

# Caring for Life-Limiting Illness in Ethiopia: A Mixed-Methods Assessment of Outpatient Palliative Care Needs

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## Abstract

**Background:** Palliative care aims to reduce physical suffering and the emotional, spiritual, and psychosocial distress of life-limiting illness. Palliative care is a human right, yet there are vast disparities in its provision: of the 40 million people globally in need of palliative care, less than 10% receive it, largely in high-income countries. There is a particular paucity of data on palliative care needs across the spectrum of incurable disease in Ethiopia.

**Objectives:** The aims of this research were to assess the overall burden of life-limiting illness, the costs associated with life-limiting illness, and barriers to accessing palliative care in Ethiopia.

**Design:** Mixed-methods case-series.

**Setting/Subjects:** One hundred adults (mean age: 43.7 ± 14 years, 64% female) were recruited at three outpatient clinics (oncology, HIV, noncommunicable disease) and hospice patient homes in Ethiopia.

**Measurements:** Four internationally validated questionnaires were used to assess physical symptoms, psychosocial distress, and disability. In-depth interviews gauged poverty level, costs of care, and end-of-life preferences. Qualitative data were analyzed by thematic content, quantitative data by standard descriptive, frequency and regression analyses.

**Results:** In oncology, 95.5% of the population endorsed moderate or severe pain, while 24% were not prescribed analgesia. Importantly, 80% of the noncommunicable disease population reported moderate or severe pain. The mean psychosocial distress score was 6.4/10. Severe disability was reported in 26% of the population, with mobility most affected. Statistically significant relationships were found between pain and costs, and pain and lack of well-being. Very high costs were reported by oncology patients. Oncology withstanding, the majority of subjects wished to die at home. Oncology patients cited pain control as the top reason they preferred a hospital death.

**Conclusion:** There are extensive unmet palliative care needs in Ethiopia. Untreated pain and high costs of illness are the major contributors to psychosocial distress and financial crisis in this Ethiopian population.

**Keywords:** global palliative care; low-resource setting; primary palliative care

## Introduction

THE PATTERN OF DISEASE in Africa is changing.<sup>1</sup> Urbanization, population growth and longevity, improved socioeconomics, and the adoption of a western lifestyle have resulted in a rise in noncommunicable disease (NCD), and an

epidemiological transition.<sup>1–3</sup> NCD has surpassed communicable illness in terms of disability-adjusted life years (DALYs), and is now the leading cause of death globally, in those older than 50 years.<sup>1,4</sup> The burden of NCD is rising fastest in low- and middle-income countries (LMIC), where a disproportionate 80% of deaths due to NCD occur.<sup>5–7</sup> As a

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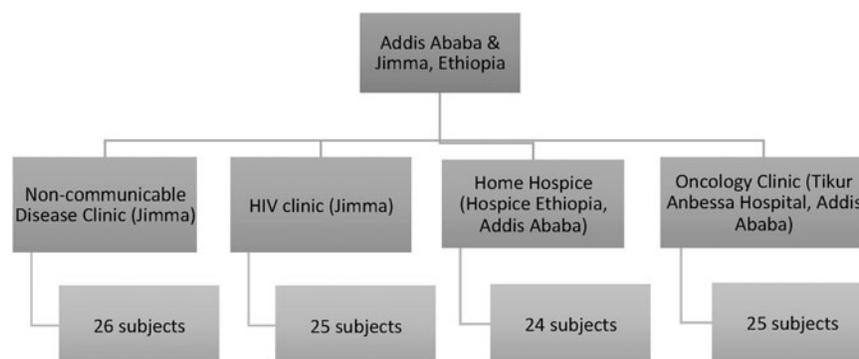


FIG. 1. Study design.

result, there is a great need to expand healthcare delivery to provide palliative care for all stages of life-limiting illness, from time of diagnosis through bereavement.

