

# Landscape of Palliative and End-of-Life Care in West Africa: Scoping Review of Barriers to the Offer and Demand for these Care and Health Services

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**Abstract:** *Objective:* In West African countries, palliative care (PC) and end-of-life care (EoL) are poorly integrated into national healthcare systems and are underused. This scoping review aims to map the landscape of PC and EoL in West Africa by identifying barriers to supply and demand for PC and EoL health services. *Methods:* Five electronic databases (Medline, Cinahl, Web of Science, Cochrane and PyschInfo) were searched to identify relevant studies published between 2010 and 2022. The sources identified included original articles published from research carried out in West African countries. *Results:* 58 publications were considered relevant. 139 barriers were mapped and grouped under five themes: (i) political governance of the healthcare sector; (ii) healthcare systems and facilities; (iii) attitudes, practices, and knowledge of healthcare providers; (iv) relationship to care and care pathways; and (v) finance and economics. 81% of the publications reviewed used a qualitative approach. *Conclusion:* As well as providing education on SP and EoL and increasing funding and subsidies for SP and EoL care, West African countries should consider integrating SP into primary healthcare. Future work could focus on the additional efforts needed to improve universal healthcare coverage and the quality of palliative and end-of-life care services, particularly in the French-speaking countries of West Africa.

**Keywords:** palliative care, end-of-life care, barriers, West Africa

## 1. Introduction

Palliative care (PC) means assessing and alleviating patients' pain symptom management and social distress (1). The definition of the PC varies depending on the approach adopted by each country. However, the International Association of Hospice and Palliative Care (IAHPC) defines it as care that includes prevention, early identification, assessment, and management of physiological, psychological, and spiritual symptoms and social needs (2,3).

Over the past few years, PCs, including end-of-life care (EoL), have been developed and implemented in several sub-Saharan African countries to improve the quality of healthcare (1,4-8). The literature has revealed the consolidation of PC and EoL services through advocacy work by regional and national CP associations (6,9). However, PCs and EoLs are not well integrated into national health programs and systems (10-12). However, efforts are being made to solve the problem and increase access to PCs and EoLs in these countries. Identifying the obstacles to PC and/or EoL offer and demand in these countries is important. This study aims to contribute to the success of the World Health Organization (WHO) strategy based on increasing access to PC services through their integration into national

healthcare systems.

This review described the possible obstacles to providing and using PCs and/or EoL services for adults in West Africa. In West Africa, particularly in the French-speaking region, there is a lack of data on PCs and EoL, which led to the selection of scope assessments, as described in another systematic literature review (13). Indeed, the scoping review is interested in assessing the breadth and depth of the literature to identify critical topics and knowledge needs that will provide ways for future research. We present this article by the PRISMA-ScR reporting checklist.

## 2. Methods

### 2.1. Research design, objectives, and strategy

Research is a scoping review of the literature related to CP and/or EoL in adult patients in West Africa. It aims to provide a narrative synthesis of barriers to the offer and demand of PC and/or EoL services in West African countries. In broad lines, the review sheds light on the purpose and content of Ph.D. research on treatment attrition among PC and/or EoL patients. Headings for systematic reviews and the extension of meta-analyses for scoping reviews (PRISMA-ScR) were considered (14).

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Sources should meet several criteria to be included in the review (Table 1). Identifying relevant sources involved three steps. First, limited research on PubMed and Google Scholar, conducted from June to July 2022, using terms and synonyms relating to Population (nurses/ physicians/

patients/ families), Intervention (PC and EoL), and Context (Obstacle to offer, demand care). From this initial research, key research terms were identified from the titles, abstracts, and index terms of the sources retrieved. A full research strategy was then developed.

**Table 1 :** Criteria for inclusion and exclusion of data sources

| Criteria          | Inclusions   | Exclusions   |
|-------------------|--|--|
| Language          | English, French  | All other languages  |
| Types of studies  | Qualitative, quantitative and mixed-methods studies on the subject                       | Letters, commentaries, conference abstracts, editorials, doctoral theses, or any type of proceedings   |
| Types of sources  | Original research articles with full texts   | Literature review  |
| Regions/Countries | West Africa  | All other regions/countries  |
| Period            | Between 2010 and 2022  | Before January 1, 2010, and after December 31, 2022  |
| Focus             | The provision and use of palliative and/or end-of-life care for adults in West Africa    | The provision and use of palliative and/or end-of-life care for children                               |
| Types of results  | Sources reported barriers to the provision and use of palliative and/or end-of-life care | Sources did not report barriers related to the provision and use of palliative and/or end-of-life care |

MEDLINE, CINAHL, Web of Science, Cochrane, and PyschInfo were the databases searched between September and October 2022 to identify published, peer-reviewed sources. Research strategies used in MEDLINE are shown in

Table 2. Reviewing the references of relevant sources selected in the second research, we found other sources that also met the eligibility and exclusion criteria.

**Table 2 :** Illustration of the search strategy in MEDLINE

| Steps | Searches Strategic   |
|-------|--|
| 1     | (Health worker or nurses or provider or patient or administrator or professional or famil*).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]                |
| 2     | (Palliative or palliative care or end of life or end-of-life or end-of-life care or palliative care needs).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] |
| 3     | (Provide or provision or deliver* or utilization or utilization or service or reference or health system).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]  |
| 4     | Exp Africa/  |
| 5     | 1 and 2 and 3 and 4  |

**2.2. Selection of articles**

Research results were cataloged using Mendeley referencing software. Once duplicates had been eliminated, two reviewers examined and selected sources using Rayyan© web software for literature reviews. Titles and abstracts were examined, and relevant sources were retained. In the absence of abstracts, the entire source was considered before being retained or not. The full texts of the retained sources were then read, and the pertinent sources were retained again. The results of the two reviewers were checked by a third reviewer.

