

## ORIGINAL ARTICLE

## Palliative care needs and barriers in an urban Ugandan Emergency Department: A mixed-methods survey of emergency healthcare workers and patients

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## ARTICLE INFO

## Keywords:

Palliative care  
Emergency department  
Uganda

## ABSTRACT

**Background:** Palliative Care offers patient-centered, symptom-focused relief for patients with incurable disease, and early integration of palliative care ensures quality of life and death while reducing medical impoverishment. The Emergency Department is an ideal yet understudied, under-utilized location to initiate palliative care.

**Objective:** To evaluate the palliative care needs of patients with incurable disease and perceived barriers amongst healthcare providers in the Emergency Department of Kiruddu National Referral Hospital, Kampala, Uganda.

**Methods:** A mixed methods survey of Emergency Department healthcare workers and patients was conducted. A cross-sectional survey of ninety-nine patients was conducted using the integrated Palliative Care Outcome Scale (IPOS). Eleven interviews were conducted with healthcare workers at Kiruddu Hospital, identified by purposive sampling. Descriptive and inferential statistics were used to analyze quantitative data. Grounded theory approach was used to construct the in depth interview questions, code and analyze qualitative results and collapse these results into final themes.

**Results:** The most common diagnoses were HIV/HIV-TB (32 %), heart disease (18 %), and sickle cell disease (14 %). The prevalence of unmet palliative care needs was substantial: more than 70 % of patients reported untreated symptoms e.g., pain, fatigue, difficulty breathing. Seventy-seven percent of the population reported severe or overwhelming pain. The main barriers to provision of palliative care in the Emergency Department as identified by healthcare workers were: (1) lack of adequate training in palliative care; (2) Challenges due to patient volume and understaffing; (3) the misconception that palliative care is associated with pain management alone; (4) Financial constraints as the greatest challenge faced by patients with incurable disease.

**Conclusions:** We report a high prevalence of unmet palliative care needs among patients in this urban Ugandan Emergency Department, and important barriers reported by emergency healthcare providers. Identification of these barriers offers opportunities to overcome them including harnessing novel mHealth interventions such as clinical support apps or telehealth palliative care consultants. Integration of palliative care in this setting would improve the care of vulnerable patients, provide healthcare workers with an additional care modality while likely adding value to the health system.

## Introduction

Palliative care (PC) aims to improve the quality of life for patients with serious health-related suffering and progressive chronic illness and

is an imperative under Universal Health Coverage [1,2]. Uganda has been a model for palliative care on the continent of Africa, with a number of underpinning drivers of its success including: integration of an educational curriculum, training healthcare providers on opioid

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<https://doi.org/10.1016/j.afjem.2023.11.005>

Received 23 March 2023; Received in revised form 24 October 2023; Accepted 7 November 2023

Available online 25 November 2023

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treatment, extension of opioid prescription privileges to specialist palliative care nurses and clinical officers, and collaboration with community-based healthcare workers for implementation [3,4]. Despite this, there are still gaps between the policies that support palliative care and delivery to the patient: a 2009 needs assessment conducted in at Mulago National Specialized Hospital in Kampala, Uganda found that 46 % of inpatients had life-limiting illness, with a high burden of symptoms (70% reported pain, while 87 % reported weakness) as well as social, psychological and spiritual distress. At the time, only 5 % of these patients were accessing palliative care services [5].

There is a great need for palliative care development on the continent of Africa: sub-Saharan Africa has the highest rates of mortality, morbidity, and disease burden when compared with other WHO regions [6]. The populations most in need of PC are those with cancer and HIV/AIDS, with the rate of cancer in Africa projected to grow more than 400 % over the next 50 years [7]. Approximately 10 % of the nearly 3.5 million people in Uganda who need palliative care have access to that care. This is because only 4.8 % of hospitals offer such services [8]. In high-income settings, it is known that early integration of palliative care into a patient's care plan can positively affect the quality of life and survival of patients with advanced cancer, reduce medical impoverishment while adding value to healthcare systems [9].

