African Palliative Care Association

Prevalence and severity of palliative care

Related problems among ambulatory patients diagnosed with cardiovascular diseases, cancer, chronic respiratory diseases or diabetes in two sub-Saharan African countries

African Palliative Care Association
Relieving Pain and Suffering

OSISA
Open Society Initiative for Southern Africa

MWAPO Health Development Group
Enhancing health and social care outcomes across Africa

African Palliative Care Research Network
Uniting to Provide Evidence

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ACKNOWLEDGEMENTS

The authors wish to thank the following for their invaluable contributions to this study: the respective country Ministries of Health; the University of Namibia (Windhoek and Oshakati campuses); the Palliative Care Association of Malawi; and the African Palliative Care Research Network.

Special mention is made to those students who assisted with data collection in Namibia, who were third year medical and nursing students from the School of Medicine and School of Nursing, Oshakati campus: Reach Nangolo, Benyamen Shivute, Iyaloo Shiimi, Lene le Roux, Dennis Noa, Gerrit de Villiers, Petrus Litula Bupe Zeko, Eino Fikameni, Rauna Mulongeni, Ndadi Tobias, Mateus Immanuel and Mateus Selma.

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LIST OF ACRONYMS

APCA African POS	African Palliative Care Association Palliative Outcome Scale
CES-D	Center for Epidemiologic Studies Depression Scale
COPD	Chronic obstructive pulmonary disease
CRD	Chronic respiratory disease
CVD	Cardiovascular disease
GDI	Global Distress Index
KPS	Karnofsky Performance Scale
LMICs	Low- and middle- income countries
MSAS-GDI	Memorial Symptom Assessment Schedule – Global Distress Index
MSAS-PHYS	Memorial Symptom Assessment Schedule – Physical symptoms sub-scale score
MSAS-PSYCH	Memorial Symptom Assessment Schedule – Psychological symptoms sub-scale score
MSAS-SF	Memorial Symptom Assessment Schedule – Short Form
NCD	Non-communicable disease
NYHA	New York Heart Association Functional Classification
OSISA	Open Society Initiative for Southern Africa
OSF	Open Society Foundations
PHP	Public Health Programme
SD	Standard deviation
TMSAS	Total Memorial Symptom Assessment Schedule score
WHO	World Health Organization

EXECUTIVE SUMMARY

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Background

There is a growing recognition in Africa of the importance of addressing non-communicable diseases (NCDs) and advancing palliative care service provision for these patient groups. However, international funding in response to the AIDS epidemic has arguably focused palliative care delivery away from patients with non-HIV diagnoses, such as NCDs.

A starting point in addressing the lack of access to adequate palliative care for patients with an NCD diagnosis is an assessment of the physical, social, psychological and spiritual symptom burden experienced by patients with an active, life-limiting NCD diagnosis. Minimal work has been undertaken to investigate this area in sub-Saharan Africa. This study aimed to contribute to the burgeoning NCD global agenda by conducting an exploratory study of the palliative care-related problems of patients diagnosed with one of the four most prevalent NCDs in the region.

Objectives

The overall goal of this study was to determine the prevalence and severity of the palliative care-related problems patients diagnosed with any of the following conditions: i.e., cardiovascular diseases (CVDs), cancer, chronic respiratory diseases (CRDs) and diabetes. The objectives of this study were to:

- Establish the prevalence of palliative care-related problems – using the WHO definition of palliative care (i.e., the domains of the physical, psychological, social and spiritual) – among people diagnosed with one of the above conditions;
- Determine the intensity of palliative care-related problems among patients diagnosed with any of the above conditions;
- Determine the symptoms commonly experienced by patients presenting with any of the above four conditions;
- Determine the symptom severity among patients presenting with any of the above conditions, and;
- Evaluate the correlation between symptom prevalence / severity and distress and socio-demographic and selected clinical factors.

Methods

This was a quantitative survey using a cross sectional, self-report study design. It was conducted among ambulatory adult patients at specialist tertiary-level referral centres in two Southern African countries (Malawi and Namibia) using the following data collection tools: a demographic and clinical questionnaire; a modified version of the Karnofsky Performance Scale; the APCA African Palliative Outcome Scale; the Memorial Symptom Assessment Schedule – Short Form (enhanced); and the Center for Epidemiologic Studies Depression Scale.