Of the 40 million people globally in need of palliative care, less than 10% receive it, largely in high-income countries.<sup>8,9</sup> Barriers to the integration of palliative care in LMIC include poor access to opioid analgesia, lack of healthcare policies that mandate palliative care, lack of palliative care teaching in medical education, and misconceptions, for example, that improving access to opioid analgesia will lead to increased substance abuse.<sup>10,11</sup> Other misconceptions include that it is only for patients with cancer or for the last weeks of life. The recognition that patients across the spectrum of chronic disease have pain and other symptoms that are not always adequately

managed has revealed an important role for palliative care in both high- and low-resource settings.<sup>12–14</sup>

Access to palliative care is a fundamental human right.<sup>15–18</sup> In addition to the moral and ethical imperative to relieve suffering, achieving Universal Health Coverage (UHC) is also now an important component of international healthcare policy.<sup>19</sup> The absence of palliative care services in many low-resource settings threatens our ability to achieve UHC and in extension, Sustainable Development Goal 3.<sup>20</sup>

The focus of this research is in Ethiopia, where there is little palliative care, limited access to opioid analgesia, and a concurrent lack of knowledge regarding the palliative care needs of the broad spectrum of patients living with life-limiting illness. Ethiopia is a large, low-income country in

TABLE 1. DEMOGRAPHIC INFORMATION

	<i>Home Hospice</i> (n=24)	<i>NCD clinic</i> (n=26)	<i>Oncology clinic</i> (n=25)	<i>HIV clinic</i> (n=25)	<i>Totals</i> (N=100)
Mean age (SD)	51.3 (14.6)	48.1 (14.7)	36.1 (11.6)	39.2 (11.6)	43.9 (14.1)
Gender (% female)	70.8	53.8	50	80	63.6
Ethnicity (%)					
Amhara	62.5	15.4	27.3	40	36.3
Oromo	25	50	40.9	28	36
Other	12.5	34.6	31.8	32	27.7
Marital status (%)					
Single	8.3	7.7	18.2	12	11.6
Divorced	12.5	3.8	0	16	8.1
Married	45.8	69.2	77.3	44	59.1
Widowed	33.3	19.2	4.5	28	21.2
Education (%)					
None	41.7	15.4	31.8	20	26.8
Reading and writing	4.2	0	31.8	4	9.3
Primary	29.2	50	13.6	36	33
Secondary	20.8	19.2	13.6	28	20.6
Postsecondary	4.2	15.4	9.1	12	10.3
Health (% with diagnosis)					
HIV	46	a	a	100	36
Cancer	42	a	100	a	35
Diabetes	13	42	a	a	14
Hypertension	17	58	a	a	19

<sup>a</sup>Not measured.

NCD, noncommunicable disease.

eastern Africa with a population of 99,000,000 and per capita income of \$590.00.<sup>21</sup> The physician to population ratio is 1/48,000.<sup>22</sup> The most common religions practiced in Ethiopia are Christianity (63%), of which 44% belong to the Ethiopian Orthodox Church, and Islam (34%).<sup>23</sup>

Ethiopia's health system comprises hospitals, health centers, health stations, and health posts, in decreasing order of clinical capabilities. In 1993, the Ethiopian government published its first health policy in 50 years and, since then, there have been improvements in many health indicators. The Health Sector Development Plan (HSDP) was launched in 1997 in an attempt to decentralize healthcare to reach more of the largely rural population and create a basic healthcare package.<sup>24</sup> The Health Extension Program (HEP) is another government strategy to increase essential health service access to rural populations by delivering a package of essential and preventive health interventions.<sup>25</sup> Due, in large part, to these and other programs, the past decades have seen an increase in the number of health facilities per population, and an improvement in health infrastructure. However, national health coverage is still poor: 75% of urban and 42% of rural dwellers live within walking distance to a health facility; most of the rural population has no access to modern medical care. National health coverage is estimated at 50%.<sup>26</sup> Ethiopia's healthcare is financed by the government (31%), by local and international nongovernmental organizations (37%), households (31%), and by private employers and funds (2%).<sup>26</sup> While some chemotherapeutics are subsidized by the government, frequent stock-outs force patients to buy these drugs at high cost outside the hospital or go without.<sup>27</sup>

Ethiopia has the highest burden of disease in sub-Saharan Africa with 350 DALYs per 1000 members of the population.<sup>28</sup> In 2015, NCD accounted for 60% of premature deaths in adults younger than 70.<sup>29</sup> Other smaller studies have also corroborated this high percentage of NCD deaths, including a verbal autopsy in Addis Ababa that reported 51% of deaths were due to NCDs.<sup>30,31</sup> A recent systematic review concluded that NCD is responsible for elevated morbidity and mortality in Ethiopia, and also that underreporting and lack of national vital statistics and epidemiologic studies hamper accurate assessments of the true burden of NCD in Ethiopia.<sup>32</sup>