However, there is a lack of data about how this integration applies to patients in sub-Saharan Africa [10–12]. Contemporaneously, there is a high prevalence of physical, psychosocial, spiritual, and financial suffering including catastrophic health expenditure that occur with incurable disease, especially for patients in fragile health systems [13–17]. Many of these patients enter the healthcare system through the Emergency Department (ED). In addition, accessing medical care for management of chronic illnesses is a challenge in many LMICs, and this is reflected in ED presentations. Therefore, the ED may serve as an ideal location to connect them with palliative care services.

The intersection of emergency medicine and palliative care is particularly important for patients with complex and advanced disease, as the decisions made in the ED may determine the trajectory of their subsequent treatments, which can include life-prolonging therapies that may not align with the patient's goals of care [18,19]. Emerging data from high-income settings suggests that [1] delivery of palliative care in the emergency setting may allow patients to address or revisit their goals of care and therefore guide medical treatment to align with their goals and avoid unwanted hospital admissions and medical expenses and that [2] Palliative care initiated in the ED for patients with advanced cancer significantly improved quality of life without having a negative impact on survival [20,21].

A study conducted by Hospice Africa Uganda (HAU) found that for many aspects of end-of-life care at HAU, patients, caregivers, and healthcare providers have different ideas about what constitutes quality care [3]. We therefore designed a study in the Kिररुदु National Referral Hospital ED to evaluate the palliative care needs of emergency patients and barriers to initiation of palliative care as identified by the health care workers caring for them.

## Methods

### Design and setting

We conducted a concurrent mixed methods study comprised of two components. First, a cross sectional survey was used to collect quantitative data from ED patients. Second, grounded theory approach was applied to in-depth interviews with emergency healthcare workers to gather qualitative data on barriers to palliative care delivery. For clarity, we have chosen to present the two components of the study separately in the remainder of this methodology section and the following results section.

Kिररुदु hospital is a public national referral hospital in Kampala, Uganda with a bed capacity of 200. There are additionally 14 outpatient

clinics and an ED. The hospital has the different subspecialties of Internal Medicine, a Burn Unit and a General Surgery ward. The Kिररुदु ED sees a volume of approximately 40 patients per day.

### Population

For the quantitative component, the population were patients with life limiting disease presenting to the Kिररुदु ED between October 1 to December 1, 2021, between 7am to 6pm, Monday through Friday. Eligible patients were those with chronic life limiting illness (including cancer, chronic organ failure, chronic infectious diseases e.g., HIV, chronic neurological disease, and genetic disorders e.g., sickle cell anemia) who were deemed by the ED staff team to have PC needs. The criteria used are those described by the World Health Organization in their definition of palliative care (anyone with serious health related suffering and with a life-limiting illness.23 Those who had altered consciousness and those too ill or breathless to respond to questions were excluded. Regarding qualitative, Kिररुदु emergency healthcare workers of all levels including nurses, junior doctors, clinical officers, and physicians were approached for inclusion in the study.

### Sample and sampling

For the quantitative component, convenience sampling was employed. Potential patients were identified by the ED team, who then informed the researchers of potential participants on a daily basis. The researchers, who are also experienced PC providers, screened the potential patients. Those whom they confirmed to have a life-limiting illness and with PC needs were given information and consent forms about the study prior to enrollment. 129 patients were screened, 8 were excluded due to being too ill or breathless, 22 declined to participate, leaving 99 participants who were recruited. For the qualitative component, purposive sampling was used to select participants. Eleven interviews were conducted.

## Data collection tools

### Quantitative component

The Integrated Palliative care Outcome Scale (IPOS) tool was used to collect data comprised of socio-demographics as well as assess the multidimensional needs of people with chronic illness including the burden of unpleasant symptoms such as pain and extends to information needs, anxiety/low mood, family concerns and an overall feeling of peace. It is included below as Appendix 1. The IPOS has previously been validated and used clinically and for research purposes in many African settings [22–26].

### Qualitative component

Grounded theory approach was used to develop the guide for conducting the semi-structured interviews. The guide includes four sections (A-D), with an intent statement for each section, followed by questions. The goal of section A was to introduce the study and address any concerns. The goal of section B was to develop a better understanding of the palliative care resources available to provider and patient. The goal of section C was to identify the challenges in providing palliative care, from the provider's perspective. The goal of section D was to ensure all the appropriate information was collected. The full guide is included as a Supplemental Figure.