Results

A total of 457 patients participated in the study: Malawi (207); Namibia (250). Over half of respondents were female (58.9%; n=269), with the mean age being 48 (SD: 15.7), and 45.5% (n=208) had attained secondary education. Primary diagnoses included 28.4% (n=130) with CVDs (of these, 69.7% [n=86] had hypertensive heart disease, 10.6% [n=13] had ischemic heart disease); 32.2% (n=147) with cancer; 16.0% (n=73) with CRD (of these, 80.6% [n=54] had persistent asthma); and 23.4% (n=107) with diabetes. Additionally, 43.8% (n=200) reported having co-morbidities, and 17.9% (n=82) reported a positive HIV sero-status.

The three palliative care-related problems with the highest intensity were: shared feelings (i.e., not at all/not very often). The proportions reporting high intensity were 28% CVDs, 23% CRDs, 22% cancer and 21% for diabetes. Second was help and advice (i.e., none/very little): 28% cancer, 26% CVDs, 22% diabetes, and 16% CRDs. Worry (i.e., most/all the time): 27% cancer, 18% CVDs, 18% diabetes and 14% CRDs. The most prevalent physical symptoms were: pain, reported by 78% (n=115) of cancer patients, 68% (n=89) of CVD patients, 68% (n=49) of CRD patients and 73% (n=78) of patients with diabetes. This was followed by lack of energy, reported by 63% (n=93), 55% (n=71), 68% (n=50) and 74% (n=79) of cancer, CVD, CRD and diabetes patients, respectively. Cough was common (68%; n=50) in patients with CRD, while dry mouth, numbness and hunger were more common in diabetic patients, with a prevalence of 61% (n=77), 64% (n=68), and 70% (n=75), respectively. Difficulty sleeping was more common in patients with CRDs (60%; n=44) and diabetes (53%; n=57). Weight loss was more common in cancer patients (58%; n=85). Worry was the most common psychological symptom, reported by 73% (n=107) of cancer, 65% (n=84) of cardiovascular, 77% (n=56) of CRD and 72% (n=77) of diabetic patients. Feeling irritable was more common in cancer patients (52%; n=77).

Qualitative data also revealed the economic burden of NCDs from the patient perspective, revealing costs as one of the main pressing problems. Costs related to transport and medication were a common theme.

Discussion

Patients with NCDs experience a high burden of palliative care-related problems. These patients also experience clinically significant psychosocial distress. Efforts should be undertaken to provide a comprehensive palliative care package for NCD patients, covering not only symptom control interventions but also mental and spiritual care and social support. There is a need to think of models of care that achieve similar outcomes with affordable transport and medication costs for patients. Potential options in this regards are investments in decentralised, community-focussed services that are more rural based than urban with limited geographic coverage and empowering nurse practitioners to take on necessary additional roles as part of a task shifting agenda. These services could also make use of improved health technology.

BACKGROUND AND JUSTIFICATION

BACKGROUND AND JUSTIFICATION

There is a growing recognition in Africa of the importance of addressing non-communicable diseases (NCDs) and advancing palliative care service provision for these patient groups.[1,2] Originating in the continent over 30 years ago,[3,4] palliative care in Africa has made significant advances over the last decade, including an increased number of service providers.[5,6,7] However, international funding in response to the AIDS epidemic has arguably focused palliative care delivery away from patients with non-HIV diagnoses,[8] such as NCDs, further limiting access to people with unmet needs. Moreover, the overwhelming majority of palliative care research to generate the evidence necessary to address patients' needs, as well as their preferences and priorities, has not been conducted in low- and middle-income countries (LMICs).[9] This is despite evidence suggesting patients with end-stage progressive chronic diseases – cancer, AIDS, heart disease, chronic obstructive pulmonary disease, and renal disease – have similar symptom profiles.[10] Commonalities in the prevalence of palliative care problems among cancer and non-cancer patients have been described,[11] and innovative models of care, (e.g., for cancer) have been demonstrated on the African continent.[12]

