

| First author (year) | Low-income countries | Setting | Study aim | Methods | Study participants |
|---------------------------|---------------------------------------|--|--|---------------|---|
| Grant, 2017 ³⁷ | Uganda, Rwanda (and Zambia and Kenya) | Government hospitals (three per country) | Evaluate a four-pillared approach of advocacy, staff training, service delivery strengthening, and international and regional partnership. | Mixed methods | 781 providers given precourse and postcourse survey |

CHWs, community health workers; PC, palliative care.

bereavement support, spiritual care, caring for children and supporting families.

Few studies explicitly addressed the concept of empowerment, even though it is one of the main objectives of health promotion. For example, in Mburu's study, the goal of the project was to 'empower people living with HIV to be able to provide care to their peers'.⁴¹ In Grant's multicountry study, senior staff believed that the integration of PC empowered patients, allowing them to plan for the future. They spoke of no longer feeling helpless because they could do something for patients and engage with families better.³⁷

The prerequisites for health mentioned in the Ottawa Charter were sometimes addressed (eg, food, income, peace and shelter). Amery's study concluded that PC for children should provide medication for symptom control, support for food and basic needs, play and learning facilities, child protection and systems for patient education, communication and follow-up.⁴³ In Bates' study, PC improved well-being by providing pain and symptom management, thereby enabling patients or

family caregivers to resume some of their household and income-generating tasks.³⁸

What are the consequences of the HPPC interventions studied?

Six studies examined the effects of a training programme^{22 33–35 37 42} and found it increased the knowledge and abilities of the learners (ie, CHWs and nurses). According to the four studies that evaluated the effects of receiving PC from the viewpoints of patients and carers, PC decreased physical and emotional symptoms by offering pain and symptom management.^{38 39 42 43} The two studies interested in CHWs' motivation for performing this role indicated that assisting others and receiving recognition were factors that encouraged them to maintain their commitment to the job.^{40 42} One study assessed the community systems supporting people living with HIV; its results revealed the extensive role of community systems, which included nutritional and bereavement support⁴¹ (see online supplemental appendix 1 for a summary of the results).

What are the sources of funding for the HPPC interventions studied?

To better understand the potential sustainability of HPPC interventions, we examined the sources of funding for these interventions. Most of the interventions included in this review were supported through British or American temporary funding. The Rupley-Church International Relations Grant, USA, contributed to funding a training programme in Malawi that resulted in three of the articles included in this study.^{22 33 34} The link nurse programme in Uganda was funded for 2 years by the Diana Princess of Wales Memorial Fund, based in the UK.³⁵ The same fund sponsored the Malawi Home Based Care Charitable Trust,⁴² which was terminated in 2018 (www.malawihbc.org). Some authors expressed worries regarding the dependency of PC on external donors. According to Bates *et al*,³⁸ the fact that centres of excellence for PC in Malawi remained heavily reliant on external donor funding challenged their sustainability while Jack *et al*³⁹ highlighted that the community-based programme offered by Hospice Africa Uganda was at risk of financial instability that could impact the programme's sustainability.

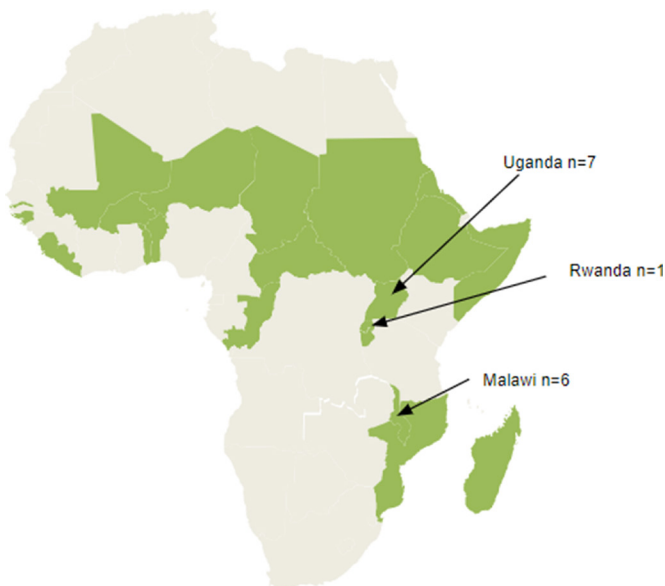


Figure 2 Map illustrating the four countries where the included studies were conducted, among the 22 low-income African countries in green. Some articles included multiple countries, hence the total (n=15) is more than the number of included articles (n=12).