**2.3. Data cartography**

Upon completing the source review, the data was extracted from the selected sources and mapped according to key conceptual categories (year of publication; design; methodology used; participants; source of data collection, and key findings). This was done using an Excel tool developed specifically for this purpose, adapted by the first author through an iterative process with the sources. All mapped data was independently verified by a second reviewer.

**2.4. Results summary**

The first author conducted a review of the content of the selected studies, looking for recurring themes and findings, then organized them under a list of thematic headings. Key topics were discussed and agreed with the second author. A narrative synthesis was produced and used as the basis for this article.

**3. Results**

**3.1. Selecting data sources**

A total of 58 publications (15-72) were considered pertinent to this review, as shown in the analysis diagram (Figure 1). Six publications with different results were written by the same author in different journals at different times (15, 16, 23, 27, 54, 70). Such publications were examined in isolation for data extraction.

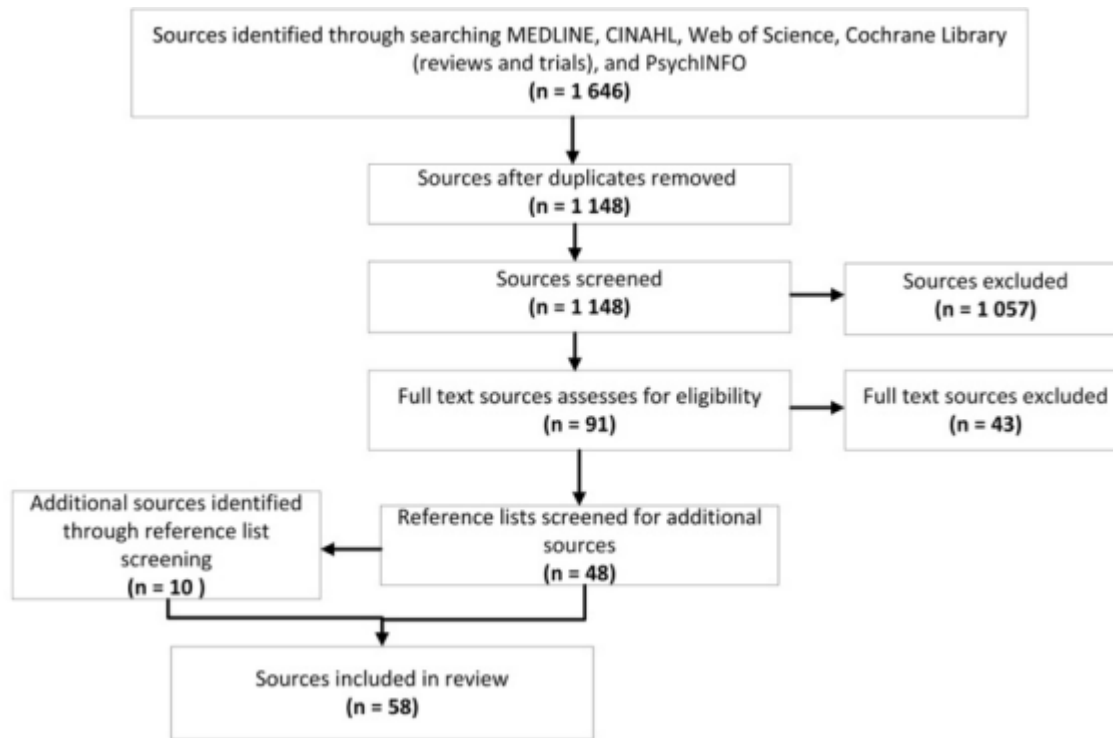


Figure 1 : PRISMA-ScR flow chart of articles retrieved, filtered and selected for review

### 3.2. Publication details included

Table 3 presents the characteristics of the included publications. They dealt with PC (n = 45/58, 77.6%), EoL (n = 6/58, 10.3%), and both (n = 7/58, 12.1%). Half (50%, n = 29/58) addressed the issue of PC and/or EoL in patients with advanced cancers. Of these, the majority (n = 13/29, 44.8%) did not specify the type of cancer in question; eight (n = 8/29, 27.6%) focused on breast cancer, and three (n = 3/29, 10.3%) specified prostate cancer, thus integrating the gender aspect with a dominance of female breast cancer. Other diseases covered in the publications included HIV/AIDS (n = 4/58, 6.9%) and terminal renal insufficiency (n = 2/58, 3.4%). Other studies focused on the association of diseases, including all life-limiting chronic diseases (n = 15/58, 25.9%), cancer and HIV/AIDS (n = 4/58, 6.9%), and cancer and diabetes (n = 1/58, 1.7%). Three publications did not report a diagnosis.

The highest number of articles were published in 2018 (n = 9/58, 15.5%), and 2019 (n = 9/58, 15.5%). 81% (n = 47/58) were qualitative studies. Seven, or 12.1% (n = 7/58) were mixed studies. As Figure 2 shows, the publications identified barriers to the offer and demand of PCs and/or EoLs in ten countries, seven of which were French-speaking (n = 12/58, 20.7%) and three of which were English-speaking (n = 46/58, 79.3%). Nearly half of the studies conducted in

English-speaking countries (67.4%, n = 31/46) came from Nigeria, followed by Ghana (30.4%, n = 14/46). The last English-speaking country represented was Liberia (2.2%, n = 1/46). Burkina-Faso was the first French-speaking country represented with n = 3/58 (5.2%) publications, followed by Benin, Togo, and Senegal, respectively with the same number of publications (n = 2/58, 3.4%).



