

## Original Research

# Characterising cancer burden and quality of care at two palliative care clinics in Malawi

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### Abstract

#### Background

This paper describes cancer burden and compares characteristics of cancer patients enrolled at 2 palliative care facilities of contrasting resources and geographical locations in Malawi. It also assesses the extent of differences in service delivery and the impact these might have on outcomes.

#### Methods

Data on all cancer patients registered between October 2010 and October 2015 at Tiyanjane Clinic (at Queen Elizabeth Central Hospital, Blantyre) and Mzuzu Central Hospital (MCH) palliative care clinics were extracted and analysed. Key informant in-depth interviews were carried out at both sites. Thematic analysis was used for qualitative data and Excel 2010 and Stata 12 were used for analysis of quantitative data.

#### Results

Quantitative: There were 1362 and 633 cancer patients at Tiyanjane and MCH, respectively. Overall, females predominated over males (55.8% vs 42.8%); however, Tiyanjane had more males (52.2% vs 45.8%), which was contrary to Mzuzu (77.4% females vs 22.6% males). The 35- to 54-year age group was predominant at both Tiyanjane (43.1%) and Mzuzu (40.1%). Overall, the most common cancers were Kaposi's sarcoma (26.9%), cervical cancer (26.8%), oesophageal cancer (14.2%), hepatocellular carcinoma (4.9%), and bladder cancer (3.0%). Histologically confirmed diagnoses accounted for 13% of cases at Tiyanjane, whereas all patients from MCH were diagnosed clinically.

Qualitative: Palliative care services were free of charge at both facilities, and owing to the expansion of services to district hospitals, the workload at central hospitals had been reduced. Between the 2 sites, there were differences in follow-up procedures, drug availabilities, as well as human resource capacity, with Mzuzu palliative care facility facing more extensive challenges.

#### Conclusions

The characteristics of patients seen at each site varied according to services available. Quality of care was assessed as superior at Tiyanjane, demonstrating the importance of multiple stakeholder involvement in the delivery of palliative care services.

### Introduction

Cancer is a leading cause of mortality and morbidity worldwide. However, cancer burden is disproportionately higher in developing countries.<sup>1</sup> In Africa alone, the burden is anticipated to double to 1.3 million new cases and 970,000 deaths by 2030.<sup>2</sup> This increase is largely driven by the aging population, population and economic growth, and adoption of traditionally Western risk factors, such as smoking, alcohol, obesity, and diet.<sup>3</sup> The problem is further compounded by late presentation in most sub-Saharan African settings, including Malawi. Most cancers are diagnosed at advanced stages and are therefore not amenable to treatment, resulting in poor prognoses. Palliative care is the most suitable treatment strategy for most of these patients. However, palliative care services remain unavailable or inaccessible in much of Africa.

Palliative care interventions can include those that extend life, and this may be an outcome of palliative treatment but primarily palliative care is about symptom control, quality of life, and support for patients and their families. The World Health Organization (WHO) defines palliative care as an approach that improves quality of life among patients and families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by

means of early identification and impeccable assessment and treatment of pain and other problems, be they physical, psychosocial, or spiritual. Evidence has shown that palliative care is beneficial in improving the quality of life of cancer patients as well as improving the treatment outcomes and survival.<sup>4</sup> In Malawi efforts have been made to make this crucial service available and accessible to those who need it. By 2010, 25 sites were providing palliative care services throughout Malawi. These sites included both government and private organisations.

Tiyanjane Clinic is an adult palliative care clinic that was established in 2003 at Queen Elizabeth Central Hospital (QECH) in Blantyre, which is the largest government tertiary facility in Malawi. Tiyanjane is supported by the Palliative Care Support Trust (PCST), a charitable trust, and the Malawi government. The clinic is situated within the hospital and provides services to inpatients referred from different departments, while also running an outpatient service for surrounding communities. The clinic team consists of 3 clinicians, 3 nurses, 1 HIV counsellor, and 2 support staff. There is a weekly Kaposi's sarcoma clinic, which includes chemotherapy for the Kaposi's sarcoma patients, and this brings in many patients from within Malawi's Southern Region.