## Data collection procedures

For the qualitative component, interviews were conducted face to face by an experienced Ugandan palliative care physician who also has a PhD in qualitative research methods (LN), thus we have strong

confidence in the trustworthiness of the qualitative data collected. The interviews were audio recorded. Transcripts were generated with Zoom electronic transcription service and by experienced, local research assistants. The transcripts were verified for accuracy by the interviewer. For the quantitative component, trained research assistants approached ED patients identified by local healthcare workers as having palliative care needs, and after consenting patients for inclusion, verbally completed the IPOS, recording results on paper case report forms.

**Data analysis**

*Quantitative component*

Counts and Percentages were used to summarize categorical variables. Mean and Standard Deviation or Median and IQR were used to summarize continuous variables, depending on normality. Univariable linear regression or the Student’s T Test was used to test for associations of patient characteristics, such as age, gender, and diagnosis with total score. These variables were then included in a multivariable linear regression model of total score. A P Value < 0.05 was considered statistically significant. All analyses were completed using SAS Version 9.4 (SAS Institute Inc, Cary, North Carolina).

*Qualitative component*

Transcripts of the recorded interviews with emergency healthcare workers were coded by DH and ER. Grounded theory approach was used to code responses. The coded concepts were reviewed and collapsed into themes with discrepancies resolved by consensus.

**Ethical considerations**

The study protocol was approved by the Mulago Ethics and Research committee and administrative clearance was given by Kiruddu hospital before the study commenced. The study protocol was also approved by the Yale University Internal Review Board. The study information sheet and consent form were read out loud for those who were illiterate. Written consent was obtained for those who agreed to participate by signature or thumb print .

**Results**

The results of our survey of ED patients and qualitative interviews with ED healthcare workers are presented separately. We will first discuss the quantitative results, followed by the qualitative results from in-depth interviews with healthcare providers.

*Quantitative results*

Ninety-nine patients completed the survey, with a median age of 36 years. Fifty-one percent were female. Four percent of the population had no formal education, while 32 % had completed either Primary 6 or 7. Forty percent of the population was employed in small business. Demographic information is shown in Table 1, below.

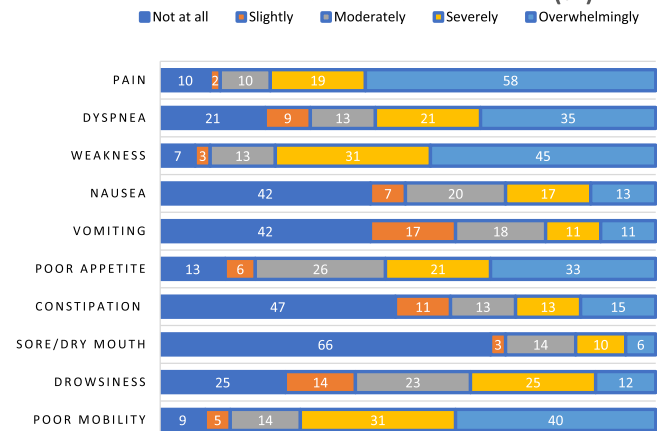
The most common diagnoses were HIV, sickle cell disease and heart disease. Please see Table 1 for a list of diagnoses by percentage of our study population.

Our study population reported high levels of untreated pain, as measured by the IPOS scale, with 77 % reporting either severe or overwhelming pain. Weakness, poor mobility and dyspnea were the next most common symptoms reported. Please see Fig. 1 for an infographic displaying the IPOS symptoms with severity, by percentage of our study population. In addition, our patient population also reported mobility deficits, with 71 % stating either severe or overwhelming lack of mobility. With its emphasis on home-based care and relief of symptoms, palliative care decreases the need for travel to medical clinics,

**Table 1**  
Demographic information.

Age	
Median (IQR)	36 (25-52)
Gender	
Female	51 (51.5 %)
Male	48 (48.5 %)
Occupation	
Petty business	36 (36.1 %)
Self employed	3 (3.0 %)
Shop attendant	1 (1.0 %)
Specialized trade	29 (29.3 %)
Student	4 (4.0 %)
Unemployed	19 (19.2 %)
Diagnoses	
HIV	26 (26.3 %)
Heart disease	18 (18.2 %)
Sickle Cell	14 (14.1 %)
Cancer	7 (7.0 %)
Liver failure	8 (8 %)
HIV-TB	6 (6 %)
TB	7 (7 %)
Renal failure	5 (5 %)
Other	9 (9.1 %)

**IPOS PATIENT-REPORTED SYMPTOMS (%)**



**Fig. 1.** IPOS Patient-reported Symptoms.

pharmacies.

