

Assessment of the Readiness and Availability of Palliative Care Services in Hospitals in Kampala, Uganda

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ABSTRACT

Background: In Uganda, there are approximately 350,000 patients with illnesses needing palliative care (Merriman, Mwebesa & Katabira, 2012) and among whom 210,000 persons in pain are in urgent need of Palliative care (American Cancer Society, 2014). Further, palliative care was introduced to improve the quality of life of patients and their families who are facing problems associated with life-threatening illness, whether physical, psychosocial or spiritual (Temel, 2010). More still, palliative care reduces unnecessary hospital admissions and the use of health services. However, the use of morphine and other controlled medicines that are essential for palliative care are overly restricted by regulations thereby hindering access to adequate pain relief and palliative care. Furthermore, palliative care has been incorporated into the Uganda's Health Sector Strategic and Investment Plans but has been hampered by minimal resources and huge shortages of health workers. Further, Uganda has one of the most rapid growth of palliative care in Africa as well as the only country in sub-Saharan Africa graded as having "Stage 4" comprehensive palliative care according to the Global Atlas of Palliative Care (Worldwide Palliative Care Alliance, 2014). Additionally, Uganda was ranked 35th out of 80 countries for the Quality of death Index (Economist Intelligence Unit, 2015). Despite these accolades, hospital based palliative care is not universally available throughout the country. In 2014 the Ministry of Health provided only 103 million Uganda shillings for development of Palliative care in its national budget. This is a small amount to share, and as most hospitals received very little funding for palliative care, it is likely that hospital medical superintendents used discretionary funds to provide the service (O'Brien et al., 2013). Therefore, the objective of this study was to assess the readiness and availability of palliative Care services in hospitals in Kampala, Uganda from April, 2016 to June, 2016. **Methods:** A cross sectional study design was used. **Results:** The study found that 7 of the 27 hospitals (26%) were offering palliative care, 6 (22%) had a specialized staff offering palliative care and only 5 (19%) had a staff designated to coordinate palliative care services. Overall, the level of readiness to provide palliative care was found to be very low with only 3 of the 27 hospitals (11%) demonstrating readiness as per the set criteria (availability of pain medication in stock, availability of morphine in stock and availability of a healthcare worker to provide palliative care).

Conclusion: Readiness and availability of palliative care services is very low among hospitals in Kampala.

Keywords: Palliative Care, Morphine, Readiness, Availability

Introduction

Each year, an estimated 40 million people worldwide are in need of palliative care, 78% of them people live in low- and middle-income countries with only about 14% of people who need palliative care currently receive it. Palliative care is required for a wide range of diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), HIV/AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care include: kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis. In Uganda, there are approximately 350,000 patients with illnesses needing Palliative care (Merriman, Mwebesa & Katabira, 2012), of these 210,000 persons in pain are in urgent need of Palliative care (American Cancer Society, 2014). The Government of Uganda provides liquid morphines free of charge to all patients who need it in public hospitals. In addition medical workers receive pre-service training in Palliative care. Despite all these interventions, hospitals in Kampala are referring patients to Hospice Africa Uganda (HAU) and often report that they do not have oral liquid morphine despite this medication being availed free of charge (PCAU, 2012). Uganda's demand for palliative care outstrips what is offered, and it is estimated that only 10% of patients in need of palliative care are being reached (Merriman, Mwebesa & Katabira, 2012). The WHO advocates for palliative care as an essential component of the overall care in HIV, cancer and other serious non-communicable diseases where treatment therapy is lacking or has become ineffective, palliative care is important. The government of Uganda recognizes that Palliative Care is a humanitarian responsibility, and that it is an essential clinical service. Since 2000, this service has been incorporated into the Uganda's Health Sector Strategic and Investment Plans.