**Table 1: Comparing palliative care services provided by Mzuzu Central Hospital and Tiyanjane Clinic at Queen Elizabeth Central Hospital in Blantyre**

Element	Mzuzu	Tiyanjane
Number of staff	1 nurse	
	Palliative care ambassadors (clinical officers with some palliative care training)	7 (1 doctor, 2 clinical officers, 4 nurses)
Staff qualifications	Training workshops by PACAM	University graduates
Support to palliative care providers	Donors	Trust funds training in Uganda and exchange visits abroad
	Hospital	Conferences abroad
	Clinical placements at QECH	
Partnerships	Church-based organisations	PCST
	Community-based organisations	Blantyre DHO
		Nongovernmental organisations
Services available		Outpatient clinic (3 x week)
	Daily outpatient clinic	Home visits (2x week)
		Kaposi's sarcoma clinic
Common medications available	Morphine + other painkillers	Morphine + other painkillers
	Antibiotics	Antibiotics
	Steroids	Anti-emetics
	Antimalarials	Laxatives
Common medications out of stock	Some antibiotics (e.g., metronidazole)	Some steroids (e.g., dexamethasone)
	Some painkillers	Some anti-emetics
	When out of stock: advice on local medication	When out of stock: PCST buys or patients are advised to buy on their own
Follow-up system	No follow-up system but sometimes make own initiatives to conduct home visits	Home visits done twice a week
		Call patients/guardians
Bereavement services		Review at DHC
	Not offered in full	Done during home visits but mostly for long term patients

PACAM = Palliative Care Association of Malawi; QECH = Queen Elizabeth Central Hospital; PCST = Palliative Care Support Trust; DHO = District Health Office; DHC = district health committee

On the other hand, Mzuzu Central Hospital (MCH) palliative care clinic is a fully government-run palliative care facility located within MCH, which is the only tertiary facility in northern Malawi. The clinic—established in 2007—provides paediatric and adult services to both outpatients and inpatients on a daily basis. It is run by 1 nurse who sometimes receives assistance from clinical officers who have had training in palliative care.

This paper compares characteristics of cancer patients registered at Tiyanjane and MCH palliative care clinics and explores the extent of differences in palliative care services delivery between the 2 clinics. The objectives of this work are to serve as a platform to enable different centres to learn from each other to allow for quality improvement in patient

care and to serve as a baseline for future studies on cancer and palliative care in Malawi.

## Methods

### *Study type and population*

This was a mixed methods study. Data on all cancer patients registered both at Tiyanjane and Mzuzu Central Hospital palliative care clinics, between October 2010 and September 2015, were extracted using the Malawi Cancer Registry Notification Form, which includes information on (a) demographic variables (age, sex, place of residence and marital status); (b) clinical data (date of diagnosis, method of diagnosis, cancer stage at diagnosis, HIV and antiretroviral therapy [ART] status); and (c) follow-up details (present living status, last seen date for the participants who were still alive or lost to follow-up, and date of death for the participants who were known to have died).

### *Inclusion and exclusion criteria*

The inclusion criteria incorporated incident cancer cases within the defined period, patients aged 15 years and above, of both sexes, who were attending either of the palliative clinics. Cases with missing data on diagnosis and cancer incident date and those attending palliative care for diagnoses that were non-cancer related were excluded, along with those who did not meet the inclusion criteria stated above.

### *Statistical analysis*

Descriptive analyses were performed in Microsoft Excel and Stata 12. Three key informant interviews were conducted with team leaders and at least 1 healthcare worker with a minimum of 2 years working experience at the respective clinics. Seeing as Mzuzu palliative care clinic was run by a single nurse, she was interviewed as team leader as well as health worker. Thematic analysis was used for qualitative data.

### *Ethical considerations*

Ethical approval to conduct the study was obtained from the University of Malawi College of Medicine Research and Ethics Committee (COMREC), and permission was

**Table 2: Demographic characteristics of cancer patients at Mzuzu Central Hospital and Tiyanjane Clinic (Queen Elizabeth Central Hospital, Blantyre) palliative care facilities**