**Qualitative results**

Four main themes emerged from our in-depth interviews with eleven Kirruddu ED healthcare workers: (1) Lack of adequate Palliative Care training among healthcare workers (2) Palliative care being associated only with pain control (3) Financial constraints for patients and (4) the ED as a challenging environment to deliver PC due to patient volume, understaffing. Table 2 presents these four themes in greater detail, with quotations from healthcare workers to help further describe the barriers to palliative care delivery in this setting.

**Discussion**

Uganda is a beacon of Palliative Care on the continent of Africa, yet despite many efforts to improve access to palliative care in this location, the need remains great. Our study of palliative care needs and barriers in ED patients and healthcare providers in Kampala, Uganda identified a number of important, actionable findings.

Table 2

Healthcare provider interviews: four most common themes.

Theme	Quotations
<p><b>Lack of adequate Palliative Care training among health care workers</b></p> <ul style="list-style-type: none"> <li>This was noted across every interviewer with training ranging from a brief course in medical school, to on-the-job training, to no training at all. This is further exacerbated as providers are unable to identify those who may have a palliative care need and if they are identified, they do not possess the skills to care for or address those needs. Multiple providers cited that increased knowledge among all healthcare providers would be beneficial to providing better palliative care to patients.</li> </ul>	<p>HCW1-K (Nursing Officer, Female): “You take those modules but we don’t practice them much...so there is no practice of it. So that much practice being limited takes time you’re not doing it and find [yourself] forgetting it and limiting the skills.”</p> <p>HCW6-K (Physician, Male): “I imagine the first challenge it would be recognizing that the patient has a need. They may not be able to tell that the patient really has a palliative care need. Okay they may know that there is a problem, but they might not recognize that there is a palliative care need for the patient.”</p>
<p><b>Palliative care is associated with pain management only</b></p> <ul style="list-style-type: none"> <li>When asked about palliative care resources, 8/11 providers associated palliative care resources in pain medications, especially morphine as the primary analgesic. Pain management was also cited as the focus in palliative care education for three of the providers. Among nursing providers, palliative care was associated with counseling and psychosocial support in addition to pain control while physicians frequently cited pain management and none had seen the psychosocial aspects of palliative care delivered in the emergency department.</li> </ul>	<p>HCW10-K (Medical Officer, Female): “I think may be the one big challenge we have is we don’t factor that these patients need palliative care. We tend to stop at giving you drugs, hopefully they will make you better or they won’t make you better and we don’t consider the other needs of the patient [such as pain control].”</p>
<p><b>Financial constraints are the greatest challenges that patients face when presenting with palliative care needs.</b></p> <ul style="list-style-type: none"> <li>Almost every provider described finances as a challenge for patients who present to the emergency department which affects the patients’ ability to access medications, nutritional supplements, and medical care at the hospital.</li> </ul>	<p>HCW2-K (Intern/Post Graduate Year 1, Female) Actually most patients come and they are paying too much because most of those [incurable] conditions, for example, patients with CKD, they’ve gone through a lot of pain, they don’t have finances, they don’t know who to run to, who can help them out, so it’s [finances] a big challenge.”</p>
<p><b>Palliative care delivery in the emergency department is challenging for providers due to patient volume and understaffing which result in decreased time for patient interactions.</b></p> <ul style="list-style-type: none"> <li>Many providers agree that having a palliative care team member present in the emergency department would be valuable and help address the palliative care needs of patients. There is also an expectation that the palliative care needs will be addressed by the wards once the patient has been stabilized in the emergency department.</li> </ul>	<p>HCW11-K (Intern/ Post Graduate Year 1, Male): “I think part of it to be attributed to the workload since you’re having a lot of patients coming in and at times staffing is down so you don’t get enough time to talk to these patients to identify their needs. You end up stabilizing them and sending them to the different wards.”</p> <p>HCW5-K (Senior Assistant Nursing Officer, Female): “I see we don’t give these patients enough time because we are very few, so we really don’t give them the holistic palliative care we are supposed—they are supposed to receive because we are very few.”</p> <p>HCW10-K (Medical Officer, Female): “In most cases you’re thinking ‘I need to just do the medical bit and send them to the wards and hopefully they can continue their care from there’.”</p>