Palliative care has not been given much attention due to minimal resources and huge shortages of health workers. According to WHO and the Uganda Ministry of Health (2003) palliative care ought to be integrated into the country's health systems and provided at all levels of care including in all hospitals but Uganda's health system has centered on preventive of immunisable illnesses and infectious diseases, curative interventions, child and maternal health services in accordance to the most critical needs. In 2015 Hospice Africa Uganda (HAU), an NGO offering specialist-level Palliative Care services received 1,633 patients referred from hospitals in Kampala for Palliative Care- a 39.4% increase in patient referrals over a 2 year period (HAU, 2015). Of these referrals 467 were for oral liquid morphine to be dispensed. This suggests that some hospitals do not have Palliative care including adequate relief of severe pain (O'Brien et al., 2013). To make matters worse, there are only 12 Hospices outlets in Uganda that offer specialized Palliative care. Thus this unmet need for Palliative Care exerts tremendous pressure on health care costs, yet when the services are not offered patients have uncontrollable pain, suffer unrelieved symptoms, have more morbidity, poor quality of life and early deaths in addition to the psychological and financial burden on their families (AAPM, 2013). This study therefore assessed the readiness and availability of palliative care services among hospitals in Kampala, Uganda.

Methods and Materials

Settings

The study focused on both public and private hospitals within Kampala City. In-charges/ medical directors of the 27 hospitals within the city were interviewed between January, 2016 to June, 2016. The time period was purposely selected to ensure that the time frame under study was as close as possible to the current time and met the inclusion criteria for the study

Design and sampling procedures

This was a descriptive cross-sectional study that focused on in-charges/medical directors of public and private hospitals in Kampala.

Data collection and management

Data was collected from in-charges/ medical directors of public and private hospitals in Kampala using a researcher administered questionnaires. The questionnaires were developed by the researcher basing on tools used for measuring readiness and availability of care by the Ministry of Health, Uganda.

Outcomes and exposure variables

The study had two main dependent variables; readiness and the availability of palliative care services in the hospitals. **Availability** of Palliative Care at a hospital denotes that the service was committable, operable, and usable upon demand by patients seeking the service. **Readiness** for Palliative Care denotes a level of preparedness of a hospital to offer an essential service at a particular point in time. The independent variables in this study were: Health facility based factors and Health Systems factors.

Sample size estimation

Kampala city has a total of 27 hospitals (public and private) and all of them were included in the study.

Ethical considerations

The study was approved by International Health Science University Research and Ethics Committee and the respective hospitals authorities.

Results

Of the 27 hospitals interviewed, public hospitals like Mulago hospital and faith-based hospitals were classified as public/private not-for-profit (PNFP) hospitals and all other hospitals were classified as private for profit (PFP) hospitals. The majority, 15(56%) of the 27 hospitals visited were for private for profit and the remaining 12(44.4%) public or PNFP hospitals.

Availability of palliative care services

The study found that 7 out of the 27 hospitals (26%) were offering palliative care (Table 1). Only 6 hospitals (22%) had a specialized staff offering palliative care and only 5 hospitals (19%) had a staff designated to coordinate palliative care services.

Table 1: Availability of palliative care services

Variable	Frequency	Percent (%)
Does facility offer palliative care?		
Yes	7	25.9
No	20	74.1
Does facility stock morphine?		
Yes	7	25.9
No	20	74.1
Does facility have staff specialized in offering palliative care?		
Yes	6	22.2
No	21	77.7
Is there a staff coordinating palliative care?		
Yes	5	18.5
No	22	81.5

Source: primary data

Funding and support for palliative care services in hospital

Only 2 of the 27 hospitals (7%) reported that they had a budget for palliative care (Table 2). Ten (22%) of the 27 hospitals had had their staff undergo in-service training in palliative care in the past 12 months. Only 4 hospitals (15%) had guidelines for the practice of palliative care and 3 (11%) had received supervision for Palliative Care from the Ministry of Health in the past 12 months.