DISCUSSION

This scoping review revealed that the state of knowledge on the consequences of HPPC in low-income African countries is scant. Research efforts have been concentrated in a few countries, namely Malawi, Uganda and Rwanda. Five studies reported that PC training programmes increased the knowledge and abilities of CHWs and nurses.^{22 33–35 42} Patients and caregivers reported that PC improved their condition by offering symptom and pain management, as well as holistic care.^{38 39 42 43} Results suggest that communities have the potential to play important roles in nutritional and bereavement support.^{39 40} CHWs were motivated to assist others,^{40 42} and they appreciated training from health professionals.^{22 33 34} However, dealing with logistics, coordination, transportation, limited resources and difficult working conditions was challenging for CHWs.^{22 33 34 39 40} The involvement of men in PC provision was also limited in some contexts.⁴¹ More formal resources are needed to develop HPPC and accompany people at the end of their lives through a holistic approach.

Dominance of community-based approaches within HPPC: navigating the challenges

The WHO has recognised the potential merits of deploying CHWs in the provision of PC in African countries.^{44 45} This helps to explain why most of the included articles relate to the effects of CHW training programmes.^{22 33 34} CHWs' motivations for performing this role^{40 42} and the effect of their work on patients and families.³⁹ All studies concluded that the effects of the CHW programmes were positive. However, only two studies adopted a quasi-experimental design (pre-post knowledge test).^{22 33} Some of the included studies pointed to challenges around CHW recruitment and retention. Jack *et al*³⁹ observed that only nine of the original 40 volunteers in the first cohort of CHWs for the Hospice Africa Uganda programme were still active after 3 years. Long distances and the difficulty of coping with multiple dialects were stated as barriers. In line with this review, other investigations have identified fatigue and lack of adequate psychological support as further obstacles to CHW retention.⁴⁶

Almost no representation of Northern, Western and Central countries, nor French-speaking countries within HPPC research

Out of 22 low-income African countries, only 3 countries—Malawi, Uganda and Rwanda—were represented in the 12 studies included, with Uganda accounting for almost half of them. One city (Kampala, Uganda) was the setting for three studies, while another (Namitete, Malawi) was the setting for three. Except for one multi-country study that included Rwanda, the other investigations were undertaken in English-speaking countries and, in most cases, with the participation of English and American scholars. Similarly, a review of publications in Africa between 2002 and 2018 revealed that South

Africa, Uganda, Kenya and Malawi, all English-speaking countries, accounted for two-thirds of the interventions seeking to incorporate PC into health systems, with South Africa hosting about one-third of them.¹⁷ Over the past decade, there have also been indications of intra-sub-Saharan African collaboration. For example, in 2013, four physicians from Niger were trained in PC at Hospice Africa Uganda.⁴⁷

We were not able to identify relevant studies conducted in Northern, Western or Central African countries. Moreover, French-speaking low-income African countries were not represented in the literature. This result is consistent with the conclusion of Rhee *et al*.⁴⁸ These authors claim that the Palliative Care World Map developed by Wright *et al* has a positive correlation with publications on PC development.⁴⁹ This map presents four categories of countries: (1) countries with no identified hospice-PC activity; (2) countries with capacity-building activity but no service; (3) countries with localised PC provision and (4) countries where PC activities are getting closer to being integrated with mainstream service providers.⁴⁹ Chad, Guinea-Bissau, Mali and Togo belong to the first category (no identified hospice-PC activity) while the Democratic Republic of the Congo and Madagascar belong to the second (capacity-building activity).⁴⁹

In the future, it would be interesting to examine whether countries with higher PC development have more HPPC initiatives. Moreover, future studies could examine whether there is a difference in types of HPPC interventions between countries with low income and high income.

Opportunities to develop HPPC and build healthy public policy in low-income African countries

PC delivery at home is the main approach in Africa.⁵⁰ This model is heavily reliant on non-governmental, external and sometimes faith-based organisations.⁵¹ Despite the fact that CHWs, most often volunteers,⁵² may appear to be a solution worldwide, such a model lays a tremendous burden of duty on them. It should be noted that CHW training requirements and scope of practice vary between countries and interventions. Depending on the nature of their roles and responsibilities, it is important to equip CHWs with the appropriate ongoing support to assist them in dealing with the multifaceted aspects of palliative and end-of-life care.⁵³ For example, open training resources about various aspects of palliative and end-of-life care are available for free online.⁵⁴

One of the main axes of the Ottawa Charter for Health Promotion aims to build healthy public policy.⁷ This approach is coherent with the WHO's four public health pillars to integrate and establish PC (government policy, PC education for health staff and the public, drug availability and a national strategy to implement PC).^{55 56} However, only one study was based on the WHO's strategy, using the quadripartite approach of policy, education, drug availability and implementation to integrate PC as part of government-funded services in Kenya, Rwanda,

Uganda and Zambia. The study involved English trainers and funding.³⁷ In Uganda, for example, strides have been made to integrate PC into the public healthcare system. In March 2021, the health ministry directed all public hospitals to establish PC units.⁵⁷ It is not possible to say with certainty that the WHO strategy for integrating PC led to the inclusion of PC initiatives in government policies, but the quadripartite approach might be one way to help PC become less dependent on outside funding. As such, developing strategies to implement PC in national public policy seems to be a promising orientation.