Variable	Tiyanjane		Mzuzu		Total n	Percentage of total (%)
	n	%	n	%		
<b>Gender</b>						
Male	711	52.3	143	22.59	854	42.81
Female	624	45.8	490	77.41	1114	55.84
Unknown	27	1.9	0	0	27	1.35
<b>Age</b>						
15-34	426	31.28	83	13.11	509	25.51
35-54	587	43.09	254	40.13	841	42.16
55-75	274	20.12	242	38.23	516	25.86
75+	61	4.48	39	6.16	100	5.01
Unknown	14	1.03	15	2.37	29	1.46
<b>HIV status</b>						
Positive	698	51.25	129	20.38	827	41.45
Negative	414	30.4	315	49.76	729	36.55
Unknown	250	18.36	189	29.86	439	22
<b>Marital status</b>						
Single	78	5.73	23	3.63	101	5.06
Married	913	67.03	387	61.14	1300	65.16
Divorced	181	13.29	52	8.21	233	11.68
Widowed	166	12.19	159	25.12	325	16.29
Unknown	24	1.76	12	1.9	36	1.81

obtained from the directors of each palliative care facility. Identification numbers instead of names were used for all data obtained, and raw data were solely available to the study investigators.

**Results**

**Quantitative**

There were 2362 cancer patients registered between October 2010 and October 2015 at the 2 clinics (1510 at Tiyanjane and 852 at MCH). Of these, 148 cases at Tiyanjane and 219 cases at MCH were excluded from the analysis because they did not meet the inclusion criteria.

Table 2 shows the demographic characteristics of cancer patients registered at both palliative care facilities. At Tiyanjane there were 711 (52.2%) males and 624 (45.8%) females. The median age at enrolment was 41 years (range 15–98), with the 35- to 54-year age group (43.1%) being the most well represented. In relation to HIV status, 51.3% of patients included in the analysis were HIV-positive, 30.4% were HIV-negative, and 18.4% were of unknown HIV status. The most common cancers were Kaposi’s sarcoma (37.4%), oesophageal cancer (16.4%), cervical cancer (14.8%), hepatocellular carcinoma (6.1%), and bladder cancer (3.4%) (Table 3). Histologically confirmed diagnoses made up 13% of all cases (Figure 1).

Mzuzu palliative care clinic had 143 (22.6%) males and 490 (77.4%) females. Median age at enrolment was 52 years (range 15–94), with a predominance in the 35- to 54-year age group (40.1%). HIV-positive patients made up 20.4% of those included in the analysis, against 49.8% HIV-negative patients, and 29.9 % with unknown HIV status (Table 2). The most common cancers at MCH clinic included cervical cancer (52.5%), oesophageal cancer (9.5%), and Kaposi’s sarcoma (4.4%) (Table 3). There were missing data on how the cancer diagnosis was established (clinically, histologically, surgically, or using other methods) for 99% of the cases at MCH (Figure 1).

**Qualitative**

Services at both centres were freely accessible and both had experienced a decrease in the number of outpatients, owing to the expansion of palliative care services to surrounding districts. MCH had no documented follow-up system because they did not have the resources to implement initiatives, such as home visits (which were carried out twice per week at Tiyanjane). However, through personal initiative, home visits were sometimes

carried out by MCH palliative care personnel:

*“We visit the patients that live close to our locations or ask fellow health workers who live close to them to check on them and report on their condition after which they are assisted through the health workers.”* (MCH team leader)

The quality of life of patients referred to district hospitals for palliative care we usually unknown, as there were no systems in place for capturing such information at either facility during the time period captured by this study. Tiyanjane had community volunteers who maintained constant communication with the facility (regarding patient progress), while MCH had no such arrangement, owing to financial constraints.

There was a wider range of drugs used at Tiyanjane compared to the MCH palliative care facility. In cases of drugs stockouts at the main pharmacy, PCST supplemented medications at Tiyanjane; at MCH, guardians were requested to purchase any drugs that were not available from the hospital stock. If patients and their families or guardians were unable to afford medications, they were sometimes advised about remedies that could be prepared at home:

