Provision of palliative care for life-limiting disease in a low income country national hospital setting: how much is needed?

Jane Lewington,1 Elizabeth Namukwaya,2 Julie Limoges,2 Mhoira Leng,2 Richard Harding3

ABSTRACT
Objectives This study aimed to measure the magnitude of palliative care needs among hospital inpatients. Objectives were to: (1) determine the point prevalence of inpatients with active life-limiting disease and (2) describe multidimensional need for palliative care among these patients.

Methods The study was a hospital inpatient census in Uganda. Patient notes were surveyed and those patients identified as having an active life-limiting disease were interviewed. Multidimensional palliative care need was assessed using the African Palliative Care Association (APCA) African Palliative Outcome Scale (POS).

Results 122/267 (46%) patient notes were found to indicate an active life-limiting disease. Diagnoses were: HIV/AIDS (74/122, 61%), cancer (22/122, 18%), heart failure (11/122, 9%), renal failure (11/122, 9%), liver failure (3/122, 2%) and chronic obstructive pulmonary disease (1/122, 1%). A total of 78/122 patients consented to be interviewed. Most patients reported multidimensional need in the three most negative of six categories for any APCA African POS question (75/78, 96%). Social problems included an inability to work (72/78, 92%), having unaffordable medical expenses (39/78, 50%) and limited access to food (11/78, 14%). Of those with a faith (72/78, 92%), more than a third (29/78, 39%) expressed the need for increased faith support.

Conclusions The prevalence of active life-limiting disease reported here (46%) is greater than in comparable European studies (5–23%). This reflects the sub-Saharan increased disease prevalence, presentation at a later stage and limited access to curative therapies. There is need for symptom control, food, financial assistance and spiritual support. Service development should be tailored to meet these needs.

BACKGROUND
The need for palliative care among inpatients in large teaching hospitals has been surveyed in well-resourced European settings.1–5 In a low income African setting the level of need is not known, although it will be reflected in the epidemiology of HIV,6 cancer7 and non-malignant life-limiting disease. In sub-Saharan Africa during 2009, there were 22.5 million people living with HIV infection; 1.8 million adults and children became infected with HIV and 1.3 million died of AIDS.6 There were an estimated 715 000 new cancer cases and 542 000 deaths from cancer in Africa in 2008.8 The burden of non-malignant disease is unknown but it has been estimated that in low income countries in 2004, heart disease accounted for 14% of all deaths, cerebrovascular diseases for 6% and chronic obstructive pulmonary disease for 4%.9 This compares with deaths from malignant neoplasms (5.9%) and HIV/AIDS (5.7%).

Palliative care has been defined as ‘an approach that improves the quality of life of patients and their 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, physical, psychosocial and spiritual’.10 In sub-Saharan Africa, specific needs under a ‘total care’ model of palliation may include financial support and also assistance with food and shelter.11 A community-based palliative care needs assessment in urban Uganda identified three main areas of need: pain and symptom control, counselling and financial assistance for basic provision such as food, shelter and school fees.12

Currently, the majority of palliative care services in sub-Saharan Africa are community-based,15 seen to be a culturally appropriate and affordable means of delivering care.14 These services are often provided by independently funded (non-governmental) organisations, and coverage beyond their geographical range is limited. This results in patchy provision of palliative care country-wide.15 Compared with high income settings, hospital-based palliative care services are rare and no evidence has been reported on how much palliative care is required for inpatient populations in sub-Saharan Africa.

The primary aim of this study was to measure the proportion of inpatients with active life-limiting disease (ALLD) who would be appropriate for palliative care intervention in a large tertiary referral hospital in sub-Saharan Africa. The secondary aim was to measure and describe the needs of this group of patients. The findings from these two aims are intended to inform resource allocation and service planning, and to assist in the development of referral criteria.

METHODS
Design
A point prevalence survey of patient notes was carried out on four wards, with subsequent cross-sectional patient self-report data on multidimensional well-being among patients with ALLD.
Setting
The survey was conducted at a tertiary referral teaching hospital (Mulago Hospital) in Kampala, Uganda, over seven consecutive working days in June 2009. The hospital has 25 ward areas with a total of 1500 inpatient beds. Two medical and two surgical wards were identified by the palliative care team as being most representative of the general hospital population, according to the following criteria: the presence of inpatient beds (ie, not an assessment unit), the absence of external funding which may provide additional nursing staff or facilities, and the ability of the team to access notes and approach the patients. The National Referral Hospital in Uganda receives patients from the entire country who are able to afford to travel to the capital, Kampala. There is no cost for an inpatient bed or for a selection of medications. For patients with no local or regional palliative care service their admission will be the only opportunity to provide palliative care, including opioid medication and education in bedside care for the patient and family if necessary. The hospital palliative care team consists of four government funded specialist nurses and two medical doctors.

