Factors affecting initiation of palliative care in a Ugandan Emergency Department

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ARTICLE INFO

ABSTRACT

Introduction: The Emergency Department (ED) of Mbarara Regional Referral Hospital serves a largely rural population of 4 million people in western Uganda. Here, ED patients with incurable illness often have prolonged stays. Palliative care (PC) is a low-cost intervention that focuses on alleviating pain and suffering for patients with incurable disease, while improving satisfaction with care and optimizing healthcare utilization. This is especially important in low resource settings. A prior needs assessment in our ED revealed that 50% of patients have PC needs. The ED is an optimal location to initiate PC, yet this rarely happens. There is a great need to identify factors affecting initiation of ED PC in our resource-limited setting.
Methods: A semi-structured questionnaire and chart review was conducted from March to August 2020. Patients admitted from the ED were assessed for PC needs. Those who met criteria were approached for inclusion and flagged for initiation of PC. The follow-up period was 7 days.
Results: Sixty two percent of those subjects flagged for initiation of PC received it. By day seven, 36.1 of the study population had died. ED initiation of PC varied significantly by diagnosis, with cancer patients more likely to receive PC ($p = 0.0097$).
Conclusion: Important barriers to PC initiation were identified in our Ugandan ED, related to diagnosis. These barriers could be overcome by improving awareness of PC amongst patients and providers alike and implementing a PC screening tool for all admissions. Future research is needed to identify other barriers, as well as strategies for improved hospital-wide uptake of PC in this resource-limited setting.

African relevance

- Research took place in western Uganda
- Palliative care is understudied in Africa and other low resource settings, yet widely needed.
- Emergency Department initiation of palliative care is a relatively novel concept, yet it is known from high income settings that the ED is also an ideal location for a number of reasons. There are no studies of this, to date, in Africa.
- Globally, there are numerous steeped cultural concepts surrounding end of life, which make it critical to study palliative care tendencies in a particular location prior to devising implementation strategies for delivery of palliative care.

Introduction

Across the globe, people are living longer with chronic disease. Non communicable diseases are on the rise, and Africans are particularly affected- 34%percent deaths due to NCDs occur in Africa [1,2]. As a result, Emergency Departments worldwide are taking care of more patients with multiple comorbidities along the spectrum of incurable disease [3].

Palliative care is a medical specialty focused on improving quality of life for patients with incurable disease [4,5]. The backbone of palliative care is patient and family-centered care: treating distressing symptoms such as pain, providing psychosocial support and identifying clear goals of care and wishes for end of life, thus enabling a 'good death' [6,7].

Benefits of early PC include improved healthcare utilization, improved satisfaction for the patient and their family, improved outcomes, shorter hospital stays and decreased cost [8,9]. Particularly

relevant to low-resource settings, by prioritizing end of life wishes for those with incurable disease, limited resources may be directed towards those with reversible illness.

The Emergency Department is an ideal location for initiation of palliative care, and this recognition is leading to ED-based palliative care interventions in high-income settings [10–12]. There is an even greater need for ED-based PC in low-income settings however it is not yet a routine component of Emergency Medicine training or practice on the continent of Africa.

Mbarara Regional Referral Hospital (MRRH) is a tertiary teaching hospital in an urban setting within largely rural western Uganda. Please see the map below, Fig. 1, for our location on the continent of Africa.

The name Mbarara translates to "the land of milk" reflecting the predominance of cattle farming in the region. Our ED was created five years ago, to meet the emergency healthcare needs of a largely rural population of about 4 million people, for the districts of Mbarara, Bushenyi, Ntungamo, Kiruhura, Sheema, Ibanda,Buhweju, Rubirizi, Mitooma and Isingiro [13]. MRRH is a government-owned hospital.

The MRRH ED treats approximately 14,600 high acuity adult medical and surgical patients.

per year. The most common disease processes include: traumatic injuries, cancer, organ failure, neurologic disease, cardiac emergencies, and diabetes. The department operates 24/7, 365 days per year. The ED shares the laboratory and radiology units with other hospital departments, and these services can be accessed during the day only. We have a 16-bed capacity with frequent crowding and throughput issues, necessitating treating patients in the hallway and on the floor. Our typical ED length of stay ranges from 1 to 7 days. The ED is staffed by two nurses during the day and one at night, 8 intern doctors per day, 6 resident doctors per day and two consultants per day. The MRRH ED is also proudly the location of Uganda's first Emergency Medicine residency training program which is a three year Master of Emergency Medicine. Our first class of residents is due to graduate in January 2021.