One of the main axes of both the Ottawa Charter for Health Promotion and Kellehear's approach is the strengthening of community action.^{5 7} This scoping review highlights the need to explore how technology can be used to empower CHWs and strengthen their role in HPPC. In Wilson *et al*'s study, CHWs were trained to send text messages in real time to the nurse coordinator.²² All participants reported that the training programme helped them review skills and understand how to use technology. Technology could be useful to strengthen community action within PC in other settings.

Both the Ottawa Charter for Health Promotion and Kellehear's approach focus on achieving equity in health.^{5 7} A few studies in this review showed how HPPC can improve health status and promote equal opportunities. Jane Bates *et al* showed that vulnerable households in low-income countries are subject to catastrophic health-related costs following a diagnosis of advanced cancer, and that PC was associated with substantially reduced dissavings.²¹ In another study, Bates *et al* showed that PC can improve patients' function, thereby facilitating income generation activities that were not previously possible due to illness.³⁸ Moreover, some studies showed that strategies can be designed to provide PC, including free drugs, food and learning activities, to vulnerable populations (eg, children, rural populations and people with HIV/AIDS).⁴³ More empirical evidence on how HPPC can influence health equity would be useful to raise awareness among leaders and policy-makers about how to improve service delivery.

Addressing the research gaps on HPPC in low-income African countries

Overall, literature about HPPC interventions in low-income African countries is scarce. Because most of the included studies used cross-sectional designs or short pre-post designs, we were unable to shed light on the long-term impacts of the interventions. The majority of studies used mixed methods, but the different components did not always adhere to the quality criteria of each type of method involved, as recommended by the Mixed Methods Appraisal Tool.⁵⁸ Moreover, the sampling sizes were quite limited, and no studies conducted a formal process evaluation or cost analysis. Researchers could, therefore, consider carrying out longitudinal studies with larger sample sizes and cost analysis. Such research could help strengthen the evidence on implementation

challenges in real-life settings, as well as on the effectiveness and cost-effectiveness of HPPC in low-income African countries, to help convince governments to integrate it into their service offerings.

The majority of the studies included in this review were led by researchers from the UK and the USA. In fact, some articles did not include any coauthors from the countries where the studies took place. Promoting African-led research could contribute to the development of local research capacity on HPPC, as African researchers possess local knowledge and insights that can be valuable when evaluating interventions. They are well positioned to understand and incorporate the cultural nuances and diversity in their communities. Such an insider's perspective can enhance the relevance of research outcomes.

The fact that the studies and interventions evaluated were mostly supported through external projects with temporary funding also raises questions regarding the development of sustainable HPPC and research in low-income African countries. A sudden withdrawal of funds could disrupt ongoing research and health programmes. According to Kasproicz *et al*, long-term investment from international donors and increased funding commitments from African governments are needed to create a critical mass of local capacity and to sustain research hubs that can address the challenges of complex health systems, such as HPPC.²³

Limitations

There are some limitations to our review. First, we only included publications in English, French and Spanish. It is possible, yet unlikely, that we missed studies in other languages. Moreover, we limited the time period to 18 years. Second, it is possible, though somewhat improbable, that some articles published before that time period could have contributed some insight on this issue. Third, there may have been a publication bias. We could not include information on interventions that were not studied and thus were not documented in scientific articles. Lastly, many studies did not include very detailed descriptions of the intervention models under study, which limited our ability to analyse their content.^{22 35 38 42 43}

CONCLUSION

All 12 papers included in this review were conducted in only three countries out of a potential 22. We discovered that USA-based and UK-based funders and researchers play a major role in the implementation and assessment of HPPC interventions based on health promotion principles in low-income countries in Africa. Despite the fact that empowerment is the primary goal of both the Ottawa Charter for Health Promotion and Kellehear's approach, few interventions evaluated explicitly addressed it. More empirical evidence on access to high-quality HPPC and on how HPPC can influence health equity in low-income African settings would be useful to raise awareness among leaders and policy-makers. This analysis reveals

that research on HPPC is still in its early stages and that other research areas need to be investigated to guide the development and sustainability of HPPC in low-income African countries. These needs include more robust research designs, longitudinal studies and process evaluations to document how HPPC interventions unfold in real-life settings.

Although PC is a human right and an ethical duty of health institutions, it is nevertheless denied to the majority of those in need, even vulnerable populations such as children. At this time of growing PC development in Africa, the emphasis needs to be on both expanding PC services and integrating them into health systems. To accomplish this huge challenge, the principles of the Ottawa Charter for Health Promotion and Kellehear's approach have proven to be useful, but still need to be fully mobilised.

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