Figure 2: Map showing West African countries where data sources report barriers to the provision and use of palliative and end of life care

Table 3: Characteristics of publications included in review

| Sources                               | Years | Country | Study design      | Treatments covered | Disease(s) covered              | Aim of the study   |
|---------------------------------------|-------|---------|-------------------|--------------------|---------------------------------|--|
| Adisa, Rasaq and al. (2019) [35]      | 2019  | Nigeria | Mixed study       | Palliative Care    | Life-limiting chronic illnesses | To explore the involvement of pharmacists in selected tertiary hospitals in Nigeria in palliative care (PC). It also sought to assess their knowledge and attitude towards PH as well as factors hindering pharmacists' involvement in PC. |
| Afolabi, Oladayo A and al. (2022)[33] | 2022  | Nigeria | Qualitative study | Palliative Care    | Life-limiting chronic illnesses | To identify preferences and expectations for primary palliative care among people living with serious  |

|  |      |         |                    |                               |                                 |   |
|--|------|---------|--------------------|-------------------------------|---------------------------------|---|
|  |      |         |                    |                               |                                 | illness and their families and the willingness of primary health care providers to provide primary palliative care in Nigeria.  |
| Agom, D. A. and al (2020)c [23]                | 2020 | Nigeria | Qualitative study  | Palliative Care               | Life-limiting chronic illnesses | Exploring PC education, while examining its impact on the delivery and use of services from the point of view of healthcare professionals, patients, and their families.  |
| Agom, DA and al. (2020)a[27]                   | 2020 | Nigeria | Qualitative study  | Palliative Care               | Cancers                         | To explore how the social complexities and organisation of healthcare influenced the decision-making process for the use of oncology and PC in a Nigerian hospital.   |
| Agom, David A and al. (2020)b[15]              | 2020 | Nigeria | Qualitative study  | Palliative Care               | Cancers                         | Understanding organizational culture to identify organizational enablers and inhibitors of PC provision and use in a Nigerian context.  |
| Agom, David A and al. 2022) [70] (             | 2022 | Nigeria | Qualitative study  | Palliative & end of life care | Life-limiting chronic illnesses | To explore the impact of the physical environment (i.e. place and people) on staff and service users and how these influence experiences of palliative and end of life care provision and use in a Nigerian hospital setting.                                     |
| Agom, David A. and al. (2019)a[54]             | 2019 | Nigeria | Qualitative study  | End of life care              | Cancers                         | To explore the ways in which cancer patients, their families and healthcare professionals (HCPs) construct meaning from their life-limiting illnesses and the impact of this on the provision and use of PC in a Niger hospital.                                  |
| Agom, David A. and al. (2019)b[16]             | 2019 | Nigeria | Qualitative study  | Palliative & end of life care | Life-limiting chronic illnesses | Identify the PC services available in a Nigerian hospital and how they are organized.   |
| Ajisehiri, Whenayon Simeon and al. (2019) [36] | 2019 | Nigeria | Quantitative study | Palliative & end of life care | HIV/AIDS                        | To assess healthcare professionals' knowledge, attitude and practice towards palliative care for PLWHA.   |
| Ajisehiri, Whenayon Simeon and al. (2021) [46] | 2021 | Nigeria | Qualitative study  | Palliative Care               | HIV/AIDS                        | Evaluate the PC services offered and referral services available for PLWHA in healthcare institutions.  |
| Akuoko, Cynthia P and al. (2022)[40]           | 2022 | Ghana   | Quantitative study | Palliative Care               | Breast cancer                   | To understand the perceived and expressed needs of women with advanced breast cancer.   |
| Alexander, CS and al. (2015) [19]              | 2015 | Nigeria | Qualitative study  | Palliative Care               | HIV/AIDS                        | To describe the training for multidisciplinary teams responsible for integrating care management in HIV clinics in order to treat the pain of people living with HIV in Nigeria.  |
| Awoonor-Williams, JK and al. (2016) [64]       | 2016 | Ghana   | Mixed study        | Palliative Care               | Life-limiting chronic illnesses | To understand how Ghana's health insurance institutions interact with stakeholders and other health sector programme in the promotion of primary health care (PHC). Specifically, the study identified key areas of misalignment between NHIS and PHC operations. |
| Azodo, C C and al. (2012) [20]                 | 2012 | Nigeria | Quantitative study | Palliative Care               | Advanced oral diseases          | To assess nurses' views on the character, prevalence, and cause of oral disease in psychiatric patients, and their approach and suggestions for the care of oral problems.  |
| Badru AI, Kanmodi KK. (2017)[30]               | 2017 | Nigeria | Qualitative study  | Palliative Care               | Life-limiting chronic illnesses | To determine the level of awareness of palliative care among religious leaders and seminarians in Ibadan, Nigeria.  |
| Bayuo, J and al. (2021) [32]                   | 2021 | Ghana   | Qualitative study  | Palliative Care               | Intensive burn care             | To explore the end-of-life care experiences of burns care staff and determine how their experiences can facilitate the development of clinical guidelines.  |
| Boateng EA, and al. (2018)[47]                 | 2018 | Ghana   | Qualitative study  | Palliative Care               | End-stage renal disease         | Evaluating choice and decision-making in the international context of end-stage renal disease   |
| Bonsu, AB and al. (2019)b[58]                  | 2019 | Ghana   | Qualitative study  | Palliative Care               | Breast cancer                   | To explore the reasons for delayed presentation in Ghanaian women with breast cancer.   |
| Bonsu, Adwoa Bemah and al. (2019)a[60]         | 2019 | Ghana   | Mixed study        | Palliative Care               | Breast cancer                   | To develop a model to facilitate the integration of breast cancer prevention and early detection into palliative cancer care.   |
| Boubacar S. (2016)[63]                         | 2016 | Niger   | Qualitative study  | Palliative Care               | Incurable tumours and diseases  | To update the state of research, teaching and services related to palliative medicine at the Sakoirra Integrated Health Center (SIHC) in Niger.   |
| Caulfield, Alexandra and al. (2020) [50]       | 2020 | Ghana   | Qualitative study  | Palliative Care               | Cancer and HIV                  | To understand how physicians position themselves when communicating a poor prognosis to patients and families in a hospital setting in Ghana.   |
| Chukwunke, F N                                 | 2015 | Nigeria | Qualitative        | Palliative                    | Breast and                      | Analyzing the ethical issues surrounding the care of  |