### Palliative care needs

First, this ED population is young, with a median age of 35 years and a great need for palliative care: 77 % reported severe or overwhelming pain, 76 % had severe or overwhelming weakness, another 71 % had severe or overwhelmingly poor mobility, and 56 % reported severe or overwhelming dyspnea. These results are similar to those found in a 2012 study of inpatients in this setting [27]. Important for palliative care delivery strategy, 71 % of patients reported either severe or overwhelming lack of mobility. The spectrum of terminal illnesses identified is also unique. As opposed to cancer, the majority had: HIV (26 %), heart failure (18 %) and sickle cell disease (14 %). Regarding the reported mobility deficits (71 % reported severe or overwhelming lack of mobility): with its emphasis on home-based care and relief of symptoms, palliative care decreases the need for travel to medical clinics, pharmacies. In this way, it is also an ideal option for patients with mobility deficits who would otherwise struggle to travel to a medical facility for care.

As a point of comparison, a similar study was recently conducted in the Mbarara, Uganda Emergency Department [28]. In this study, researchers looked at palliative care needs and whether those patients who were identified as having palliative care needs then went on to receive palliative care during their hospitalization. The Mbarara study provides a relatively similar population for comparison, though it is noted that a different palliative care screening tool was used. In this study, ED patients were screened for palliative care needs, those who screened in were followed up at day 7 of their hospitalization to determine whether PC was initiated and mortality. Of 760 patients screened, 120 were found to have PC needs, and 86 were included in the study. The population was similarly young (mean age 49 years) and most common diagnoses were cancer, heart disease, and stroke. Mortality in this cohort was high: 37 % of admitted patients had died at day 7, reflecting severity of disease at presentation. In addition, 63 % of the patients who screened in for PC needs actually received it during their hospitalization. Researchers concluded that there is a need for a PC screening tool to be adapted for use by ED providers for every patient, which would help identify patients with PC needs and thus increase access to PC for these ED patients advanced disease. They also conclude that education in PC should be mandatory for ED providers, so that they have the skills to initiate PC themselves as opposed to waiting for a consulting service.

Adult palliative care in developed settings often describes an elderly demographic with the median age above 70, with incurable cancer or multimorbidity as the most common terminal illnesses [29,30]. However we describe a relatively young population. Therefore, the approach to identification and provision of palliative care in this setting must be contextual, locally derived and built as opposed to transplanted. The ED could serve as a vital area for early patient assessment and identification of these patients with unmet palliative care needs.

### Palliative care barriers

On the provider side, the main barriers to palliative care delivery in this ED setting were: lack of palliative care training, challenges to delivery of palliative care in the ED such as high volumes of patients with few staff and lack of privacy, lack of knowledge of the full spectrum of palliative care, and financial barriers to care due to the high costs.

Additionally, 40 % of this population run small businesses and 20 % were unemployed. The financial constraints are further exacerbated as only 1 % of Ugandans have private insurance [23]. In Uganda, a free healthcare system exists however, financial and resource constraints often require patients to purchase medications and services out of pocket. These so called ‘out of pocket payments’ are cash exchanges at point of care, are unregulated and particularly problematic: in Uganda and other LMICs, health-related costs may become catastrophic expenditures which push families into poverty. The reasons are multifactorial but include out-of-pocket payments, lack of health insurance programs,

and limited savings [15,12]. Palliative care may offer a resource-sparing alternative to care that is non-beneficial, thus adding value to health care [31–33]. In line with this, all healthcare providers we interviewed stated that financial constraints were a barrier to patient care. Palliative care is a patient-centered, value-added approach which offers a favorable cost profile for both health systems and households, and in this way, would address the barrier of financial constraints early on in the disease trajectory rather than later when catastrophic expenditure has already occurred.