A starting point in addressing the lack of access to adequate palliative care for patients with an NCD diagnosis is an assessment of the physical, social, psychological and spiritual symptom burden experienced by patients with an active, life-limiting NCD diagnosis. Minimal work has been undertaken to investigate this area in sub-Saharan Africa,[13,14] unlike in the field of HIV research,[15,16] and specifically among those not under palliative care services. Improving cancer care is in part dependent upon research evidence.[17] This study aimed to contribute to the burgeoning NCD global agenda by conducting an exploratory study of the palliative care-related problems of patients diagnosed with one of the four most prevalent NCDs in Sub-Saharan Africa (i.e., cardiovascular diseases [CVDs], cancers, chronic respiratory diseases [CRDs] and diabetes). [18]

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Non-communicable diseases in Africa

NCDs are non-infectious, non-transmissible and "of long duration and generally slow progression", with the four most prevalent globally being CVDs (e.g., heart attacks and stroke), cancers, CRDs (e.g., chronic obstructed pulmonary disease and persistent asthma[19]) and diabetes.[20] These diseases can share major risk factors: tobacco use, unhealthy diet, physical inactivity and harmful alcohol use. They are the principal cause of mortality globally, accounting for 36 million deaths in 2008 (63% of total fatalities),[21] with the majority (four-fifths) occurring in LMICs. Although conditions such as diabetes are treatable, palliative care remains important in resource-limited settings where equitable and regular access to appropriate essential medication for chronic conditions remains problematic and where effective symptom control commonly remains a clinical challenge.[22,23,24] Unlike in other regions, and as illustrated by the data from the two target countries in this study (Malawi and Namibia), the proportion of annual mortality attributable to NCDs in Africa is less than that of communicable diseases – especially HIV/AIDS (Table 1).

TABLE 1: NCD DEATHS IN TWO AFRICAN COUNTRIES IN 2014

Country	2014 population (millions)	Total NCD deaths (000s)	NCDs as % of all deaths	Probability of dying*	Communicable, maternal, perinatal and nutritional conditions as % of all deaths
Malawi	15.9	151	28%	19%	65%
Namibia	2.6	14	43%	20%	47%

Source: Adapted from WHO [25]

Note: * Between 30-70 years old from the four main NCDs (i.e., CVDs, cancers, CRDs and diabetes).

However, diabetes and cancer, for example, are increasing on the continent. Diabetes cases in sub-Saharan Africa are expected to increase from 4.8% prevalence (19.8 million) in 2013, to 5.3% (41.5 million) cases in 2035, comprised overwhelmingly of the type 2 variant.[26]

[18] World Health Organization. *Non-Communicable Diseases: Country Profiles*. Geneva: World Health Organization, 2014.

[19] Persistent / severe asthma is of concern for palliative care given patients with inadequately controlled persistent / severe asthma are at particularly high risk of exacerbations, hospitalization and death, and often have severely impaired quality of life. See Peters SP, Ferguson G, Deniz Y, Reisner C. Uncontrolled asthma: A review of the prevalence, disease burden and options for treatment. Respir Med 2006; 100:1139-1151.

[20] World Health Organization. *Non-communicable diseases*. Fact sheet, March 2013. Source: www.who.int/mediacentre/factsheets/fs355/en/ (accessed 17 April, 2014). Conditions such as diabetes and persistent asthma are incurable and often require the same approach as palliative care. A reasonable proportion within this group are at high risk of death in settings where there is limited access to medications and complex symptom control is a common clinical challenge. The World Health Organization therefore recommends palliative care alongside standard clinical care, as conditions quality for the receipt of palliative care. See Hain R, Devins M, Hastings R, Noyes J. Paediatric palliative care: Development and pilot study of a 'Directory' of life-limiting conditions. *BMC Palliat Care* 2013;12: 43.

[21] Alwan A, Maclean DR, Riley LM et al. Monitoring and surveillance of chronic non-communicable diseases: progress and capacity in high-burden countries. *Lancet* 2010; 376: 1861-1868.