A prior and unpublished needs assessment conducted in our ED population one year prior to the current study revealed that over 50% of patients had palliative care needs, yet none were initiated on PC while in the ED as palliative care was not part of the ED work flow and no policies or procedures existed to allow for it. Based on these results, we began to plan for a larger research study in order to better understand the underpinning barriers surrounding initiation of palliative care in our emergency setting.

In our ED, there is no program in place for screening or referral of patients for PC, and ED clinicians were not aware of their role in providing PC. ED staff are faced with a large number of patients, and due to overcrowding, there is no privacy for sensitive discussions with patients and family. In our ED, patients with life threatening and incurable illness often have longer ED stays, frequently up to seven days. This is due to a number of complex hospital factors including delays on the inpatient side (e.g., no bed available, patients who are deemed too sick for the floor thus kept in the ED where it is perceived that monitoring is better) or delays while the family plans for the patients' return to home and arranges transportation. Furthermore, during these prolonged stays, patients with PC needs are not identified and therefore are not initiated on or linked to PC services. MRRH is fortunate to have a hospice team that is located a short distance from the hospital (10-min walk), however historically this team has been focused on inpatient care, not ED patients. Indeed, PC becomes available if the patient is transferred out of the ED to the main ward where the consultation is made later during the hospitalization. Furthermore, there is no mechanism currently in place for linking patients who are discharged home from the ED with outpatient PC services.

In addition, there are other reasons that ED-based initiation of PC is not standard at MRRH. These factors can be grouped into patient factors (age, gender, socioeconomic status, language barriers, misconceptions and stigma), illness factors (diagnosis, disease progression, symptom burden) and hospital factors (provider knowledge of PC, ED crowding,
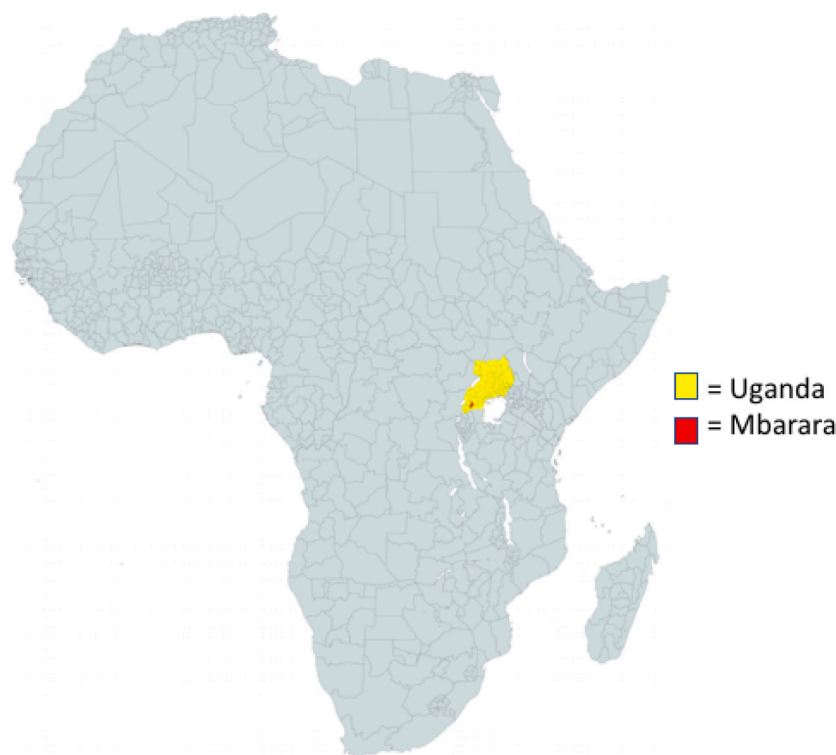
Map created with mapchart.net

Fig. 1. Map detailing Mbarara, Uganda. Map created with mapchart.net.

understaffing, availability of analgesia, access to PC services). To better identify the particular barriers to PC initiation in our ED so that they might be addressed and overcome, we designed an interventional prospective cohort study in which ED patients who met criteria for needing PC were flagged for initiation of PC during their hospitalization.