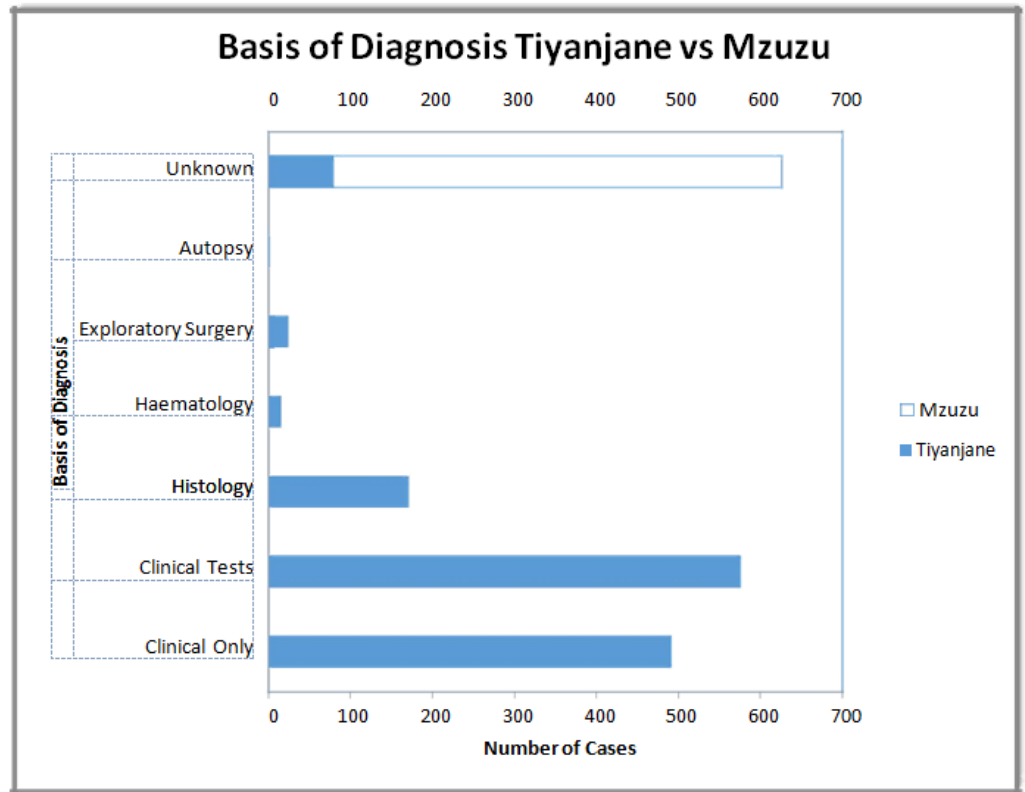
*“We never really went in class to learn some of these local remedies, but these are based on personal knowledge. I feel like this is better than just leaving them to go with a symptom unattended to.”* (MCH healthcare worker).

**Discussion**

The findings demonstrate a young age at enrolment into palliative care services and a predominance of AIDS-defining cancers, especially Kaposi’s sarcoma, at the 2 sites. The median age at enrolment at MCH palliative clinic was higher than that of Tiyanjane (52 years vs 42 years). The number of female cases was higher than the males; this possibly results from the high incidence of cervical cancer in the region and a scale-up in cervical cancer screening.

Malawi has an estimated adult HIV prevalence of 10.6% ( in the 15–64 age group).<sup>5</sup> Among males at Tiyanjane Clinic, Kaposi’s sarcoma was the most common cancer, followed by cancer of the oesophagus and hepatocellular carcinoma (Table 4a). A similar pattern was observed at MCH. Kaposi’s sarcoma was more common among men, likely because (compared to women) they are usually diagnosed with HIV later, and they present to healthcare facilities with advanced disease (including Kaposi’s sarcoma). However, Kaposi’s sarcoma was less common at MCH clinic, evidently related to the higher proportion of female patients treated at Mzuzu (favouring a higher prevalence of cervical cancer compared to other diagnoses). Additionally, the high proportion of Kaposi’s sarcoma at Tiyanjane was likely influenced by their provision of chemotherapy at their Kaposi’s sarcoma clinic (which was not available at Mzuzu).

Despite immense efforts put into awareness and screening, cervical cancer remains the most common cancer among women in the country. Among female patients seen at both palliative clinics, cervical cancer was the most common cancer diagnosis; this was not surprising, given that Malawi has one of the world’s highest age-standardised incidence rates of cervical cancer, estimated at 33.6 per 100,000 population.<sup>6</sup> In terms of both



**Figure 1: Basis of cancer diagnoses among patients at Mzuzu Central Hospital and Tiyanjane Clinic (Queen Elizabeth Central Hospital, Blantyre)**

**Table 3: Comparison of cancer types presenting to Mzuzu Central Hospital and Tiyanjane Clinic (Queen Elizabeth Central Hospital, Blantyre) palliative care facilities**