Table 2: Funding and support for palliative care services in health facility

Variable	Frequency	Percent (%)
Does hospital have a budget for pain relief medication?		
Yes	25	92.6
No	2	7
Does hospital have a budget for palliative care?		
Yes	2	7
No	25	92.6
In the past 12 months has staff received any in-service training in palliative care?		
Yes	10	22.2
No	17	77.7
Does facility have guidelines for palliative care?		
Yes	4	14.8
No	23	85.2
Has facility received supervision from MOH in the past 12 months?		
Yes	3	11.1
No	24	88.9

Source: primary data

Readiness of palliative care services

Readiness was measured using three questions which sought for the availability of pain medication, the availability of morphine and a health worker who could provide palliative care at the time of interview. The majority of hospitals, 26 (96%) had pain medication in stock. Only 5 hospitals (19%) had oral morphine in stock and only 4 (15%) had a healthcare worker available to provide palliative care (Table 3).

Table 3: Readiness of palliative care services

Variable	Frequency	Percent (%)
Are pain medications available today?		
Yes	26	96.3
No	1	3.7
Is oral morphine available today?		
Yes	5	18.5
No	22	81.5
Is a health care worker who can provide palliative care available today		
Yes	4	14.8
No	23	85.2

Source: primary data

Overall readiness of palliative care services in hospitals

Overall, only 3 of the 27 hospitals (11%) were ready to provide palliative care services (Figure 1).

Figure 1: Overall readiness of palliative care services in hospitals



Challenges and way forwards to improve palliative care services in health facilities

Lack of specialized staff in palliative care (47%), the cost of establishing palliative care services being high (18%) and hospital management not being interested in palliative care (15%) were reported as the main challenges faced by hospitals (Table 4 below). Further, 15 hospitals (43%) reported that there were no plans for starting or improving palliative care at the hospital. This is a sign that many hospitals were not interested in providing the service at the time of data collection. However, some hospitals stated that they required training of their health workers in palliative care, 6 (17%) and accreditation with the PCAU, 4 (11%) as the way forward. Four hospitals (11%) stated that Palliative care was being considered in the institution’s strategic plan for the next period.

Table 4: Challenges and way forwards to improve palliative care services in health facilities

Variable	Frequency	Percent (%)
Challenges		
Cost of establishing the service is high	6	17.7
Lack of specialized staff	11	47.1
Its costly to patients	4	11.8
Patients do not have interest	1	2.9
Facility management has no interest	5	14.7
Not being accredited by PCAU	2	5.9
Ways forward to start or improve palliative care services		
None	15	42.9
Strategic plan been formed	4	11.4
Inclusion/expansion of budget	2	5.7
Training healthy workers	6	17.1
Accreditation by PCAU	4	11.4
Stocking pain medicine	2	5.7
Opening Palliative Care clinic	2	5.7

Hospital characteristics and availability of palliative care services

Only 1 (6.7%) of the 15 private-for-profit hospitals was offering palliative care while a half (50%) of public/PNFP hospitals were offering palliative care. Only type of facility (P=0.024) and total number of patients per month (P= 0.012) were significantly associated with availability of palliative care (Table 5).

Table 5: Hospital characteristics and availability of palliative care services

Variable	Availability of palliative care		p-value
	Yes (%)	No (%)	
Type of health facility			
Public/ Not For profit	6 (50)	6 (50)	0.024*
For profit	1 (6.7)	14 (93.3)	
Total number of patients in a month			
<1000	0 (0)	8 (100)	0.012*
1000-5000	2 (18.2)	9 (81.8)	
8000-132000	5 (62.5)	3 (37.5)	
Total Staffing			
7-25	2 (22.2)	7 (77.8)	0.829
26-50	0 (0)	3 (100)	
51-1880	4 (28.6)	10 (71.4)	
Does facility stock oral morphine			
Yes	4 (57.1)	3 (42.9)	0.050
No	3 (15)	17 (85)	
Does facility have staff specialized in offering palliative care			
Yes	3 (50)	3 (50)	0.290
No	4 (19.1)	17 (80.1)	
Staff coordinating palliative care			
Yes	3 (100)	0 (0)	0.091
No	4 (16.7)	20 (83.3)	

*Significant variables with P-value <0.05

Funding and support and availability of palliative care services in health facility

Five out of 10 hospitals (50%) with staff that received in-service training in palliative care and only 2 out of 17 (11.8%) hospitals without any staff trained in palliative care in the past 12 months were offering palliative care (Table 6). Additionally, in-service training in palliative care in the past 12 months ($P=0.045$) was the only factor under funding and support that was significantly associated with availability of palliative care. All other aspects of funding and support were not associated with availability of palliative care.