This is especially true for oncologic diagnoses. The Ethiopian Federal Ministry of Health estimates 120,500 cancer cases and 50,000 cancer deaths per year, however, available data are limited.<sup>33,34</sup> There is currently one oncology hospital in the country and three practicing oncologists.<sup>35,36</sup> The latest Economic Intelligence Unit 2015 Quality of Death Index ranked the country 70th out of 80 countries assessed.<sup>37</sup>

Palliative care in Ethiopia is in its infancy, yet due to the tireless efforts of its advocates and supporters, it continues to grow. Nevertheless, Ethiopians living with life-limiting conditions have limited access to palliative care. Palliative care is currently not part of medical training nor is it an option for specialty training.<sup>38</sup> Hospice Ethiopia and Strong Hearts are two small nonprofit organizations located in Addis Ababa, which are the only licensed palliative care institutions in the country.<sup>39,40</sup> Each provides home-based hospice care to a census of 20–30 patients at any given time. Services include home visits by a nurse, pain and symptom management including oral morphine, and psychosocial support. Oral morphine is available for outpatients in Ethiopia by prescription

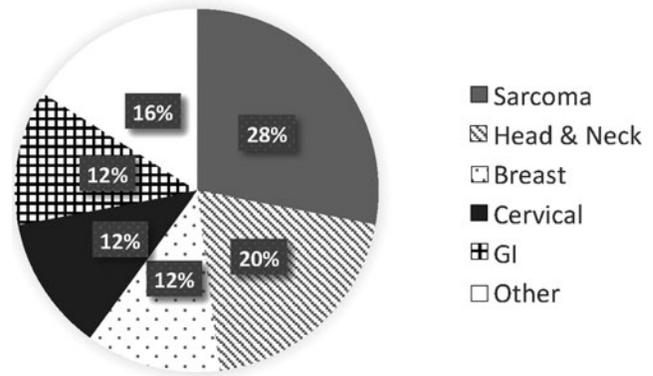


FIG. 2. Most common cancers in oncology clinic.

through tertiary hospital pharmacies and for patients being cared for by Hospice Ethiopia and Strong Hearts.

The aim of this research was to assess the need for affordable palliative care among patients with life-limiting illness in Ethiopia.

**Materials and Methods**

**Design**

A case-series, mixed-methods survey was conducted in four representative populations of patients with life-limiting illness in Ethiopia. A study design schematic is provided in Figure 1.

Adults older than 18 were recruited at the NCD clinic and HIV clinic at Jimma Hospital, oncology clinic at Tikur Anbessa Hospital, and Hospice Ethiopia's home-based care program, in Addis Ababa. Study enrollment was from May 2 to 25, 2016. Exclusion criteria included aphasia or other significant communication barrier. At each site, every patient was approached for study participation at the time of check-in for his or her appointment.

**Ethical considerations**

Informed consent was obtained from all participants using a modified World Health Organization template.<sup>41</sup> Care was

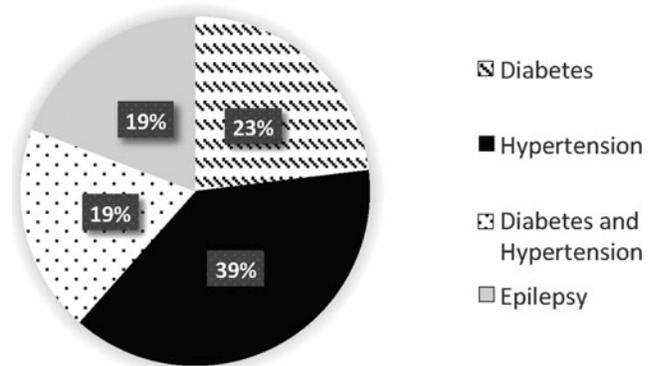


FIG. 3. Most common diagnoses in NCD clinic. NCD, noncommunicable disease.