PC training has been incorporated into most medical training curricula in Uganda. The majority of healthcare workers interviewed admitted to having a module or two on palliative care but went on to describe non-utilization of this theoretical education due to a number of practical hindrances such as high patient volumes and understaffing. This therefore highlights the need for a shift of focus in the way that we train palliative care, especially for the ED provider, to emphasis practical integration of theoretical knowledge for example by enhancing mentorship and support supervision [34,35].

Many healthcare providers cited the challenges of sharing news regarding prognosis with a new patient in the emergency department because they are only caring for the patient for a brief time in their disease course. It is important to note that palliative care is not synonymous with end-of-life care, and one of the primary goals of palliative care is to ensure that the care plan is consistent with the patient's goals of care, regardless of whether that includes pursuing all life-sustaining procedures or comfort measures only and discharge to hospice. As the ED is often the entry point into the health system, it is an ideal location to clarify the care plan and ensure the correct trajectory for the patient's medical care going forward.

#### Strengths and limitations

Although our study provides novel insights into the needs and barriers to delivery of palliative care in this resource-limited setting, there are several important limitations. First, due to the study design and convenience sampling it is unclear whether our study population is representative of the larger ED presenting population, which may in turn limit the generalizability of our qualitative findings. In the future, it would be interesting to conduct a larger study collecting data on baseline presenting chief complaints and medical comorbidities of the larger population. This would also enable us to compare our results with those of others both locally and regionally. Nevertheless, our inclusion criteria were broad, the Ugandan research team is highly experienced using the IPOS tool and enrolling subjects in palliative care research in this setting, which are all strengths of this study. Second, while the interviews included healthcare workers of various clinical positions, the results from the interviews may not reflect the experiences of healthcare workers in other similar settings. We utilized several strategies to minimize researcher and measurement bias and ensure data reliability including consistent use of the interview guide, audio recording interviews, standardized coding, and maintenance of materials to achieve auditability.

#### Conclusions

While not traditionally linked with Palliative Care, the ED is actually, radically, an ideal location to initiate palliative care. This study provides insights into the palliative care needs of patients presenting to an urban Ugandan ED, and barriers to palliative care delivery as perceived by the healthcare workers caring for them. As such, the findings are relevant for the management of African EDs and in particular for the recognition, assessment and management of palliative care needs in ED patients, integration of palliative care competencies for healthcare providers, and referral pathways for specialist palliative care support. These novel insights can be used to guide the development of applications to assist with identifying patients with palliative care needs, and also to address

barriers to palliative care delivery in the ED. Clearer indications regarding when and how to approach a patient with possible palliative care needs and improved education/clinical support models aimed at equipping providers with the skills to assess and address these needs are critical next steps.

#### Dissemination of results

Results from this study were shared with staff members at the data collection site through an informal presentation. The results are also being included and incorporated into Palliative Care teaching modules for junior doctors in this location as well as a medical simulation case for junior doctors and Master of Emergency Medicine Students in this location. The results were presented at the 2022 African Conference on Emergency Medicine.

#### Declaration of Competing Interests

The authors declared no conflicts of interest.

#### Author's contribution

Authors contributed as follows to the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; and drafting the work or revising it critically for important intellectual content: ER contributed 20 %; Dao Ho contribute 20 %; Liz Namukwaya contributed 20 %; Mhoira Leng contributed 15 %, Peace Bagasha contributed 10 %; Michael Lukoma contributed 15 %. All authors approved the version to be published and agreed to be accountable for all aspects of the work.

#### Acknowledgments

The authors would like to thank all who participated in the interviews including interviewees and research assistants. We also extend our thanks to the Yale Downs Fellowship for their funding of this research and the Yale Department of Emergency Medicine for its support. Finally, we thank the Yale Center for Analytical Sciences for providing statistical analysis.

#### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.afjem.2023.11.005](https://doi.org/10.1016/j.afjem.2023.11.005).

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