Procedure
Following approval from the local ethics committee, all sets of patient notes on three wards were reviewed by a palliative care clinician. One ward was the location of a pilot survey of 50 patients. As no methodological changes were made, these pilot data were included in the final dataset. Those identified from their notes as having ALLD were approached for consent to a structured interview of 45 questions. The questionnaire includes seven patient-oriented questions from the African Palliative Care Association (APCA) Palliative Outcome Scale (POs). This is the only POS validated for use in sub-Saharan Africa and measures the presence and validity of multidimensional problems in line with WHO definition of palliative care. Questions were also adapted in part from the only prior published research into the palliative care needs of community palliative care patients in Uganda, with items assessing nutritional, financial, psychosocial or spiritual support. The proportion of the sample already known to the palliative care team and those who were receiving morphine was also documented.

Inclusion/exclusion criteria
Inclusion criteria were patients aged 13 years and above with life-limiting disease, specifically: HIV/AIDS, malignancy, chronic renal failure, chronic liver failure, congestive cardiac failure and chronic obstructive pulmonary disease. This age limit was set because patients aged 13 years or older are admitted to the adult wards. Any diagnosis of malignancy was included. For patients with no local or regional palliative care service their admission will be the only opportunity to provide palliative care, including opioid medication and education in bedside care for the patient and family if necessary. The hospital palliative care team consists of four government funded specialist nurses and two medical doctors.

Definitions
ALLD is defined for the purpose of this study as a disease which affects the patient which is likely to be terminal. For the purpose of describing the sample, the primary diagnosis was selected.

Analysis
Data were extracted and entered into SPSS v.16. Descriptive data were produced and the percentage calculated of patients in the sample with ALLD and their primary diagnoses. Socio-demographic data were described. The item-level responses for the APCA African POS were described and the proportion of patients with the worst half of the response range was calculated for each item. POS scores were not compared by diagnostic group due to the relatively small numbers of non-HIV patients. The proportion of patients with ALLD and palliative care needs as defined above were calculated.

RESULTS
Prevalence of patients with an ALLD
Of 267 patient notes examined, 122 (46%) were found to have an ALLD. This consisted of 23/121 (19%) of surgical patients and 99/146 (68%) of medical patients surveyed. The number of patients by diagnosis is shown in table 1.

Characteristics of those with ALLD
Of 122 patients with ALLD, 78 consented to be interviewed. Socio-demographic information was available for those patients who were interviewed; 50 (64%) were female, with a mean age of 58 years (range 13–80 years, SD 15.89). The mean length of stay prior to data collection was 10 days (range 0–38 days, SD 9.54). There are 43 recognised languages spoken in Uganda; interviews were conducted in seven different languages, with 63% (49/78) of patients questioned in their mother tongue. The majority (46/78, 60%) of patients lived up to 50 km from the hospital and 9% lived the furthest distance of 300–400 km away. All patients reported having a religious affiliation; 49% were Protestant, 34% Catholic and 17% Muslim. The most frequently reported employment (26%) was farmer/fisherman/manual labourer.

Respondents were asked to categorise their performance status; a third reported being confined to bed more than 50% of the time and needing help with care and 13% (10/78) reported...
being confined to bed 100% of the time and being fully dependent on others for care.

Most respondents had a relative or friend staying with them in hospital (52/78, 67%) or visiting daily (14/78, 18%). It is expected that a relative or friend brings food, washes sheets and clothes and collects and administers medication if the patient is unable to do so himself or herself. Eleven (14%) patients reported struggling to access food daily.

The majority of patients were too unwell to work (51/78, 65%) or did not have a job (21/78, 27%). Of the 50% (39/78) of respondents who were the primary economic provider for their family, two had a salary which was reduced due to their illness, and most (35/39) were unable to work or had no job. The median monthly income for those who responded (75/78) was 5000 Ugandan Shillings (£1.20 at the time of writing),18 with a mean income of 73 000 Shillings (£17.50), range of 0–300 000 Shillings (£0–£226). Half of respondents (39/78) had been asked to pay for medical expenses during their current admission and were unable to.

Three patients (4% of the sample) were known to the palliative care team at the time of the study.

The majority of patient notes examined (163/267, 63%) had no documented HIV status. Of those with a documented HIV positive status, the majority (46/48, 96%) had an advanced stage HIV, as classified by WHO staging criteria19 stage 3 or 4 disease.