TABLE 2. PALLIATIVE CARE INDICATORS

	Home hospice (n=24)	NCD clinic (n=26)	Oncology clinic (n=22)	HIV clinic (n=25)	Total (n=97)
Pain, % <sup>a</sup>					
No pain	20.8	19.2	0.0	64.0	26.0
Mild pain	0.0	0.0	9.1	12.0	5.3
Moderate pain	37.5	50.0	31.8	20.0	34.8
Severe pain	41.7	30.8	59.1	4.0	34.0
Psychosocial distress, mean (SD) <sup>b</sup>	6.8 (4.0)	6.0 (3.7)	8.0 (2.2)	4.9 (4.4)	6.4 (3.8)
Well-being, mean (SD) <sup>b</sup>	6.0 (3.4)	4.8 (2.3)	7.4 (2.0)	4.6 (2.8)	5.6 (2.8)
Disability, % <sup>c</sup>					
No disability	4.2	7.7	40.9	24.0	19.2
Some disability	24.8	42.3	32.1	44.0	35.8
Severe disability	71.0	50.0	27.0	32.0	45.0

<sup>a</sup>Pain experienced anytime in the last month was reported on a scale of 0–10 and then stratified based on severity (0=no pain; 1–3=mild pain, 4–6=moderate pain, 7–10=severe pain).

<sup>b</sup>Psychosocial distress and well-being were scored on a 0–10 scale, where 0 was lowest distress/best sense of well-being and 10 was the worst distress and worst sense of well-being.

<sup>c</sup>Subjects were classified as some disability if they reported “some difficulty” in at least one of six domains surveyed. Severe disability was determined by a report of severe impairment in at least one of the six domains or moderate impairment in more than two domains.

taken with respect to vulnerable subjects’ consent based on prior research in this area. Consent forms were developed with the knowledge that the study population would have a low literacy rate and thus were provided in both written and oral format, in the patient’s native language. Signatures or inked thumb prints were obtained to confirm study consent.<sup>42,43</sup> Interviews took place in a private room with a closed door and were structured such that the subject had a one-on-one conversation with the research assistant, who in real time translated responses to Eleanor Reid for recording. Family was permitted to stay if the subject wished. Bottled water and a small snack were provided for all subjects (total: 1 USD). The maximum allowed interview time was one hour. All information was kept confidential and anonymous.

The study was approved by the Jimma University College of Health Sciences Internal Review Board and granted exemption by the Yale University Internal Review Board.

### Data collection

Data collection consisted of both qualitative and quantitative methods, using a composite questionnaire. The composite questionnaire was translated into the two main

languages of Amharic and Oromo by native speakers and then translated back into English. Each question was asked in the patient’s native language by a research assistant, who then translated the responses back into English for data recording. If clarification was needed, Eleanor Reid/Yoseph Mamo prompted the research assistant with additional questions. Eleanor Reid/Yoseph Mamo recorded subject responses to both qualitative and quantitative questions on paper data collection forms, thus generating a paper transcript in English. The quantitative data were then entered into Microsoft Excel, cross checked, and imported into SPSS (IBM SPSS Statistics for Macintosh, Version 22.0. Armonk, NY) for analysis. Paper transcripts of qualitative data were entered into Microsoft Excel. All data collected were deidentified. All subjects completed both the qualitative and quantitative portions of the questionnaire. All research assistants completed a training session with Eleanor Reid and Yoseph Mamo before commencing patient interviews. The data are stored on a password-protected computer, and paper data collection forms are stored in a locked office in Addis Ababa, Ethiopia.

The questionnaire comprised basic demographic information (e.g., age, gender, diagnosis), questions regarding

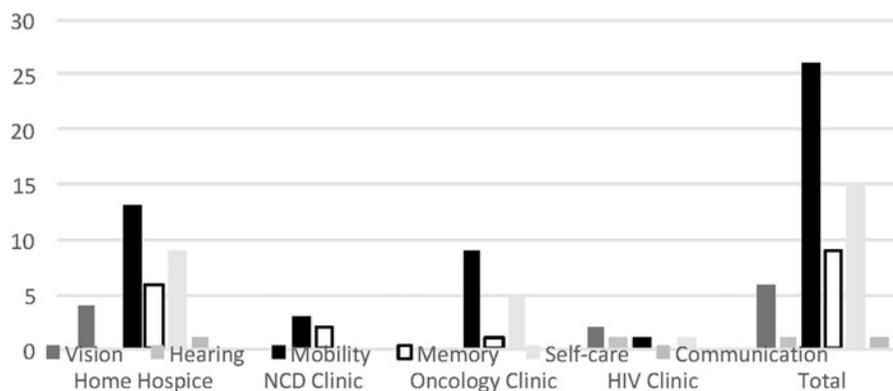


FIG. 4. Severe disability by modality.