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Cancer is also a significant public health problem in the region.[27] In 2012 there were 645,000 new cases of cancer and 456,000 cancer-related deaths in Africa, and these are projected to nearly double (1.28m new cases and 970,000 deaths) by 2030.[28, 29] Specific cancer-related problems in African countries include the high percentage related to infection (36%, twice the global average),[30] late presentation to clinical services – critical to determining survival rates – and limited access to treatment, including to essential analgesics, surrounded as they are by legal and regulatory restrictions, inadequate training of healthcare providers, procurement difficulties and weak health systems.[31,32]

By 2030 it is projected that deaths due to NCDs will be the most common causes of mortality in developing countries,[33] attributable to a combination of increasing and aging populations, the adoption of risk-factor lifestyles, and deficient diagnostic, preventative and curative treatment services. It is anticipated that by 2020 the largest increases in NCD fatalities will occur in Africa.[34] The vast majority of these patients will suffer from pain, dyspnoea and other physical symptoms or require support with psychosocial or spiritual problems as their diseases progress.[35,36] Reflecting regional disease prevalence, late-stage clinical presentation and limited access to curative therapies, symptom prevalence and palliative care need in Africa is significantly high. In their assessment of palliative care needs among Ugandan hospital inpatients using patient clinical documentation, Lewington et al found 122 of the 267 (46%) cases examined indicated an active life-limiting disease with NCD diagnoses including: cancer (18%), heart failure (9%), renal failure (9%), liver failure (2%) and chronic obstructive pulmonary disease (1%). Most patients reported multidimensional need – defined as the worse half of the response range on the APCA African Palliative Outcome Scale (POS) scale – in the three most negative of six categories for any question from the APCA African POS (75/78, 96%).[37]

Harding et al's study of symptom prevalence and burden amongst 112 advanced cancer patients attending palliative care in two African countries found the mean number of symptoms was 18 (SD=6.6), higher than reported in other studies, with the five most prevalent being pain (87.5%), lack of energy (77.7%), feeling sad (75.9%), feeling drowsy (72.3%) and worrying (69.6%). The five symptoms ranked as most severe were pain (23.2%), sexual problems (21.4%), weight loss (18.8%), 'I don't look like myself' (18.8%) and lack of energy (17.9%).[38] A recent study by Harding et al measured the three-day period intensity of multidimensional problems among advanced cancer patients in Kenya and Uganda. It revealed that patients were most severely affected by pain and a lack of information to plan for the future, and their need increased as function declined.[39]

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Against this background, palliative care on the African continent has advanced significantly in the last decade across a range of metrics, including the extent and quality of clinical coverage.[40] In 2011 the World Palliative Care Alliance reported that nine countries progressed from no known activity/capacity building (groups 1/2), to isolated provision (group 3a), while four countries moved from group 3 to group 4a (preliminary integration into mainstream service provision), with Uganda determined to be in group 4b (advanced integration into mainstream service provision).[41] Despite the relative historical neglect of NCDs within these developments, however, there have been a number of important related recent initiatives: in September 2011 the United Nations held the first High-Level Meeting on NCDs, at which Resolution 66/2 on the Prevention and Control of Non-Communicable Diseases was adopted by the General Assembly.[42,43] The resolution included the recognition of palliative care as an integral part of the response to such illnesses – using access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer[44]– and supplemented the WHO's 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Non-Communicable Diseases, which include a commitment to increase the availability of palliative care[45]. In May 2014, the World Health Assembly Resolution 67.19 urging member states to implement and monitor palliative care actions that were included in the agreed World Health Organization's (WHO) global action plan for the prevention and control of NCDs. [46]

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OBJECTIVES

OBJECTIVES

The overall goal of this study was to determine the prevalence and severity of the palliative care-related problems patients diagnosed with any of the following conditions: i.e., CVDs, cancer, CRDs or diabetes. The objectives of this study were therefore to:

- Establish the prevalence of palliative care-related problems – using the WHO definition of palliative care (i.e., the domains of the physical, psychological, social and spiritual) – among people diagnosed with one of the following NCDs: CVDs, cancer, CRDs or diabetes.
- Determine the intensity of palliative care-related problems among patients diagnosed with any of these four conditions.
- Determine the symptoms commonly experienced by patients presenting with any of these four conditions.
- Determine the symptom severity among patients presenting with any of these four diseases.
- Evaluate the correlation between symptom prevalence / severity and distress and socio-demographic and selected clinical factors.

METHODOLOGY

METHODOLOGY

The methods employed in the study are outlined below.