Methods

From March through August 2020, on Monday through Friday on study days, charts of all patients admitted from the ED in the last 24 h were screened to identify those patients that meet criteria for PC. Due to travel limitations and adaptations for staff in the setting of the Covid-19 pandemic, study days were limited to days when our data collectors were able to travel to the ED as opposed to every day, as had been planned. Over the study period, our data collectors were able to travel to the ED on 60 days.

A PC needs screening tool, modified from the World Health Organization and African Palliative Care Association, and adapted to our setting, was used to identify potential patients with PC needs [14]. It is included as Supplementary Material 1, and includes questions regarding diagnosis, uncontrolled symptoms and irreversible functional decline. The screening tool was used by two data collectors trained in both Emergency Medicine (one as an RN, one as a Resident doctor) and the use of the tool. The data collectors reviewed charts of ED patients at midday to avoid interruption of ward rounds. Patients who were still physically in the ED were approached and screened using the palliative care screening tool.

If patients were found to have PC needs and meet our study inclusion criteria, written informed consent was obtained and a case report form (Supplementary Material 2) was completed. Exclusion criteria were as follows: 1. Already enrolled in a PC program; 2. Glasgow coma scale below 14 with no attendant; 3. Patient or family decline PC.

Next, each included patient was referred for initiation of PC by either the Emergency ward doctors or direct referral to the palliative care team. This referral was made through documentation in the patient's chart, direct conversation with the Emergency doctors on shift. Seven days later, our patients were followed up by chart review for documentation of palliative care initiation and mortality. If this information was missing from the chart, a phone call was made to the patient or attendant.

Please see Fig. 2 below for a diagram of study flow.

Three social economic classes were generated for the purpose of this study. A number of complex parameters are used to define social classes, with global heterogeneity however inclusive of income, societal arrangements such as social participation, health behavior, education, and occupational class [15]. For this study, socioeconomic class was determined based on scores for level of school education, amount of income and employment. This stratification is included in Supplementary Material 3. Lower social economic class was defined by a total score of 1–2, middle social economic class by a total score of 3–5, and upper social economic class by a total score of 6–7.

Ethical approval was obtained through MRRH. We considered these patients to be a vulnerable population given their advanced disease and thus took a number of precautions to ensure the ethics of the research and their informed consent based on prior research in this area and our experience working in this setting. First, one of our exclusion criteria was lack of an attendant for this very reason- to ensure that the patient and their family could discuss the research, palliative care, and then make an informed decision regarding study participation. Written informed consent was obtained from every subject and/or attendant. Only adult patients were included. Furthermore, consent forms were developed with the knowledge that the study population might have a low literacy rate, the consent forms will be read out loud in the patient's native language, and the consent process was interactive, whereby subjects were queried at chosen pause points whether clarification is needed.