TABLE 3. COSTS OF ILLNESS

	<i>Home hospice</i>	<i>NCD clinic</i>	<i>Oncology clinic</i>	<i>HIV clinic</i>	<i>Total</i>
Financial hardship, mean (SD)	7.2 (3.0)	6.2 (4.0)	8.4 (1.4)	8.8 (2.5)	7.6 (3.0)
Worried about costs of medical care, %	79.2	84.6	95.5	88.0	87
Sold personal assets to pay for medical care, %	50	19.2	63.6	44.0	44.2
Someone has taken time off school/work to care for me, %	58.3	26.9	68.2	68.0	55.3
Reported costs of medical care in last month, mean (SD)	17.6 (30.4)	8.9 (11.0)	207.1 (273.4)	3.3 (7.5)	55.4 (154.9)

costs of care, and end of life preferences (see Appendix 1: Qualitative Survey) and four previously validated surveys:

- APCA African Palliative Outcome Scale (POS)<sup>44</sup>
- Needs at End-of-Life Screening Tool (NEST13)<sup>45</sup>
- Edmonton Symptom Assessment Scale (ESAS)<sup>46</sup>
- Washington Group Disability Assessment Short Set<sup>47</sup>

Pain experienced anytime in the last month was reported on a scale of 0–10 and then stratified based on severity (0 = no pain, 1–3 = mild pain, 4–6 = moderate pain, 7–10 = severe pain). Subjects screened in for disability if they reported “some difficulty” in at least one of six domains, including vision, hearing, mobility, self-care, communication, and memory. Severe disability was determined by a report of severe impairment in at least one of the six domains or moderate impairment in more than two domains. Socioeconomic status was assessed through the number of items reported from a list of 15 common personal and household items, number of meals eaten per day, materials the subject’s home was made from, and type of toilet. Costs of medical care were out-of-pocket over the last month and were self-reported.

### Data analysis

Quantitative data were analyzed using standard descriptive and frequency analyses. Regression and correlation analyses were used to explore relationships between total costs of care and study site, cost and quality of life, cost and psychosocial distress, and sociodemographic features. Qualitative data were analyzed for common themes and coded by ER by theme (e.g., for type of item sold to pay for medical costs 1 = livestock, 2 = gold, 3 = land), for frequency analysis. A priori codes were established before study start and emergent codes were added for trends that were revealed during data analysis.<sup>48,49</sup>

### Results

Baseline demographic features are summarized in Table 1. Two patients were excluded due to aphasia. Two patients aged 16 were included because they were married. The mean age was 44 years. The overall study population was 64%

female. Almost 30% of the population had received no formal education. Across groups, subjects reported a similarly small number of personal assets (4.1). The number of meals eaten per day was lowest in Home Hospice (58% reported eating three meals per day), compared with 84% for the study population. Ninety-one percent of subjects reported living in a home with a corrugated iron roof, 84% reported walls made from mud, and 84% had a pit latrine at home.

The most common medical diagnoses carried by patients in Home Hospice were HIV (46%) and cancer (42%), of which the most common cancers were breast (70%) and lung (20%). In the oncology clinic, the most common cancers were sarcoma (28%) and head and neck cancers (20%) (Fig. 2). Within the NCD clinic population, the most common diagnoses were hypertension and diabetes: 38.5% of this site population was hypertensive, 23% diabetic, and a separate 19% carried diagnoses of both hypertension and diabetes. The remaining five subjects at this site were diagnosed with epilepsy (19%) (Fig. 3).