Selection of countries

The two study countries (i.e., Malawi and Namibia) were selected because: (i) they are priority countries for either the Open Society Foundations (OSF) Public Health Program (PHP) and / or its Open Society Initiative for Southern Africa (OSISA); (ii) each has a strong advocate for palliative care that has developed effective working relationships with its respective government; (iii) they both have existing strategic frameworks to provide aspects of palliative care services at the national level; and (iv) less research has been conducted in the two countries compared with other countries in sub-Saharan Africa.

Study sites

Specialist tertiary-level referral centres with specialised clinics for common NCDs were selected for recruitment in the two chosen countries. Importantly, these sites focused on the care and treatment of the target patient populations and provided services in a clinical setting with established providers rather than fledgling care and treatment services. These were identified in close collaboration with the respective national palliative care associations, the African Palliative Care Research Network and the respective country Ministries of Health. The study sites were purposively selected to cover both rural and urban settings, as much as possible.

Study population

The study focused on ambulatory adult patients with a confirmed primary diagnosis of one of the four most prevalent NCDs: i.e., CVDs (including rheumatic heart disease, hypertensive heart disease, ischemic heart disease, cerebrovascular disease, and inflammatory heart disease), cancers, CRDs (including COPD or persistent asthma, and pulmonary hypertension) or diabetes, regardless of disease stage.

Study design

This was a quantitative survey using a cross sectional, self-report study design.

Sample size estimation

The sample size was estimated using the formula for prevalence studies by Kish.[47] It was hypothesised that the prevalence of pain as the most common symptom in past patients needing palliative care would be approximately 50% in any of the four diagnostic groups.

$$N = \frac{Z_{2\alpha/2} * P(1-P)}{D^2}$$

Where:
N is the required sample size;
D is the tolerable sampling error (5%);
P is the assumed true population prevalence of NCDs at 51.8%; [48]

[47] Kish L. *Survey Sampling.* New York: Wiley, 1965.
[48] Phaswana-Mafuya N, Peltzer K, Chirinda W, Musekiwa A, Kose Z, Hoosain E, Davids A, Ramlagan S. Self-reported prevalence of chronic non-communicable diseases and associated factors among older adults in South Africa. Glob Health Action 2013; 6: 20936.

$Z_{\alpha/2}$ is the standard normal value corresponding to a 5% level of significance (1.96).

The resulting total sample size of patients with any of the four diagnoses in the two countries was 384. The number of patients selected from each participating country was determined using the sampling-proportional-to-size approach, undertaken at the country level. This was calculated using the following formula:

Sample size = $\frac{n}{N} \times n_i$

Where:
n is the total number of patients with the four diagnoses in each country's tertiary referral institutions;
N is the total number of patients with any of the four diagnoses in the two countries, and;
ni is the total sample size required for the study sample size of 384 derived above.

For reasonable recommendations, we aimed to recruit at least 50 patients per diagnosis in each country where possible, as opposed to sampling-proportional-to-size by diagnostic type. A total of 400 patients were therefore to be recruited: 200 from Malawi and 200 from Namibia. The sample size for Namibia was increased to 250 to cater for an additional rural-based hospital in the Northern part of the country that also care for patients with NCDs. It was contended that this would provide a true representation of patient NCDs as both rural and urban settings would have been catered for. For the analytical component, power calculations for sample size using EPIINFO 6.04 with a 5% level of significance and power of 80% gave sample sizes of: 292 for age, 308 for sex, 299 education, and 290 for co-morbidity variables. The sample size of 384 calculated for prevalence was therefore sufficient for the analytical component of the study. The resulting actual sample size of 457 was confirmed adequate for additional multivariate analyses to explore relationships between variables.

Inclusion and exclusion criteria

Inclusion criteria

The study focused on ambulatory patients attending NCD specialised clinics in each of the two countries' tertiary hospitals who were consecutively recruited if they fulfilled the following inclusion criteria:

- Patients aged at least 18 years or over;
- Having a confirmed primary diagnosis of any of the four most prevalent NCDs irrespective of disease stage (i.e., CVDs [including rheumatic heart disease, hypertensive heart disease, ischemic heart disease, cerebrovascular disease, inflammatory heart disease], cancers, CRDs [including COPD, occupational lung diseases, persistent asthma and pulmonary hypertension] and diabetes);
- Who knew their diagnosis; this was determined by self-report, confirmed by clinical record in patients' files;
- Capable of providing written informed consent;
- Able to read and speak any of the following languages: English or Chichewa in Malawi; English, Afrikaans and Oshiwambo in Nambia, these were local languages in which interviews were to be conducted, and;
- With sufficient cognitive ability to answer the study questions (e.g., have no demonstrable evidence of dementia, delirium or significant cognitive impairment that might make it difficult to complete the protocol, as determined by the clinical staff.