Table 6: Funding and support and availability of palliative care services in health facilities

Variable	Availability of palliative care		P-value
	Yes (%)	No (%)	
Does hospital have a budget for pain medication			
Yes	7 (28)	18 (72)	1.000
No	0 (0)	2 (100)	
Does hospital have a budget for palliative care			
Yes	1 (100)	0 (0)	0.459
No	6 (23.1)	20 (76.9)	
In the past 12 months has staff received any in-service training in palliative care			
Yes	5 (50)	5 (50)	0.045*
No	2 (11.8)	15 (88.2)	
Does facility have guidelines for palliative care			
Yes	2 (50)	2 (50)	0.269
No	5 (21.7)	18 (78.3)	
Has facility received supervision from MOH in the past 12 months			
Yes	1 (33.3)	2 (66.7)	1.000
No	6 (25)	18 (75)	
Facility accredited			
Yes	2 (100)	0 (0)	0.060
No	5 (20)	20 (80)	

*Statistically Significant variable ($P < 0.05$)

Hospital characteristics and readiness for palliative care services

The study further found that only number of patients seen in a hospital per month ($P=0.038$) and stocking oral morphine ($P=0.012$) were associated with readiness for palliative care services (Table 7 below). All other factors did not show any statistical association with readiness of the health facility to offer palliative care.

Table 7: Hospital characteristics and readiness for palliative care services

Variable	Readiness of palliative care		P-value
	Not Ready (%)	Ready (%)	
Type of health facility			
Not For profit	9 (75)	3 (25)	0.075
For profit	15 (100)	0 (0)	
Total number of patients in a month			
<1000	8 (100)	0 (0)	0.038*
1000-5000	11 (100)	0 (0)	
8000-132000	5 (62.5)	3 (37.5)	
Total Staffing			
7-25	9 (100)	0 (0)	0.346
26-50	3 (100)	0 (0)	
51-1880	11 (78.6)	3 (21.4)	
Does facility stock morphine			
No	20 (100)	0 (0)	0.012*
Yes	4 (57.1)	3 (42.9)	
Does facility have staff specialized in offering palliative care			
No	20 (95.2)	1 (4.8)	0.115
Yes	4 (66.7)	2 (33.3)	
Staff coordinating palliative care			
No	21 (95.5)	1 (4.6)	0.079
Yes	3 (60)	2 (40)	

*Statistically Significant variables ($P < 0.05$)

Funding and support to health facilities and readiness for palliative care services

In-services training in the past 12 months ($p=0.041$) and having guidelines for palliative care ($p=0.049$) were the only factors found to have statistically significant association with readiness of health facilities to offer palliative care services (Table 8). All other factors under funding and support were non-significant.

Table 8: Funding and support to health facilities and Readiness for palliative care services

Variable	Availability of palliative care		p-value
	Not Ready (%)	Ready (%)	
Does hospital have a budget for pain medication			
Yes	22 (88)	3 (12)	1.000
No	2 (100)	0 (0)	
Does hospital have a budget for palliative care			
Yes	1 (50)	1 (50)	0.214
No	23 (92)	2 (8)	
In the past 12 months has staff received any in-service training in palliative care			
Yes	7 (70)	3 (30)	0.041*
No	17 (100)	0 (0)	
Does facility have guidelines for palliative care			
Yes	2 (50)	2 (50)	0.049*
No	22 (95.7)	1 (4.3)	
Has facility received supervision from MOH in the past 12 months			
Yes	3 (100)	0 (0)	1.000
No	21 (87.5)	3 (12.5)	
Facility accredited			
Yes	1 (50)	1 (50)	0.214
No	23 (92)	2 (8)	

*Statistically Significant variables ($P < 0.05$)

Discussion

Availability of palliative care services; funding and support; and readiness for palliative care services: Study findings revealed that only 26% of the hospitals in Kampala were offering palliative care services. This low percentage could be attributed to the high burden of communicable diseases in Uganda coupled with high cost of palliative care (Maponga et al., 2007). This view is reflected in the response of one of the respondents;

“Of course being private we are not subsidized by donors, we are not sure but I think it would be expensive because we have to charge for every single service we have to offer. It might be much more expensive than hospice because we would charge for every single service”.