|   |      |            |                    |                               |                                     |   |
|---|------|------------|--------------------|-------------------------------|-------------------------------------|---|
| (2015)[42]                              |      |            | study              | Care                          | cervical cancer                     | terminally ill cancer patients in a poor economy, with a critical overview of end-of-life issues from an African perspective.   |
| Dickerson, James C and al. (2021)[57]   | 2021 | Nigeria    | Qualitative study  | Palliative Care               | Breast and cervical cancer          | Assess acceptability and provide education. Secondary aims were (1) to describe the collaboration, (2) to assess the knowledge gained from the intervention, (3) to assess the patient's understanding of their therapeutic intent and (4) to explore the patient's experiences through qualitative analysis. |
| Diene JL and al. (2018)[38]             | 2018 | Senegal    | Mixed study        | Palliative Care               | Cancers                             | Assessing the palliative care needs of referral hospitals in Senegal.   |
| Edwin, AK and al. (2016)[22]            | 2016 | Ghana      | Qualitative study  | Palliative & end of life care | Cancers                             | To determine whether a structured approach to end-of-life decision making led by a compassionate interdisciplinary team would improve the quality of care for terminally ill patients in a teaching hospital in Ghana.  |
| Eke GK and al. (2018)[44]               | 2018 | Nigeria    | Mixed study        | Palliative Care               | N/A                                 | To assess the knowledge and perception of palliative care among healthcare providers in Rivers State.   |
| Elumelu TN and al. (2013)[68]           | 2013 | Nigeria    | Qualitative study  | Palliative Care               | Advanced cervical and breast cancer | To evaluate the pain management and palliative care services available to patients with advanced cervical and breast cancer.  |
| Fadare JO, and al. (2014)a[61]          | 2014 | Nigeria    | Qualitative study  | Palliative Care               | Cancer and HIV                      | To study nurses' knowledge of and attitudes towards palliative care in a tertiary level hospital in Nigeria.  |
| Fadare JO, and al. (2014)b[17]          | 2014 | Nigeria    | Quantitative study | Palliative Care               | N/A                                 | To examine the knowledge and attitudes of healthcare workers in a tertiary level hospital in Nigeria where a palliative care unit is being set up.  |
| Fearon, D and al. (2019) [24]           | 2019 | Mauritania | Qualitative study  | Palliative Care               | Cancer and HIV                      | To determine whether the principles of palliative care are congruent with the perspectives of healthcare professionals, families, and communities in rural areas of the Islamic Republic of Mauritania, West Africa.  |
| Gobatto I and al. (2016)[66]            | 2016 | Mali       | Qualitative study  | Palliative & end of life care | Diabetes and hiv                    | Understand the main dynamics and rationale behind the development of chronic disease management in a low-income country.  |
| Hamdi H. and al. (2018)[28]             | 2018 | Senegal    | Mixed study        | Palliative Care               | Life-limiting chronic illnesses     | . Assessing the capacity and need for palliative care in Senegal.   |
| Hanrahan, KB (2018)[67]                 | 2018 | Ghana      | Qualitative study  | Palliative Care               | Life-limiting chronic illnesses     | Analyzing the mobility constraints experienced by married girls living away from home in order to provide care for a parent at the end of life in northern Ghana.   |
| Jegede AS, Adegoke OO. (2016)[26]       | 2016 | Nigeria    | Qualitative study  | End of life care              | N/A                                 | To document the Yoruba definition and view of death, cultural beliefs about decision-making at the end of life, the factors that influence it and the role of the ethics committee.   |
| Kolawole IK and al. (2014) [25]         | 2014 | Nigeria    | Qualitative study  | Palliative Care               | Cancers                             | To highlight the challenges of providing palliative care in a hospital set up primarily to provide curative and preventive healthcare services.   |
| Kpanake, L and al. (2014) [45]          | 2014 | Togo       | Mixed study        | End of life care              | Life-limiting chronic illnesses     | To study the views on the acceptability of physician-assisted suicide (PAS) of lay people and health professionals in an African country, Togo.   |
| Kpassagou BL & Hatta O. (2016)[48]      | 2016 | Togo       | Qualitative study  | End of life care              | Cancers                             | To document the way in which the end of life is managed by public hospital services in a country with limited resources: Togo.  |
| Ndiok, A and al. (2021) [71]            | 2021 | Nigeria    | Qualitative study  | Palliative Care               | Cancers                             | To identify the barriers and benefits in establishing a model for integrating palliative care for cancer patients into daily clinical practice in tertiary care settings.   |
| Ndiok, A. N., & Ncama, B. P. (2018)[34] | 2018 | Nigeria    | Quantitative study | Palliative Care               | Cancers                             | Assessing the care needs of oncology inpatients and clinical patients or families in two tertiary health care institutions.   |
| Ndiok, Akon and al. (2019)[31]          | 2019 | Nigeria    | Qualitative study  | Palliative Care               | Cancers                             | To examine the effect of home visits and resources for the introduction of the programme as a follow-up strategy in the integration of palliative care into daily clinical practice by nurses caring for cancer patients in Nigeria, and how it can be used to improve the care of cancer patients.           |
| Odigie, VI and al. (2012) [37]          | 2012 | Nigeria    | Qualitative study  | Palliative Care               | Breast cancer                       | Studying the use of mobile phones as a tool for improving cancer care in a low-resource   |