Results

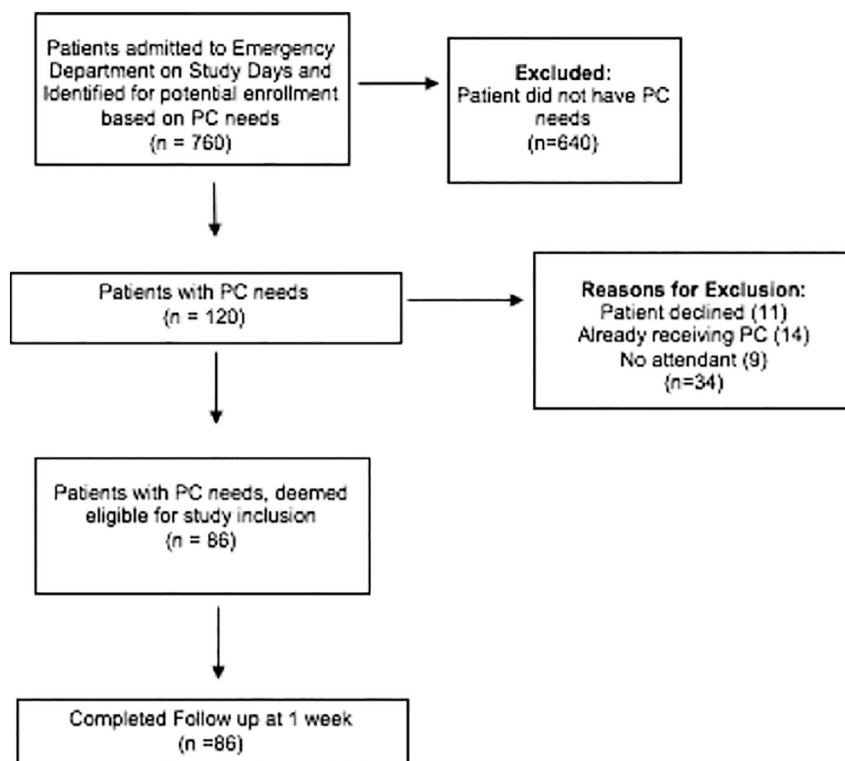Eighty-six patients were enrolled in our study, of which the mean age

Fig. 2. Study flow diagram.

was 49 and 40% of the population was female. Nearly 43% of our population reported a daily income of less than 6500 Ugandan shillings ($1.90 USD), or fourteen cents above the World Bank criteria for extreme poverty ($1.76 USD) [16]. Twenty percent of the population had no formal education. Please see Table 1, below, for demographic information of our study population.

The most common diagnoses in our population were cancer, end stage renal disease, end stage heart disease, stroke and bed-bound. The percentages that comprised each are presented below, in Table 2.

We found trends in uptake of PC by diagnosis: those diagnosed with cancer had 75% initiation while heart disease and stroke had 50% and renal disease had 47% and 50% respectively ($p < 0.01$). Those with a cancer diagnosis had 4.3 times the odds of receiving palliative care compared to those with other diagnoses, adjusting for age, sex, mortality at day 7, socioeconomic class, and marital status. Table 2 below summarizes our main findings with respect to gender, age, diagnosis, socioeconomic status and whether or not palliative care was initiated.

There was no difference in initiation of palliative care based on the following demographic features: age, gender or socioeconomic class. We did find a statistically significant relationship between cancer versus all non-cancer diagnoses and initiation of palliative care (0.0097, odds ratio 3.3).

Eighty seven percent of our population met criteria for lower or middle socioeconomic class. Additional statistical analysis was performed for socioeconomic class: the odds ratio for initiation of PC from upper socioeconomic class to lower was 0.4 (CI 0.0685–2.3371, $p = 0.3090$) and upper to lower or middle socioeconomic was 0.67 (CI 0.1882–2.4206, $p = 0.5464$).

By follow up at day seven, 63% of those patients who had been flagged for initiation of PC had received it, and 37% of the study population had died.

Discussion

The high degree of morbidity in this population is reflected in the 7-day mortality rate of 37%. In addition, two important trends were noted with respect to uptake of PC: first, those patients with a cancer diagnosis were more likely than others to be initiated on PC while bed bound patients were least likely to receive PC. As PC is historically thought of as an intervention for those with cancer diagnoses, these findings are not surprising. There is room for improvement in uptake of PC for patients with non-oncologic diagnoses, especially the most frail and vulnerable of patients: those that are bed bound. While there was not a statistically significant relationship between socioeconomic status and initiation of PC, it would be interesting to further explore this with a larger study as the number of subjects in the low and high social class were small, and

Table 1
Demographic information.

Variable	Result
Mean age (SD)	49 (19)
Gender	
Male (%)	52(60)
Female (%)	34(40)
Socioeconomic status (%)	
Lower	12(14)
Middle	63(73)
Upper	11(13)
Education (%)	None (20)
	Primary (53)
	Secondary (19)
	Tertiary (8)
Unemployed	10%
Daily Income Stratification in UG shillings (USD; %)[a]	0–6500 (0-$1.76; 43%)
	6500–19,500 ($1.76–$5.27,20%)
	>19,500 (>$5.27, %)

[a] 1 Ugandan Shilling = 0.00027 USD as of 9/24/2020.