**Symptom multidimensional burden reported using the APCA African POS**

**Pain and other symptoms**
Just under half of the sample reported pain (37/78, 47%) and other symptoms (38/78, 49%) in the three worst (most negative) categories of the APCA African POS (table 2). Two-thirds of respondents with HIV/AIDS reported pain (29/44, 66%), as did the majority of those with a diagnosis of cancer (12/14, 86%). There was a high prevalence of pain in the small number of patients with non-malignant disease: 4/6 (67%) with heart failure, 8/9 (89%) with renal failure, all three patients with liver failure and the single patient with chronic obstructive pulmonary disease. Of patients reporting the worst three out of six possible pain scores (37/78, 47%), only three were receiving oral morphine.

**Psychosocial**
POS questions 3, 4 and 7 were intended to identify psychosocial need (table 2). Approximately half of respondents answered in the three worst categories for worry (43/78, 55%), ability to share their feelings (37/78, 47%) and whether help with future planning had been available (41/78, 53%).

**Spiritual**
Two questions from the APCA African POS concerned the spiritual/existential aspect of need (table 2; questions 5 and 6). Fewer than half (31/78, 40%) answered in the three most negative categories concerning life being worthwhile. Patients were also asked whether they felt at peace, with nearly half (31/78, 40%) responding in the three worst categories.

Most patients in this sample reported multidimensional need in the three worst (most negative) of six categories for any APCA African POS question (75/78, 96%).

Additional questions were asked concerning faith. The majority of respondents reported that they had a faith (76/78, 97%). However, over a third (29/76, 38%) considered the spiritual support they were receiving was insufficient.

**Table 2 APCA African POS scores for the 78 patients interviewed**

<table>
<thead>
<tr>
<th>APCA African POS score</th>
<th>Best</th>
<th>Worst</th>
<th>Missing data</th>
</tr>
</thead>
<tbody>
<tr>
<td>POS question</td>
<td>0</td>
<td>1</td>
<td>2  3</td>
</tr>
<tr>
<td>1. Please rate your</td>
<td>14</td>
<td>13</td>
<td>10  15</td>
</tr>
<tr>
<td>pain (from 0=no pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to 5=worst/overwhelming</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pain during the last</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 days</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Have any other</td>
<td>11</td>
<td>12</td>
<td>15  17</td>
</tr>
<tr>
<td>symptoms (eg, nausea,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>coughing or constipation</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>been affecting how you</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>feel in the last 3 days?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Have you been</td>
<td>11</td>
<td>19</td>
<td>13  9  8</td>
</tr>
<tr>
<td>feeling worried about</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>your illness in the past</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 days?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Over the past 3</td>
<td>22</td>
<td>3</td>
<td>12  7  27</td>
</tr>
<tr>
<td>days, have you been</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>able to share how you</td>
<td></td>
<td></td>
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<tr>
<td>are feeling with your</td>
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<td></td>
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<tr>
<td>family and friends?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5. Over the past 3</td>
<td>12</td>
<td>12</td>
<td>7  8  23</td>
</tr>
<tr>
<td>days, have you felt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>that life was</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>worthwhile?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Over the past 3</td>
<td>17</td>
<td>12</td>
<td>9  13  13</td>
</tr>
<tr>
<td>days, have you felt at</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>peace?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7. Over the past 3</td>
<td>17</td>
<td>9</td>
<td>15  10</td>
</tr>
<tr>
<td>days, have you had</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>enough help and advice</td>
<td></td>
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<tr>
<td>for your family to</td>
<td></td>
<td></td>
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<tr>
<td>plan for the future?</td>
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</table>

**DISCUSSION**

This is the first prospective study to measure palliative care need among hospital inpatients in sub-Saharan Africa. This sample was drawn from a representative population of hospital inpatients, unlike previous studies of need in patients already receiving palliative care services. A total of 46% of the sampled inpatients were identified as having an ALLD. This is a larger proportion of inpatients than has been found in European settings (5–23%).1–4 This finding is not unexpected and reflects the increased prevalence of diseases such as HIV/AIDS, presentation to medical services at a later stage of disease and limited access to curative therapies.20

Need for palliative care was defined as the presence of unresolved physical symptoms, and/or psychosocial or spiritual needs. Approximately half of those with ALLD responded in the three worst categories for each of the APCA African POS questions. Almost all patients in this sample with ALLD reported need in the three worst of six categories for any APCA African POS question (75/78, 96%). This demonstrates a very high prevalence of multidimensional palliative care need among patients with ALLD.