On each clinic day, patients were approached before seeing the medical personnel. They were briefed about the study and the aims as detailed in the information sheet (Appendix 1). Patients who consented (Appendix 2 for consent form) were consecutively recruited into the study. Enrolment lists were compiled at each site and were double checked, to avoid duplicative re-enrolment.

Exclusion criteria

The exclusion criteria used was as follows;

- Patients with a primary diagnosis of non-progressive asthma or respiratory allergies, and;
- Lack of psychological or physical capacity to engage in study processes.

Ethical considerations

Ethical approval to conduct the study was sought from the Ministry of Health and Social Services in Namibia (Ref: 17/3/3) and the Ministry of Health in Malawi (Ref: NHSRCH #1369). Permission to conduct the study was also sought from the health managers of the referral centres involved in data collection.

Patients were given a transport refund of USD5 per patient. To ensure the anonymity and confidentiality of the respondents, the dataset was anonymised and separated from any identifying personal information. Data was subjected to restricted access. All hard copy data was stored in a locked filing cabinet in a secure store room, retained with restricted access (to the study investigators) at the African Palliative Care Association and stored according to national data protection act guidelines.

The study's research assistants were trained in the maintenance of confidentiality and the protection of hard copy data. The study collected personal information (e.g., sex, age, level of education and basic clinical data, such as functional performance), and a unique identifier code was assigned to each study participant. Stored hard copy data with identifier codes were separated from participants' names. Also, an anonymised data set was provided to the data analyst who did not have access to any individual or referral centre linkage information.

Informed consent

Patients were consecutively recruited into the study if they fulfilled the above inclusion criteria. After greeting the patient (and his/her carer if present), the research assistants read out the information sheet, describing the purpose, procedures, benefits, risks, discomforts and precautions of the study. Emphasis was placed, but not unduly, on the utility of the study and the confidentiality of the information. Patients were given ample opportunity to ask questions before they made their decision. They were also reminded that they would be able to change their mind and discontinue participation in the study at any time. If they did not wish their data to be used in the analysis stage of the study, their contribution would be verifiably destroyed by the research assistants. However, they were informed that after the data had been written up for publication, withdrawal was no longer possible. Written informed consent was subsequently obtained for every individual patient being interviewed.

Distress protocol

The study did not involve participants who were particularly vulnerable or unable to provide informed consent or in a position of dependency (e.g., vulnerable children, students, over-researched groups, people with learning difficulties, people with mental health problems, young offenders, or people in care facilities, including prisons).

No adverse events (considered as those introducing more than a merely minimal risk) were anticipated as part of this study. However, given that the target populations had a confirmed NCD diagnosis, there was potential that some patients might become distressed when talking about their illness and their experiences of care. Consequently, a distress protocol was developed and provided to all participating centres. The protocol allowed those respondents who appeared to have become distressed during data collection an opportunity to cease the interview and to either abandon or restart it when they were comfortable. The researcher passed on any information or request to their clinician at the patient's request. All information was treated as confidential except in the situation of the patient's safety being at risk, in which case the information could be acted upon.

LIMITATIONS OR CONSTRAINTS

LIMITATIONS OR CONSTRAINTS

First, the study was intended to be exploratory in nature and therefore it is possible the identified needs may not be comparable with other patient populations. However, the instruments used (see below for details) are well validated in palliative care populations, and consequently the findings can be placed in perspective. Second, the number of participants might not be high enough for a representative sample. However, the number is sufficient to demonstrate the prevalence of palliative care-related problems in the two countries studied. Thirdly, patients with NCD were recruited regardless of comorbidities (e.g., with HIV/AIDS), and these comorbidities may have contributed to symptom load and distress.