Table 2
Main results.

	Palliation, n (%)	No palliation, n(%)	p value
Age (mean(SD))	49.3(19.4)	49.2(18.7)	0.98
Gender			
Female	11(34.4)	23(42.6)	0.5
Male	31(57.4)	21(65.6)	
Cancer	36 (75)	12 (25)	0.0097
Bed bound	4 (44)	5 (56)	0.11
Heart disease	4 (50)	4 (50)	
Renal disease	7 (47)	8 (53)	
Stroke	3 (50)	3 (50)	
Total non-cancer diagnoses	18 (33.3)	20 (62.5)	
Alive at day 7			
Yes	36(66.7)	18(56.2)	0.47
No	18(33.3)	13(40.6)	
Socioeconomic class			
Lower	9(16.7)	3(9.4)	0.59
Middle	39(72.2)	24(75)	
Upper	6(11.1)	5(15.6)	

we observed that 75% ($n = 9$) of patients of the lower socioeconomic status were initiated on palliative care. An overall PC initiation of 63% in a population of patients who all met criteria for initiation of PC implies that there are potentially multiple additional barriers that need to be addressed in order to meet the PC needs of this population.

There are a number of strengths and limitations of the study. First, the study took place during the COVID-19 pandemic which greatly affected available resources and service delivery, in part due to strict, police- enforced lockdown period. The pandemic presented additional challenges and also opportunities, as much of the focus and efforts of our ED were on preparing for and treating increased numbers of patients with lower respiratory tract infections and sepsis. The strengths of the study include its pragmatic nature: there were no interruptions to normal work flow in our department or patient management, and the intervention provided was complimentary to ongoing patient care. Limitations include the non-randomized study design and bias this introduces, our inability to include all diagnoses (for example pulmonary, liver disease were omitted), the small sample size and single site which may not be representative of EDs in other locations. In addition, our screening tool was limited and as a result, we may have failed to identify patients who could benefit from PC. There is thus a great need for the development and validation of a low-resource, Africa-specific ED screening tool for palliative care needs.

The fact that the study staff responsible for screening and enrolling patients were ED providers could have introduced selection bias, however this was mitigated by the staff not being on shift when recruiting study patients, and by referring to the ED doctor on shift or to the PC team to offer the care, instead of being directly responsible themselves. As both the philosophy and practice of PC are novel in our emergency setting, we felt it was important to involve ED staff in these very initial stages of development, for transparency and to increase familiarity with PC as early as possible. Finally, we regret not collecting qualitative data particularly on those subjects who declined the intervention, as this might have helped to reveal additional barriers to PC implementation in this setting.

Conclusions

There is a need to implement a PC screening tool to be used by ED clinicians to screen for patients with PC needs. This would help to identify patients with PC needs, and increase access to PC in our high acuity, high morbidity ED. In addition, including primary PC education in our Master of Emergency Medicine training would enable ED providers to initiate PC themselves during prolonged ED stays, as opposed to waiting for the PC service to do so from the in-patient side. This, in addition to PC champions in the ED, would also serve to strengthen the

ED-PC referral pathway. Finally, we propose a larger implementation and cost-effectiveness study that includes an education component for front-line providers, focus groups to better understand hospital and provider-side barriers, involvement of the community and an awareness-spreading campaign, and creation of champions at the leadership level both in the ED and hospital-wide.

Supplementary data to this article can be found online at https://doi.org/10.1016/j.afjem.2021.06.005.

Dissemination of results

Results from this study were shared locally with staff in the Mbarara ED including nurses, residents and the head of the department, through an informal presentation. Results were also shared with the Faculty of Medicine through a written report and oral presentation. The results were shared via oral presentation at the African Conference of Emergency Medicine (Nov 2020), for more widespread dissemination.

Authors' 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: LN contributed 50%, DH 25%, and ER25%. All authors approved the version to be published and agreed to be accountable for all aspects of the work.

Declaration of competing interest

The authors declared no conflicts of interest.

Acknowledgements

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