There are several limitations to this study. The population of patients with ALLD was defined from a review of the notes. Patient notes are limited in the amount of information provided, as they often contain only information from the current admission and therefore may be incomplete. This study is...
limited to patients admitted to adult wards and was unable to include the needs of children and those too unwell to consent. Mulago Hospital aims to offer to HIV test all persons admitted if their status is not already known. However, this information was not recorded in 63% of ward notes surveyed. It is likely therefore that the estimate of palliative care need presented in this study is a conservative one.

Many languages were spoken by patients and wherever possible the interview was conducted in their first language or ‘mother tongue’ (achieved in 65%). However, there remains a risk of misinterpretation of questions or answers.

Of patients reporting pain in the three worst APCA African POS categories, only three were in receipt of oral morphine. This study did not ask further questions concerning analgesic regimes and patients may have been taking paracetamol, codeine, ibuprofen or sodium diclofenac (no other analgesics are commonly prescribed due to expense and lack of availability). Oral liquid morphine is available free of charge from the hospital pharmacy, but there are barriers to its use including prescriber and patient fears.\(^2\) The large proportion of patients in pain indicate the need for greater education of staff and patients and greater advocacy for adequate symptom control for ward patients with ALLD. The symptom burden among this sample of patients with ALLD is higher than that seen in other studies in sub-Saharan Africa.\(^1,2\)

The sample contained smaller numbers of patients with life-limiting non-malignant/non-HIV disease but these patients reported symptom burden and worry at least as frequently as those patients with HIV/AIDS or malignant disease. None of these patients were known to the palliative care team at the time of the study, integrating palliative care skills within generalist practise and agreeing criteria for referral to specialist palliative care.

The inpatient population of a government referral hospital tends to be from lower socioeconomic groups. A large proportion of our sample was unemployed or too sick to work (92%). Over half (51%) were unable to pay for necessary medical expenses such as for medication not available in the hospital pharmacy, radiotherapy, X-rays, CT scans or histology. It is possible to have some charges waived or funded by a small ‘comfort fund’ available from various sources, but this is not often known by the patient and a role of the palliative care team is to advocate for this on a patient’s behalf.

Faith is an important aspect of Ugandan life. The expressed need for increased spiritual support (38%) indicates a need for increased access to religious representatives during inpatient admissions and perhaps basic spiritual support from trained hospital staff.

The need for palliative care for those patients with ALLD in this survey is high. Three patients were known to the palliative care team at the time of the study. Palliative care as a specialty does not have the resources to review all patients in need, and appropriate education across other specialties should mean many needs can be met at generalist level with only those with complex needs being referred to specialist palliative care. In addition within this hospital system are resources (adequate analgesia, financial or spiritual support) which could be accessed by those in need. This survey has identified a need for education of hospital medical and nursing staff in the management of symptoms and other multidimensional problems. This has led to the development of postgraduate physician training and a nurse link programme. Those patients with complex unresolved symptoms should be referred to the palliative care team through agreed referral pathways.

On discharge, it is appropriate for patients to be referred to local community-based palliative care services. Where these are not available, it is essential that the patient is discharged with good symptom control and that the patient and family are provided with enough information to be able to continue effective care at home. In the absence of many community-based palliative care providers, hospital admissions may be a rare opportunity to access palliative care. Government health centres providing primary care may not be able to provide generalist palliative care due to a multitude of problems which include a lack of palliative care awareness and skills as well as few clinicians able to prescribe morphine even when it is available.

Mulago Hospital is the National Referral Hospital for Uganda. It is better resourced and has a larger hospital palliative care team than other government funded hospitals in the country. As a tertiary referral hospital it might be expected to admit more complex patients than a district general hospital, however as 60% of patients in this survey lived within 50km this may not be the case. It is likely that these results are generalisable to similar settings and that there is a large unmet need for palliative care among hospital inpatients across sub-Saharan Africa.

CONCLUSIONS

This survey aimed to inform the development of palliative care provision within a national referral teaching hospital in Sub-Saharan Africa. A high prevalence of palliative care need was found among this sample of inpatients. It is likely that these needs will be met only by a combination of education of all staff in basic palliative care and access to the specialist palliative care team for consultancy or comanagement for complex cases. In a low resource setting, a needs assessment as reported here is essential to prioritise finite resources to meet the multidimensional needs of people with life-limiting disease.

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Contributors J.Lewington designed the study, collected and analysed data, managed data collection and drafted the manuscript. E.N and M.L assisted design, collected data, assisted in interpretation and commented on drafts. J.I.Image assisted design and managed data collection. R.H assisted with study design and commented on drafts. All authors read and approved the final manuscript.

Competing interests None.

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