DATA COLLECTION

DATA COLLECTION

Study sites

In Malawi, the central region was purposively selected because most patients with NCD conditions are referred to tertiary hospitals in this region. Participating hospitals were: Zomba Central Hospital; Queen Elizabeth Central Hospital; Kamuzu Central Hospital, and; Mzuzu Central Hospital. In Namibia, the key hospitals with NCD specialised clinics were purposively selected and comprised of Windhoek Central Hospital; Katutura Hospital (both urban based); and Oshakati Intermediate Hospital (rural based). Average outpatient attendance figures are presented in Table 2.

TABLE 2: SELECTED HOSPITALS AND AVERAGE OUTPATIENT ATTENDANCE

	Hospitals	Location	Monthly average outpatient attendance for NCD units
Malawi	Zomba Central Hospital Elizabeth Central Hospital Kamuzu Central Hospital Mzuzu Central Hospital	Urban Urban Urban Urban	1,152 7,003 7,671 7,045
Namibia	Windhoek Central Hospital Katutura Hospital Oshakati Intermediate Hospital	Urban Urban Peri-Urban	5,377 25,779 14,057

Data collection instruments

Socio-demographic and clinical questionnaire

Basic patient demographic and clinical profiling data was collected using a brief questionnaire (Appendix 3). Clinical questions asked included: date of primary NCD diagnosis; date of enrolment into care; functional performance status; and asking for the presence of any co-morbidities. Patients were also asked to list their most pressing problems in living with their primary diagnosis.

The Karnofsky Performance Scale (modified)

The Karnofsky Performance Scale (KPS) is an observer-rated scale used for reporting a patient's level of physical functioning ability (Appendix 4 for modified version used in this study). Patients are rated on a scale of 0-100, with 0 corresponding to no functioning ability (i.e., death) and 100 corresponding to complete, independent functioning.[49] The KPS is commonly used in HIV patients in Uganda.[50] The data collectors were trained to use the KPS and rate patients' functional performance using its definitions rating (%) criteria.[51] This study used a modified version of the KPS, adapted from Anderson et al.[52]

[49] Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: CM Macleod (Ed.) *Evaluation of chemotherapeutic agents* (pp. 199-205). New York: Columbia University Press, 1949.

[50] Katwere M, Kambugu A, Piloya T et al. Clinical presentation and aetiologies of acute or complicated headache among HIV sero-positive patients in a Ugandan clinic. *J Int AIDS Soc* 2009; 12:21.

[51] Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: CM Macleod (Ed.) *Evaluation of chemotherapeutic agents* (pp. 199-205). New York: Columbia University Press, 1949.

[52] Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative performance scale (PPS): A new tool. *J Palliat Care* 1996; 12: 5-11.

APCA African Palliative Outcome Scale

Data on the nature and severity of palliative care-related needs were assessed using the 10-item multi-dimensional, validated APCA African POS (Appendix 5)[53, 54] which is the most frequently used palliative outcome measure used in African palliative care settings.[55] The APCA African POS has ten questions, 7 for the patient and 3 for the family care giver. In the absence of the caregiver, the patients answer the 7 questions from which a total APCA African POS score is computed.

Memorial Symptom Assessment Schedule – Short Form (enhanced)

Given the paucity of tools with adequate properties to measure needs and outcomes in sub-Saharan Africa, [56] despite it having the greatest burden of progressive illness, the study also used the Memorial Symptom Assessment Schedule – Short Form (MSAS-SF) (Appendix 6). The MSAS-SF is a patient-rated symptom assessment tool commonly used in HIV-infected populations[57] that records the presence and burden of 28 physical symptoms and 4 psychological symptoms in the 7 days prior to the assessment.[58,59,60] Each physical symptom experienced by the patient is scored for the level of distress it caused on a five-point (0-4) Likert scale (i.e., not at all, a little bit, somewhat, quite a bit, and very much). The burden of psychological symptoms is scored on a scale of 0 if a symptom is absent, 1 if the symptom is present and occurs rarely, 2 if the symptom is present and occurs occasionally, 3 if the symptom is present and occurs frequently, and 4 if the symptom is present and occurs almost constantly. These scores are added and a mean taken to calculate the MSAS-SF subscales. The first subscale, the global distress index (GDI), is calculated on the basis of 10 items, namely 6 physical symptoms and 4 psychological items. The second subscale is physical symptoms; the third subscale is psychological symptoms. Each symptom is scored according to the level of discomfort experienced (i.e., not at all = 0.8, a little = 1.6, somewhat = 2.4, quite a bit = 3.2, and very much = 4). Subscale indices of global distress, physical symptoms distress, and psychological distress are calculated from the mean burden ratings.[61] The African version[62] of this tool was used in this study and includes the following additional items: difficulty walking, hunger, difficult seeing, muscle aches, difficulty hearing, bad smell/odour, sores/lumps on genitals, and discharge from genitals.