This would raise the overall cost of care making it unaffordable and therefore non-profitable particularly for the private for profit hospitals. This finding is comparable to the 17% got from a study of 107 hospitals in California, US (Pantilat & Billings, 2003). Similarly, The American Hospital Association (2007) reported that only 30% of USA hospitals were having a palliative care programme. The similarities in the findings may be attributed to the high cost of providing palliative care making the service unattractive for most hospitals. Additionally, availability of palliative care in hospitals may also be influenced by the perceptions of hospitals' management about palliative care (Rodriguez, Barnato & Arnold, 2007). Further, only 30% of the hospitals surveyed reported stocking morphine, a vital drug in management of severe pain. Contrary to this finding, Harding et al., (2014) in their review of pharmacy stock among 120 President's Emergency Plan for AIDS Relief (PEPFAR)-funded health facilities in Uganda and Kenya to determine the availability of medications for pain and symptom control for patients with HIV, found that morphine was available in only 7% of the facilities, and was the least available medication. The difference in the findings of the two studies could be attributed to the sources of funding for the facilities. PEPFAR funding support has strict guidelines (Harding et al., 2014) on utilization of the funds making it difficult to procure medications or other items not included in the funding guidelines. This might have resulted in the lower level of morphine stock among the PEPFAR funded facilities. Further, only 7.4% of the hospitals surveyed reported having a budget for palliative care services. This is rather depressing given that no services can be offered effectively without adequate funding (O'Brien et al., 2013). Additionally, lack of budget for palliative care services could be attributed to the high burden of communicable diseases in Uganda which puts emphasis on saving lives rather than improving quality of lives of persons with chronic diseases like cancer. Hence low level of budget allocation for palliative care among the hospitals surveyed.

Compared to availability of palliative care, readiness of hospitals to offer palliative care was even lower as only 11% of the hospitals surveyed in Kampala were found to be ready to offer palliative care services. This implies that only a small proportion of the hospitals that reported having palliative care were actually prepared to provide the care whenever demanded. The readiness to offer palliative care is also closely linked to the availability of appropriate medications for the management of severe pain in hospitals. Clark (2007) in the multi-method review of hospice and palliative care development among 47 countries in Africa found a close relationship between the 29 countries that reported no morphine use in the period 2000-2002 and their readiness to offer palliative care services. This correlates to the finding of this study which found a significant relationship between the readiness to offer palliative care in hospitals and the availability of morphine for the management of severe pain. This is understandable since it would be impossible to control pain in palliative care without strong opioid. Further, lack of interest from hospital administrators was highlighted as one of the challenges facing provision of palliative care services in this study. Lack of interest is likely to affect the budgeting process of the hospital, a key process in determining availability of pain medication, staffing and other resources needed to provide palliative care.

Hospital characteristics; funding and support; and availability and readiness for palliative care services:

A systematic review by Jang and Lazenby (2013) ascertained that hospital inpatient care gave better opportunity for opioid availability and the management of pain and symptoms at the end of life when compared with home-based palliative care. Findings of this study indicate that the type of hospital was associated with availability of palliative care services. Additionally, the results showed that palliative care was provided mainly by public and private not-for-profit hospitals (85.7%). This could be due to the fact that these hospitals are not providing the services for profit and therefore less concerned with marginal interest from providing the service unlike the private for profit hospitals. Further, public and not for profit hospitals are more likely to attract funding or other support for palliative care from donors and high profile companies. On the contrary, private health facilities mostly depend solely on the investment of the owners and cost recovery from patients who use the hospital services and therefore may look at provision of palliative care as untenable.