### Palliative care indicators

High levels of pain and distress were found across the study population (Table 2). Pain scores were highest in oncology clinic, where 59% reported severe pain and 32% reported moderate pain. Nearly 42% of Home Hospice patients also reported severe pain despite receiving oral morphine. Importantly, 80% of the NCD clinic population reported moderate or severe pain. The lowest pain scores were found in the HIV population. Psychosocial distress also scored highest in oncology and Home Hospice patients.

Disability levels were calculated across the domains of vision, hearing, mobility, memory, self-care, and communication. Severe disability was highest in the Home Hospice group (70%). The NCD population also reported high disability levels (50% severe disability, 42.3% some disability).

Of the different domains of disability surveyed, mobility was most affected (26.8% of the total population reported severe disability in mobility), followed by self-care, where 15.4% of the total population reported severe disability (Fig. 4).

TABLE 4. PALLIATIVE CARE COVERAGE

	<i>Home hospice</i>	<i>NCD clinic</i>	<i>Oncology clinic</i>	<i>HIV clinic</i>	<i>Total</i>
Clarity of information given by medical providers, mean (SD)	5.7 (4.2)	3.0 (3.9)	7.7 (3.4)	1.0 (2.0)	4.2 (4.3)
My medical care aligns with my goals, mean (SD)	5.3 (3.3)	2.7 (2.9)	5.6 (2.9)	0.7 (1.7)	3.5 (3.4)
Preferred location of death, %					
Home	79.2	57.5	27.3	64.0	57.0
Hospital	20.8	42.3	63.6	32.0	39.7

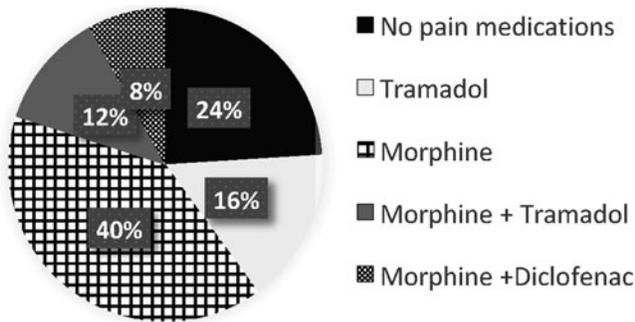


FIG. 5. Pain medications prescribed in oncology clinic.

### Costs of illness

The out-of-pocket costs of medical care over the preceding month, including medications, medical treatments, and transportation to receive medical care or purchase medications, were highest in the oncology group (mean \$207 compared with \$55.4 for study population). In the oncology and HIV groups, 68% reported that a family member or friend had taken time off work to care for them, resulting in a second lost salary (Table 3).

Qualitative analysis on reported costs of care revealed common themes of families being so devastated by the costs of medical care that they were forced to sell major assets such as wedding gold, livestock, and land. Oncology patients were the most financially devastated: 64% of patients reported having sold their homes and other significant sources of wealth to pay for medical care. In addition, while many of the oncology clinic patients had extensive, advanced disease, none was aware of his or her terminal diagnosis. Using Spearman's rank correlation analysis, we found a statistically significant relationship between cost and pain ( $\rho = 0.394, p < 0.01$ ) and cost and well-being ( $\rho = 0.325, p < 0.01$ ).

### Palliative care coverage and end-of-life preferences

With respect to clarity of information received from medical staff regarding diagnosis, the most clarity was reported in the HIV clinic, while the lowest scores for clarity

were found in oncology and Home Hospice (1.0, 7.7, and 5.7 out of a worst possible score of 10, respectively). When subjects responded to whether their medical care aligns with their goals, again the highest scores were found in the HIV clinic and the lowest scores were found in oncology and Home Hospice (0.7, 7.4, and 6.0 out of a worst score of 10, respectively) (Table 4).

In oncology clinic, 24% of patients were not prescribed any analgesia. Sixteen percent were prescribed tramadol only, while 40% were prescribed morphine (Fig. 5).

Across the study population, the majority of subjects expressed a preference for a home death (57% home vs. 39.7% hospital). When analyzed by study site, only the oncology subjects in majority preferred a hospital death (63.6% hospital vs. 27.3% home). The reasons cited for preference for a hospital death by oncology patients were most often related to pain control. Results from this qualitative analysis on end-of-life preferences are shown in Table 5.