|   |      |              |                   |                               |                                 | environment.  |
|---|------|--------------|-------------------|-------------------------------|---------------------------------|---|
| Ofosu-Poku R, and al. (2020)[51]              | 2020 | Ghana        | Qualitative study | Palliative & end of life care | Cancer and diabetes             | To explore the factors that influence the referral of patients with chronic non-malignant illnesses to specialist palliative care.  |
| Ojedoyin, OluwaseyiEmiola and al. (2022)[62]  | 2022 | Nigeria      | Qualitative study | End of life care              | Alzheimer                       | To assess nurses' perceptions of the advantages, disadvantages and their role in initiating and implementing advance directives (ADs) in private and public secondary care units.                           |
| Oji N. and al. (2022)[65]                     | 2022 | Nigeria      | Qualitative study | Palliative Care               | Life-limiting chronic illnesses | To gain an insight into the perspectives, perceived self-efficacy and preparedness of newly qualified Nigerian physicians in palliative care practice and identify potential variables that influence them. |
| Olaitan S, and al. (2016) [52]                | 2016 | Nigeria      | Qualitative study | Palliative Care               | Cancers                         | Describe the activities of the Ibadan Palliative Care Group and review the one-year holistic care programme offered by the team to support patients and their families.                                     |
| Omoyeni N and al. (2016)[41]                  | 2016 | Nigeria      | Qualitative study | Palliative Care               | Cancers                         | To examine the spectrum of adult cancer patients involved in palliative care at home, the services provided, outcomes and benefits.   |
| Onyeka, Tonia C. (2011)[18]                   | 2011 | Nigeria      | Qualitative study | Palliative Care               | Life-limiting chronic illnesses | Examine the challenges faced in establishing and implementing new palliative care practice in an emerging and developing economy  |
| Pfister JA (2011)[69]                         | 2011 | Burkina-Faso | Qualitative study | Palliative Care               | Cancer and HIV                  | Relate, in a narrative rather than scientific mode, a year's experience of palliative care with some of the patients followed by the author.  |
| Pfister JA (2013)[59]                         | 2013 | BurkinaFaso  | Qualitative study | Palliative Care               | Breast cancer                   | Analyzing the rotation and unavailability of medicines in palliative care   |
| Pfister JA (2014)[53]                         | 2014 | BurkinaFaso  | Qualitative study | Palliative Care               | Cancers                         | Analyzing palliative care between the misery of patients and families and the ignorance of political decision-makers  |
| Prudencio RD and al. (2017)[49]               | 2017 | Benin        | Qualitative study | Palliative Care               | HIV/AIDS                        | To assess the knowledge of staff in charge of people living with HIV about pain and to determine the obstacles to analgesia.  |
| Prudencio RD and al. (2018)[43]               | 2018 | Benin        | Qualitative study | End of life care              | Life-limiting chronic illnesses | Assess knowledge and review nursing practice in terms of support for patients at the end of life  |
| Salifu Y, and al. (2018)a[21]                 | 2018 | Ghana        | Qualitative study | Palliative Care               | Prostate cancer                 | Exploring the experiences of family carers caring for men with advanced prostate cancer.  |
| Salifu Y, and al. (2018)b[29]                 | 2018 | Ghana        | Qualitative study | Palliative Care               | Prostate cancer                 | Explore the experiences of patients and family members who provide care while living with advanced prostate cancer.   |
| Salifu, Y and al. (2021) [39]                 | 2021 | Ghana        | Qualitative study | Palliative & end of life care | Prostate cancer                 | Exploring the palliative and end-of-life care experiences of family carers and patients living at home in a resource-poor setting in Ghana.   |
| Sarfo-Walters, Catherine, and al. (2020) [55] | 2020 | Ghana        | Qualitative study | Palliative Care               | End-stage renal failure         | To explore the perceptions of people with ESKD and their informal carers about palliative care as a treatment option for the disease in Ghana.  |
| Sieh, SonponBlamo and al. (2019) [72]         | 2019 | Liberia      | Qualitative study | Palliative Care               | Tuberculosis and hiv            | To describe the Centre's integrated approach and carry out a descriptive analysis of the HoD patient population.  |
| van Gurp, Jelle and al. (2015)[56]            | 2015 | Nigeria      | Qualitative study | Palliative Care               | Life-limiting chronic illnesses | Exploring healthcare professionals' concepts of a good death and how telemedicine technologies and services would fit with current palliative care practice   |

3.3. Findings from the publications included

Figure 3 summarizes the contextualized and mapping data

from the literature. Brackets indicate the number of publications included for each finding.

Figure 2 : Mapping of data from the sources included in the review

3.4. Summary of results

The first author carried out a content review of the included publications, looking for recurrent themes and findings, then organized them under a list of thematic headings. Five main themes were identified in the synthesis of the included studies:

- 1) Obstacles related to political governance in the health sector
- 2) Obstacles relating to health systems and health facilities
- 3) Obstacles related to the attitudes, practices, and knowledge of care providers
- 4) Obstacles relating to the relationship between care and care pathways
- 5) Financial and economic obstacles

These themes detailed in Table 4 are described in more detail in the following sections.