Type of cancer	Tiyanjane		Mzuzu		Total n	Percentage of total (%)
	n	%	n	%		
Kaposi’s sarcoma	509	37.37	28	4.42	537	26.92
Cervical cancer	202	14.83	332	52.45	534	26.77
Oesophageal cancer	223	16.37	60	9.48	283	14.19
Hepatocellular carcinoma	83	6.09	14	2.21	97	4.86
Bladder cancer	46	3.38	14	2.21	60	3.00
Colon and anorectal cancers	29	2.13	15	2.37	44	2.21
Breast cancer	29	2.13	14	2.21	44	2.21
Prostate cancer	35	2.57	5	0.79	40	2.00
Abdominal cancers	20	1.47	14	2.21	34	1.70
Bone cancer	19	1.40	14	2.21	33	1.65
Other cancers	167	12.26	123	19.43	290	14.54
<b>Total</b>	<b>1362</b>	<b>100</b>	<b>633</b>	<b>100</b>	<b>1995</b>	<b>100</b>

absolute frequency (332 vs 202) and proportion of all cancer diagnoses at each site (52.4% vs 14.8%), there was a higher burden of cervical cancer at MCH. It is unclear why there were more cases seen in the Northern Region compared to the Southern Region.

**Table 4a: Common cancer types among males presenting to Mzuzu Central Hospital and Tiyanjane Clinic (Queen Elizabeth Central Hospital, Blantyre) palliative care facilities**

Type of cancer	Tiyanjane	Mzuzu	Total
Kaposi's sarcoma	350	20	370
Oesophageal cancer	121	39	160
Hepatocellular carcinoma	54	7	61
Bladder cancer	27	5	32
Colon and anorectal cancers	13	6	19
Prostate cancer	35	5	40

Overall, the continuous high numbers of cervical cancer patients seen may result from an increase in the number of women presenting to health facilities for screening, and thus contributing to an increase in the number of diagnoses made (early rather than late). However, a study done by Munthali et al., in 2015, showed that despite the success of screening programmes, there were still a large number of females who did not present to health facilities to be screened, and some of the barriers included: inadequate knowledge, lack of spousal involvement, long distances to health facilities, male providers for services, shortages of equipment and staff, as well as screening not being done on a daily basis in some centres.<sup>7,8</sup> Other reasons for the high cervical cancer burden could include late screening, negligence, use of communication channels that might not be accessible to everyone, and transmission of misleading messages (for example, emphasis on screening only for HIV-infected and older women).

More than half of the patients at Tiyanjane (51.3%) were HIV-positive (compared to 20.4% at MCH). This might be explained by the higher prevalence of HIV in the Southern Region of Malawi compared to the Northern Region.<sup>9</sup> However, it could also be explained by the higher number of Kaposi's sarcoma cases seen at Tiyanjane (as mentioned previously)—most of whom were HIV-positive. Of all Kaposi's sarcoma cases treated at each clinic, 96.3% and 75.0% were HIV-positive at Tiyanjane and MCH, respectively. Owing to continually increasing access to ART, the incidence rates of AIDS-defining cancers seem to be decreasing. For example, the number of non-Hodgkin's lymphoma (NHL) cases was unusually low and more cervical cancer patients were HIV-negative. Tiyanjane integrated HIV testing and counselling into their services and therefore had fewer patients with unknown HIV status compared to MCH (18.4% vs 29.8%).

This study demonstrated a male predominance and young age at diagnosis for oesophageal cancer and hepatocellular carcinoma. The high prevalence of oesophageal cancer in the young population is contrary to what is reported elsewhere.<sup>10</sup> The increase in incidence of oesophageal cancer could be related to genetic factors, as well as shared environmental risk factors, such as low socioeconomic status, which was

**Table 4b: Common cancer types among females presenting to Mzuzu Central Hospital and Tiyanjane Clinic (Queen Elizabeth Central Hospital, Blantyre) palliative care facilities**

Type of cancer	Tiyanjane	Mzuzu	Total
Cervical cancer	202	332	534
Oesophageal cancer	91	21	112
Kaposi's sarcoma	156	8	164
Breast cancer	25	14	39
Hepatocellular carcinoma	24	7	31
Bladder cancer	18	9	27

shown in a study carried out at Tenwek Hospital in western Kenya.<sup>11</sup> The hepatocellular carcinoma prevalences are consistent with other studies. It is estimated that one in four men drink excessively in the Malawi,<sup>12</sup> and this high rate likely contributes to the high rate of hepatocellular carcinoma seen in this study. Other contributing factors include dietary aflatoxins, and chronic hepatitis B or hepatitis C infection.<sup>13,14</sup>