### Discussion

While prior investigators have sought to better understand the palliative care needs of oncology and HIV patients in Ethiopia,<sup>39,50</sup> we believe this is the first assessment of palliative care needs across the spectrum of life-limiting illness in Ethiopia. As such, it has revealed a plethora of information regarding the challenges of living with life-limiting illness in this low-resource setting. Most importantly, the study uncovered a great need for palliative care, coupled with low coverage and high costs of illness, especially in the oncology population.

Pain control was inadequate across sites but especially in cancer patients. Accessing oral analgesia seems to be the major constraint, however, even in oncology clinic where oral morphine was available, 24% of the population was not prescribed any form of analgesia. This suggests a role for both providers and patients in insisting on improved pain control.

Previous investigators have reported the need for palliative care in chronic disease to address the disability, pain, and psychosocial distress that often accompany physical illness.<sup>12,51</sup> Our results mirror these findings: in NCD clinic, 50% of subjects reported high disability while mobility was most affected, which has important implications for delivery

TABLE 5. THEMATIC AND ANALYSIS-PREFERRED PLACE OF DEATH

Home Death preferred
"I want to be surrounded by my family."
-Subject 15, female aged 52, diagnosed with cancer, cared for by Home Hospice.
"So I can take care of my son. If I'm in the hospital, who will take care of him?"
-Subject 8, male aged 56, diagnosed with HIV, cared for by Home Hospice.
"Because there is respect at home. I will be happy when my life has passed in the company of my family."
-Subject 65, male aged 60, diagnosed with hypertension and diabetes, care for in Chronic Disease Clinic.
"I don't want my family to pay the high costs of me dying in a hospital. Home is less stressful and it is peaceful compared to the hospital. These two are connected."
-Subject 53, female aged 46, diagnosed with HIV and cared for in HIV Clinic.
"In the hospital the health care workers give treatment but no comfort. I will be comfortable in my own. There is nowhere as comfortable as my home."
-Subject 63, female aged 37, diagnosed with HIV and cared for in HIV Clinic.

of services to reach this population with limited mobility, and potentially an increased role for home-based care. In addition, 50% and 31% of subjects in the NCD clinic reported moderate and severe pain, respectively. The etiology of elevated pain scores in this population is unclear but may be related to undiagnosed arthritis or other sources of physical pain, including complications of diabetes such as neuropathy. Alternatively, these scores may reflect a multifactorial representation of total pain which is not just physical but also psychological, social, and spiritual.<sup>52-54</sup> A deeper exploration of elevated pain scores in this population is currently in planning stages.

Mental health sequelae of physical disease, including high levels of anxiety and depression, were also prevalent in this patient population (from 4.9 in HIV clinic to 8.0 out of 10 in oncology clinic) and thus merit being assessed and addressed. As Ethiopia is a highly spiritual/religious country, it is possible that nonpharmacologic interventions such as increased support from family and members of the appropriate religious community might mitigate some of this distress, as has been true in other similar locations.<sup>53,55,56</sup>

High health expenditures are known to lead to impoverishment, especially in low-resource settings, and financial protection is a core tenet of universal access to affordable care.<sup>54,57</sup> Economic models demonstrate that chronic disease simultaneously destroys the internal family resources and stunts local economic growth.<sup>58</sup> Although this study was not designed as a cost/effectiveness analysis, it did assess the personal cost of life-limiting illness and found it to be very high, particularly in oncology. We also found a correlation between cost and pain level, and cost and well-being, which replicates prior qualitative results that have highlighted the frequency of financial stressors at end of life, and the importance of addressing financial needs in end-of-life care, in particular as a component of emotional, social, and spiritual care.<sup>57</sup> Future studies designed to address and analyze the economics of palliative care will be better able to answer the crucial question regarding its cost/effectiveness and potential role as a poverty protection strategy.

Despite a lack of knowledge of the possibility of home-based care and analgesia, the majority of subjects preferred to die at home, except in oncology. An explanation for this discrepancy relates to pain. Oncology patients had the highest pain scores and no familiarity with the concept of home care, and thus, they chose the hospital to not die suffering. A second explanation has to do with the delivery of bad news: although many oncology patients had advanced or terminal disease, none was aware of his or her prognosis. As most had not been appropriately counseled on prognosis, many were still searching for a cure, often at high cost. Supporting this hypothesis is the result that oncology subjects also reported the lowest scores for clarity of information received from medical providers.