**Theme 1: Obstacles related to political governance in the health sector**

25 articles described the obstacles to political governance in healthcare. Those commonly identified included: non-implementation of policies and guidelines for PC (n = 9/25, 36%); insufficient development of PC infrastructure (n = 8/25, 32%); insufficient PC education programs (n = 6/25, 24%); inadequate policies for the acquisition of and access

to morphine (n = 3/25, 12%); inadequate government subsidies for PC assistance (n = 3/25, 12%); and the non-existence of health insurance for primary health care and PC (n = 3/25, 12%).

Weaknesses in health education programs to promote PC have been reported mainly as a failure on the part of health sector leaders (73-78). Studies also describe a context of growing taboos on death and life-limiting illnesses, restricted access to adequate medico-technical care, and the assimilation of religion with medicine; all this is due to the lack of policies for the successful integration of PC (27,56). This situation creates confusion between the operation of non-orthodox services (spiritual and traditional healing services, patent medicine merchants, prayer houses) and that of the three-tier health care system (primary care, secondary care, and tertiary care) described by governments as conventional (27).

Additionally, inadequate morphine acquisition and access policies are described in contexts of fear of misuse of potent narcotics and under-prescribing (52,56,68). Appropriate pain treatment is therefore no longer assured, especially when governments fail to renew national guidelines on the availability, cost, prescribing, and storage of opioids (18,25,52). Moreover, low government subsidies (18,39,52,56), underlie low capacity for PC and/or EoL

management (39); disruption of the quest for a good death (56); difficulty in medical advances and funding of PC programs (56); contribution to poorly maintained cancer registries (18); and lack of national policies on pain relief (52).

### Theme 2: Obstacles relating to health systems and health facilities

37 included publications that identified obstacles related to healthcare systems and facilities. Approximately half of the publications (n = 17/37, 46%) described limited access to PC in care facilities as a major obstacle (16,19,31,33,38-40,46,48,49,52,53,56,63,66,69,70). Patients and families unsuccessfully express the need for access to support, even though it is available under various indicators.

Firstly, there was a lack of attention to patients in PC (33,69,70); poor availability of nurses (32,51,68,69); limited access to morphine and ordinary molecules (38, 49, 52, 56, 63, 69); lack of support for medical procedures, including laboratory tests (48, 66); insufficient effective medical treatments (39, 48, 53). Secondly, there is the mistrust of receiving inappropriate care (33) and limited access to reliable information (on the parameters of effective treatment of the disease) (39). Thirdly, there is the lack of support for bereavement (46); the lack of opioids (46, 49, 52, 56, 69); and the difficulty of geographical accessibility of PC services (18).

14 publications (n = 14/37, 38%) mentioned the lack of knowledge among carers about PC (15, 17-19, 23, 28, 33, 35, 36, 49, 61, 63, 65, 71). It was therefore people with very little knowledge who provided this care (19, 23, 28, 33, 36, 65). An interesting fact is that the healthcare providers were unable to satisfy their desire for training in PC, due to a lack of local training opportunities and the high cost of such training abroad (23). Four articles (n = 4/37, 11%) identified the unsuitability of the physical environment for PC as an obstacle (16, 18, 34, 70). A medical environment with limited resources, both human and material (18), and the absence of services or patient rooms (70) did not facilitate the offer and use of PC services.

Also, the lack of qualified PC staff (n = 10/37, 27%) has been identified (16, 18, 20, 28, 33, 36, 51, 64, 69, 70). It encourages overwork among healthcare professionals, which affects the quality of PCs (33, 36, 70). Moreover, inadequate patient/family education on PC was identified in seven publications (n = 7/37, 28%) as an obstacle (18, 22, 23, 25, 51, 52, 65). This resulted in patients dying without PC or EoL (22, 51). However, other obstacles, such as the lack of an up-to-date protocol or hospital or organizational guidelines (n = 5/37, 14%); the lack of an outpatient clinical model for PC (n = 5/37, 14%); lack of spiritual support for patients and families (n = 2/37, 5%); late referral culture to PC units (n = 2/37, 5%); and difficult access to PC with the help of professional organizations (n = 1/37, 3%) were identified.

### Theme 3: Obstacles related to the attitudes, practices, and knowledge of care providers

39 publications included identified obstacles related to the attitudes, practices, and knowledge of care providers. They

were identified in terms of care professionals (n = 25/39, 64%); family/friends/community members (n = 14/39, 36%); and patients (n = 18/39, 42%).

### Attitudes, practices, and knowledge of care professionals

In all, 13 obstacles relating to the attitudes, practices, and knowledge of carers were identified (15, 17-20, 23, 31-34, 36, 37, 43-45, 48, 49, 51, 52, 54, 56, 61, 62, 65, 66). They include carers' practices in keeping information about the disease and treatment (n = 6/25, 24%); the diffusion of wrong ideas and insufficient knowledge about PC and EoL (n = 6/25, 24%); carers' difficulties in talking about death with the patient (n = 5/25, 20%); the diffusion of wrong ideas about opioids (n = 5/25, 20%); and perceptions of life-limiting illnesses as rooted in cultural and religious beliefs (n = 4/25, 16%).

Regarding caregivers' practices in retaining information (18, 23, 32, 52, 56, 34), users of PC services did not have information about the purpose of their diagnosis, prognosis, treatment, and management (23). This could be due to the fear of being tagged as a "bad news conveyor" (23); and the low competence of caregivers to explain the different possible treatment scenarios (56). These arguments also partly underlie caregivers' difficulties in talking about death (18, 32, 36, 56, 65). Caregivers also protect patients from bad news (18, 23, 56) by censoring information. Also, the misconceptions about PC disseminated by caregivers, identified in three qualitative studies (18, 19, 43); two quantitative studies (17, 36); and one mixed study (44), concern the fact that PC is focused on the illness and not on the patient; PC is about prolonging life; PC is only terminal care; PC is only for people living with HIV/AIDS; and that the use of placebos is appropriate for treating certain types of pain (36). One of the reasons for this is that carers have insufficient knowledge about PC (17, 18, 43, 44) and cultural beliefs (18,19).