Other cancers common among women were Kaposi's sarcoma, oesophageal cancer, and breast cancer, which is consistent with other studies done in the Malawi.<sup>6,15</sup> A much lower proportion of cancers of the large bowel (anus, rectum, and colon) was observed. This was not surprising, as low prevalences of these cancers have previously been demonstrated in our setting.<sup>6</sup>

Despite histology being the gold standard for diagnosing cancer, only 13.8% of the cases at Tiyanjane and none of the cases at MCH had histologically confirmed diagnoses. Other studies carried out in Malawi showed similar patterns of low proportions (usually less than 20%) of laboratory-verified diagnoses. Some of the factors contributing to this include inadequate laboratory capacity and long waiting times for reporting of histology results.<sup>15,16</sup>

Tiyanjane Clinic is an example of how partnerships with multiple stakeholders can improve delivery of palliative care services. The expansion of palliative care services to district hospitals has improved access to these services outside of central hospitals and has reduced clinic workloads at central hospitals; reductions in outpatients visit numbers is evidence of this. However, referral systems between palliative care facilities need to be strengthened. Communities should be involved in taking care of palliative care patients, as there is evidence that much of the day-to-day care and building of relationships between patients, the palliative care team, and the community is done by volunteers within the community. The effectiveness of these volunteers is largely influenced by their closeness to the communities they work in.<sup>17</sup> The responsibilities of community-based volunteers should not be underestimated, especially since they provide home-based care, which is crucial to identifying critically ill patients as well as to providing ongoing social support and end-of-life care. The success of volunteerism and involvement of multiple stakeholders around activities organised by Tiyanjane Clinic serves as an example for other centres and programmes in Malawi to follow, as it allows for improved patient care and better follow-up for the patients at minimal costs.

The observations made during the conduct of this study provide evidence for the human resource capacity building

for palliative care in Malawi. For example, at the MCH palliative care clinic, as much as the efforts made should be commended, it is unreasonable to expect a single person to provide holistic care to the entire patient population served by the clinic. The ability of an institution or organisation to provide holistic care (which is said to have a profound effect on patient quality of life) is strengthened by a multidisciplinary, multiple-stakeholder team approach.

Palliative care has been shown to play a critical role in the management of chronic conditions, including HIV and AIDS, even in places where ART is available. A study done at Tiyanjane emphasised that palliative care may still be required for patients with HIV who are on ART, especially those who have treatment-related side effects, poor adherence, or HIV-related malignancies.<sup>18</sup> In light of this, MCH can expand its palliative care services to the patients seen at the oncology unit, who are on chemotherapy for Kaposi's sarcoma and other cancers, allowing for a holistic approach to their conditions.

Limitations of this study included time constraints, which only allowed for the investigation of 2 facilities, and this limits the generalisability of the results. Missing data on disease stage, diagnostic modality, and ART status made it difficult to establish the prognostic importance of these variables. Additionally, the high rate of clinical (as opposed to histologic) diagnoses may have led to the misdiagnosis of some cancers; for example, precancerous or other oesophageal lesions may have been diagnosed as oesophageal cancer, which would partly explain the high rate of oesophageal cancer among relatively young patients in this analysis.

There is a need to strengthen referral systems between palliative care facilities and involve more stakeholders to allow optimisation of patient care. In addition, focus should be put on risk factors for cancer other than HIV. Therefore, more research exploring risk factors for different cancers in the country is needed. There is need to scale up histopathology infrastructure in Malawi.

## Conclusions

The palliative care facilities investigated differed greatly in terms of resources. The characteristics of cancer patients enrolled at each site was affected by the various services that the two facilities provided. There continues to be a great unmet need for palliative care in Malawi, despite increased awareness over the years however. This findings outlined in this report provide support to advocate for external funding to help improve palliative care service provision. Future studies should examine patient perspectives about quality of life, patient and family support, as well as the effectiveness of available symptom control interventions.

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## Competing interests

All authors declare that they have no competing interests related to this work. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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