Limitations to this study include its small sample size, the self-reported nature of the data, and case-series study design. Future surveys could use hospital, pharmacy, and clinic records for objective measures of direct costs and diagnoses, although it is unclear how complete these financial records may be, or whether a medical record would be more reliable than a self-report in characterizing symptoms. Nevertheless, we have collected both qualitative and quantitative data on 100 patients, using a questionnaire that comprised over 100

data points per patient, and in-depth questions regarding the culturally sensitive and complex issues surrounding end-of-life preferences in this population.

A large percentage of our study population had little formal education, and our study scales were all numeric, potentially causing comprehension issues. The Wong-Baker FACES scale could be used in future studies to mitigate this. In the NCD clinic, it is unknown whether diabetes and hypertension were controlled, which could affect questionnaire responses.

Another potential limitation is site selection. We purposively chose the four sites with the aim of capturing a representative sample reflective of the Ethiopian population that may benefit from palliative care. At the time of this needs assessment (May 2016), Hospice Ethiopia's Home Hospice had a census of 32 patients, and we recruited 24 for participation. The sample size for the remaining sites was determined by convenience sampling as well as time and funding constraints. With the exception of the Home Hospice site, all other patients were seen in an outpatient setting, thus any home-bound patient would be missed. As such, these results are likely an underestimation of the actual need for palliative care in Ethiopia and should not be generalized outside of Ethiopia.

## Conclusion

There is distinct need and role for increased access to palliative care in Ethiopia, across the spectrum of life-limiting illness. Ethiopia's vibrant, rich, and ancient culture prioritizes a family approach to end-of-life care, through which the burden of disease is shared among family members, while the person who is ill is protected from receiving the bad news, instead receiving the care and support of family. There is an Ethiopian proverb that states, "For one person, fifty lemons are a burden, for but fifty people, fifty lemons are like jewelry." This proverb speaks about the importance of shared burden in Ethiopian culture. Efforts to improve palliative care delivery in Ethiopia must be cognizant of the communication and cultural differences that exist between western and Ethiopian culture, through tailoring western concepts of transparency and the delivery of bad news to a family-based model. Promisingly, the majority of subjects interviewed stated that they wished to die at home, and the medical providers we worked with embraced the concept of palliative care and, specifically, being able to offer patients and their families something when curative treatments were no longer effective.

Crucial next steps include a clear demonstration of the cost/effectiveness of palliative care in this setting, which in turn will guide healthcare policy and funding. To this end, we are planning a pragmatic combination of implementation and economic analysis, with the goal of increasing knowledge of and access to palliative care in Ethiopia, securing this human right for all.

## Author Disclosure Statement

No competing financial interests exist.

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#### APPENDIX 1: QUALITATIVE SURVEY

1. What has it been like for you dealing with your healthcare costs?
  - a. Are you worried about the cost of your care?
  - b. In the last month, how much money did you spend on medications?
  - c. In the last month, how much money did you spend on medical visits (clinic visits, emergency room, procedures)?
  - d. In the last month, how much money did you spend on travel for medical care?
  - e. Have you had to sell any of your belongings to pay for medical care?
  - f. Is there anything we haven't discussed about how you've been dealing with the expenses?
2. Does anyone help take care of you?
  - a. Are they reimbursed?
  - b. Have any family members taken time off work or school to help care for you?
  - c. Have you helped to take care of ill family members or friends before?
1. Have you been given a prognosis by your doctor?
 

YES    3 months    6 months    12 months    >12 months

NO
2. (For clinic patients) What do you know about hospice care?
5. (For clinic patients) If you or someone in your family had a disease without a cure, would you like to be cared for by hospice?
6. (For clinic patients) Would you prefer to die at home or in a hospital?
7. (For Home Hospice patients) What medication/service/practice has been most important in helping decrease your pain?
8. (If answer to 7 is a medication) Is it ever hard to get this medication?
 

NO (I can always get this medicine)

SOMETIMES

OFTEN

MOST OF THE TIME (I rarely can get this medication)
9. Do you have a religion?
10. What do you believe is the origin of your disease? Is there a cause?