### Attitudes, practices, and knowledge of family/ friends/ community members

14 publications included (19, 23, 24, 26, 27, 30, 33, 53, 54, 56, 57, 59, 65, 67) identified a total of 13 obstacles, including: a strong cultural belief in life-limiting illnesses (n = 5/14, 36%); poor knowledge of PCs (n = 3/14, 21%); and poor knowledge of healthcare facilities offering PCs (n = 2/14, 14%).

Cultural, religious, and spiritual concepts influence opinions on the offer and demand for PC services (24, 26, 53, 54, 65), insofar as they influence the prognosis and diagnosis of death (65). The prognosis and diagnosis of a terminal illness are always seen as divine punishment (53, 54). Elsewhere, they are perceived as spiritual attacks provoked by mystical beings (54). Moreover, the question of a 'good death' has led to the rejection of PC in favor of curative care (24, 26, 54). Families' relationship with the concepts of culture, religion, faith, and spirituality influences the decisions they make regarding PC and/or EoL (24, 26, 53, 54, 65). From another point of view, the terminal stage of a life-limiting illness has been perceived as an individual and collective spiritual burden (53), leading families and relatives to confide in religious leaders who contribute to the rejection of advice from the CP team (53,54).



Family and community knowledge of PC was also limited (30, 56, 57). For example, religious leaders providing spiritual and emotional care to palliative patients were unaware of PC (30). This is explained by low community awareness of PC (30, 56, 57). Limited knowledge about PC and/or EoL hinders early palliative treatment and choice of professional care (56).

#### **Obstacles relating to patients**

As shown in Table 4, unmet emotional, physical, and spiritual needs (n = 4/18, 22%); feeling marginalized by care staff (n = 2/18, 11%); feeling abandoned by care staff (n = 2/18, 11%) and lack of/insufficient family support (n = 2/18, 11%) were described in five publications included (16, 19, 34, 40, 48, 68). Failure to meet emotional, physical, and spiritual needs (34,40,48,68) can be explained, in part, by lack of empathy towards patients, the inability of carers to reassure patients about their condition, lack of opportunity to discuss spiritual concerns, the inability of carers to relieve pain (34, 40, 48, 68).

Also, the unavailability of healthcare staff to respond to concerns is cited as facilitating patients' feelings of abandonment (19,48). The reduction and then abandonment of clinical examinations throughout the hospital stay (48); the feeling of being left out of the care system following a poor response or absence of a response from careers (19) created a feeling of exclusion from the care system experienced by the patient (19, 34, 48). Moreover, the lack of an appropriate relational approach, inability to manage the patient's situation, and lack of information about the disease and the terminal phase on the part of healthcare staff accentuated the feeling of marginalization of careers experienced by patients at the end of life (48).

The rejection of PC or EoL in favor of cultural or religious beliefs (n = 5/18, 28%) and the perception of the home as a good place to die (n = 1/18, 6%) were described in the opinions of the various actors as obstacles (16, 18, 24, 26, 28, 41). Also, inconsistent perception of the capacity of the healthcare system to provide PC (n =1/18, 6%); and feeling incompetent to decide on the type of care to receive (n =1/18, 6%) hindered patients' decisions in PC (33).

#### **Theme 4: Obstacles relating to the relationship to care and care pathways**

18 sources identified barriers related to the relationship between care and care pathways. Eleven qualitative studies (18, 22-24, 32, 33, 39, 41, 50-52, 56, 59, 71) and two quantitative studies (20, 36) referred to inadequate communication between patients/families and healthcare staff (n = 13/18, 72%). The reasons given were of several kinds. Firstly, there were reasons relating to time: the studies referred to document that care staff gave little time to patients/families (33, 56). Moreover, it is difficult for care staff to tell patients/families of impending death (18, 36), as they do not have transcultural skills for breaking bad news (18, 22, 56). In addition, healthcare staff don't involve patients/families in the care decision process (18, 23), one of the corollaries of which is a poor prognosis for the outcome of the illness (32,50). Emotional challenges for carers have also been highlighted (39). Elsewhere, pluralistic health beliefs and the poor integration of the patient's family into

care (50) are not negligible. Finally, it should be noted that a lack of knowledge of the challenges of PC (18,24) and linguistic difficulties (50,69) provide fertile ground for caregiver-patient relations.

Decision-making in PC and/or EoL care continues to be difficult for many clinicians due to fear of upsetting patients and/or families; and limited time and space for EoL decision-making (18, 23, 32, 33, 36, 56). Clinicians from different medical services were reluctant to refer patients to appropriate care services because of limited collaboration with PC units (n =5/18, 28%). The main reasons cited were medical paternalism (16, 51); difficulties for the PC team to obtain the necessary authorizations for transfer (15, 41); negative perception of PC nurses by their colleagues in other medical services (15, 16, 41); and struggle for ownership of patients through the care delivery system and staff (52). One study found that difficult collaboration between these services was due to a lack of awareness of care on the wards (15). In addition, collaborative networks with PC units were hampered by the lack of understanding of PC by carers in other medical services (15); and the fact that other medical services felt they were providing good care without necessarily collaborating with the palliative care team (15,41,51). Some medical services only call on the PC team when patients can no longer be offered active treatment (15, 52).