WHO (2004) states that 50% of HIV patients; and 80% of cancer patients will experience severe pain during the terminal phase of their disease. The availability of opioid medications for the management of severe pain is

therefore a cornerstone in palliative care, and the WHO (1990, 1996) encourages a public health approach to palliative care and pain management. This study found that the availability of oral morphine at the hospitals was associated with readiness to offer palliative care services. This is consistent with PCAU (2013) assertion that hospitals need regular access to pain management medication in order to provide palliative care to patients who require the care. However, the readiness of the health facilities was poor with only 11% of the hospitals surveyed ready to provide palliative care services. Poor readiness to provide palliative care among Kampala hospitals could be attributed to high cost and difficulty in procuring oral morphine, a key medication in palliative care. This therefore leads to persistent stock-outs of the medication hence low level of readiness for provision of palliative care. The challenge of persistent stock out of oral morphine was highlighted by one of the respondents below;

“We get it from people; they always come with their oral morphine because we request the patients to come with it and as I speak now I don’t think it’s in stock”.

Therefore, a concerted effort is needed to increase access to oral morphine in order to improve hospitals’ readiness for palliative care services. This finding is similar to the outcome of ethnographic study in South Africa which found a positive relationship between availability of opioid in hospitals and readiness of the hospitals to offer palliative care (Beck, 2001). Further, similarity in findings of the two studies could be attributed to the influence of the availability of oral morphine on other factors for readiness. For instance, stocking morphine would dictate that a trained person in prescribing and administering the medication be employed at the hospital. This in essence improves the readiness of the hospital to offer the services.

Consistent with Rampanjato et al., (2007) findings in Central Africa, many respondents in this study identified poor awareness and myths about oral morphine as an impediment to palliative care provision in Kampala. This is reflected in the statement of one of the respondents below;

“...There is the fear of oral morphine addiction which is probably not well founded”.

Three other different key informants outlined that the fear of addiction was real. For instance, another key informant stated;

“...oral morphine is thought to be too strong and when you (clinician) give it to somebody it fastens death”.

These myths and misconceptions about morphine are hospital-based factors which influence availability and readiness for palliative care.

Additionally, barriers to the stocking of essential medicines at hospitals can affect the availability and readiness to provide palliative care. While these were not explicitly explored it is possible that these factors are at play in causing widespread unavailability of opioids in Kampala’s hospitals.

Further, having health workers who had received in-service training in palliative care over the last 12 months was associated with both availability ($P=0.045$) and readiness ($P=0.041$) of palliative care services at hospitals. This finding is consistent with Rampanjato et al., (2007) assertion that availing health workers with knowledge about palliative care is paramount if palliative care services are to be made available to the population. Lack of specialized staff in the area of palliative care was indicated as one of the factors affecting the provision of palliative care services in hospital. Similarly, a study by Uys (2003) among trained professional nurses in 7 urban and rural sites in South Africa showed that lack of adequately trained palliative care health workers led to gross under-management of pain when patients were admitted to hospitals. A hospital with staff trained in palliative care is likely to confidently offer the service to the patients. This finding is further supported by a study of 23 Emergency Department nurses in Central Africa which showed that poor pain control was prevalent in 25% of the hospital nurses with no formal education on pain management (Rampanjato et al., 2007). Additionally, these nurses were also unable to properly recognize symptoms of pain which made it difficult for them to effectively manage pain. Further, availability of palliative care guidelines ($p=0.049$) in the hospital was associated with readiness of palliative care services. This could be attributed to the fact that availability of the guidelines provides a valuable consultation reference resource on which to base the provision of palliative care services. This builds capacity of the staff as well as their confidence in the staff to always be ready to offer palliative care services.

Despite the gains made by Uganda in provision of palliative care, this study found a low level of availability of palliative care and very low level of readiness for palliative care among the hospitals in Kampala city. Therefore, there is urgent need for the Uganda’s Ministry of Health to embark on a national campaign to improve the availability and readiness for palliative care among the country’s hospitals.

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