#### **Theme 5: Financial and economic obstacles**

Several papers (n = 20/58, 34%) identified financial and economic obstacles (15, 19, 21, 23, 25, 27, 29, 31, 34, 40, 42, 48, 51, 53, 55, 56, 63- 65, 68). Most common were the high cost of PC benefits (n = 14/20, 70%) and the low economic status of the patient/family (n = 7/20, 35%). Some studies added the financial toxicity of treatment (21, 29, 42, 48) and the high cost of morphine (31, 68).

Some studies have added the financial toxicity of treatment (21, 29, 42, 48) and the high cost of morphine (31, 68). The poverty of populations, patients, and families (19, 27, 51) characterizes their difficulty in accessing quality PC and/or EoL. As a result, most service users were less likely to pay for care (19, 27, 31, 48, 51, 64, 68).

## **4. Discussion**

This scoping review identified barriers (at several levels) to the offer and demand of PC and/or EoL services by adult patients in West Africa. Barriers related to political governance in the health sector; and barriers related to health systems and health facilities were predominantly reported in the publications included. This observation is probably linked to the low development of PC and EoL in West African countries.

In Africa, apart from Nigeria, countries specializing in PC and EoL were Uganda and South Africa; countries strong in overall PC development were, in order, Uganda, South Africa, and Kenya; those in PC and EoL policy development and implementation were Botswana, Ethiopia, Rwanda and Swaziland; and those in PC and EoL health education were Uganda, Kenya, Ghana and Zambia (79). English-speaking countries in West Africa, Nigeria, and Ghana in particular,

seem to stand out when it comes to developing PCs. This is reflected in the large number of publications on the issue in these countries.

Seven included publications identified limited access to PCs and/or EoL in healthcare facilities as a barrier in Benin, Burkina-Faso, Mali, Niger, Senegal, and Togo. Apart from Togo, where this limited access was explained by the high cost of PC services, other studies carried out in the French-speaking countries of West Africa reported that families and patients were spending catastrophically on PC and/or EoL and that people in need of palliative care were financially incapable. In contrast, the design of the included studies developed in the English-speaking countries of West Africa prioritized availability of health insurance for patients; difficulties encountered by healthcare institutions in pre-financing PCs; and difficulties encountered by healthcare workers in accessing training in PCs.

PC education for healthcare professionals is one of the important indicators for ensuring the integration of PC and EoL in Africa (5,79,81). Seven of the publications included also reported inadequate patient/family health education on PCs as a barrier in Nigeria and Ghana. This remark seems to corroborate the conclusions of another literature review which reveals a certain neglect of the public in raising awareness of PC and/or EoL, unlike healthcare professionals (80). Despite this, 11 of the publications mentioned inadequate training and knowledge of healthcare professionals about PCs as an obstacle in Nigeria. Similarly, Niger, Senegal, and Benin were identified as French-speaking countries where a lack of PC and/or EoL training for healthcare professionals was an obstacle. The limited education of healthcare professionals could underlie other obstacles identified in this review, such as those mentioned above. D. Agom *et al* (80) concluded in their scoping review that insufficient knowledge of PCs appeared to have an impact on health system factors and relational barriers influencing the provision and use of PCs.

PCs and EoLs encourage a holistic, multi-professional approach to patient care, but this overlooks transcultural skills. Beyond the control of physical symptoms, attention must also be paid to the psychosocial, cultural, and spiritual aspects of the patient's experience of illness. Cultural context can shape patients' or families' responses to a life-threatening illness, as can patients' beliefs (82). The results of this review revealed that culture beliefs and religion are major barriers to the offer and demand of PCs and/or EoLs services in West Africa. They were addressed through the opinions of stakeholders, using an essentially qualitative study design. To this end, fifteen or so publications have pointed out that in Nigeria, Mauritania, Burkina Faso, Senegal, Ghana, and Togo, they are often neglected in the practice of PC, and constitute unmet needs that hinder the provision and use of this care. Because they are at the heart of the daily lives of everyone involved in PC (83,84). These reflections are shared even with non-Westerners who have experienced PC in Europe (85).

## 5. Strengths and limitations

The first limitation of this scoping review is that it did not

include grey literature. Also, few studies from French-speaking West African countries were mapped. However, the contextual similarity of healthcare systems in these countries is an asset that could facilitate future research. The considerable number of studies from English-speaking West African countries makes it plausible to use the data for knowledge transfer to countries with less developed PCs and/or EoLs. We note that this scoping review has identified sufficient barriers to the supply of, and demand for, CPs and/or EoL in West African countries.

## 6. Conclusion

This scoping review has revealed obstacles, at various levels, to PC and/or EoL in West Africa. Firstly, the fact that the integration of PC and/or EoL into health systems is not yet what it should be in terms of WHO guidelines. Secondly, there are problems such as insufficient funding from governments, inadequate public policies at the global level and health policies (e.g. on opioid use), the mismatch between biomedical standards and cultural and religious norms in PC and/or EoL, and inadequate practices on the part of care providers. Finally, despite notable progress in some West African countries, further efforts are needed to improve universal health coverage and the quality of PC and/or EoL services, particularly in French-speaking African countries.

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### Author Profile



Currently in the process of defending a PhD, I have over 15 years' experience in planning, organizing, implementing, and monitoring national and multi-country health research activities and projects. My current research work is related to universal access to quality services, in particular (i) in the field of sexual and reproductive health and rights, (ii) in the field of studies on non-communicable diseases, in particular diabetes and cancer diseases, (iii) in the field of palliative and end-of-life care (in Benin and other West African countries such as Togo). I have good skills in health policy and systems research, including the use of a variety of methodologies. The design and management of research projects and interventions on (complex) health policy and systems issues - realist evaluation - is also one of my skills.