Center for Epidemiologic Studies Depression Scale

The Center for Epidemiologic Studies Depression Scale (CES-D) is a short, 20-item self-report scale designed to measure depressive symptomatology in the general population over seven-day period, using symptom items associated with depression that have been used in previously validated longer scales (Appendix 7).[63] Scoring for all except questions 4, 8, 12, and 16 is as follows: 0 points – rarely or none of the time (< 1 day); 1 point – some or a little of the time (1-2 days); 2 points – occasionally

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[53] Powell RA, Downing J, Harding R et al. Development of the APCA African Palliative Outcome Scale. *J Pain Symptom Manage* 2007; 33: 229-32.

[54] Harding R, Selman L, Agupio G et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *Health Qual Life Outcomes* 2010; 25;8: 10.

[55] Downing J, Simon ST, Mwangi-Powell FN, et al. Outcomes 'out of Africa': the selection and implementation of outcome measures for palliative care in Africa. *BMC Palliat Care* 2012; 11: 1.

[56] Siegert R, Selman L, Higginson IJ et al. A psychometric evaluation of the Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) scale with palliative care samples in three African countries. *J Pain Symptom Manage* 2014; 48: 983-991.

[57] Makoae LN, Seboni NM, Molosiwa K et al. The symptom experience of people living with HIV/AIDS in Southern Africa. *J Assoc Nurses* AIDS *Care* 2005; 16: 22-32.

[55] Wakeham K, Harding R, Bamukama-Namakoola D et al. Symptom burden in HIV-infected adults at time of HIV diagnosis in rural Uganda. *J Palliat Med* 2010; 13: 375-380.

[59] Harding R, Molloy T, Easterbrook P et al. Is antiretroviral therapy associated with symptom prevalence and burden? *Int J STD AIDS* 2006; 17: 400-405.

[60] Harding R, Selman L, Agupio G et al. Prevalence, burden, and correlates of physical and psychological symptoms among HIV palliative care patients in Sub-Saharan Africa: an international multicenter study. *J Pain Symptom Manage* 2012; 44: 1-9.

[61] Chang VT, Hwang SS, Thaler HT et al. Memorial Symptom Assessment Scale. Expert Rev *Pharmacoecon Outcomes Res* 2004; 4: 171-178.

[62] Wakeham K, Harding R, Bamukama-Namakoola D et al. Symptom burden in HIV-infected adults at time of HIV diagnosis in rural Uganda. J *Palliat Med* 2010; 13: 375-380.

[63] Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1977; 1: 385-401.

or a moderate amount of the time (3-4 days); and 3 points – most or all of the time (5-7 days). For questions 4, 8, 12, and 16, the scoring is the same but reversed: "Most or all of the time" is scored 0 points, "rarely or none of the time" is scored 3 points, etc. Generally, the higher the score, the greater the depressive symptomatology. The screening test scoring ranges are: less than 16 no clinically significant psychological distress; 16-20 – mild to moderate depressive symptomatology or clinically significant level of psychological distress; ≥21 – possibility of major depressive symptomatology.[64] The CES-D and the proposed cut offs have been previously used in Africa, mostly in HIV populations.[65] The possible range of scores is 0-60. It was hypothesised that the prevalence of clinically significant psychological distress (≥16) would be greater than the 20%, that is expected in normal populations.[66]

Translation of data collection tools

All study documentation (information and consent sheets, socio-demographic and clinical questionnaire and the remaining questionnaires) were forward and backward translated from English into Chichewa in Malawi and into Oshiwambo and Afrikaans in Namibia. This was undertaken with support from the study coordinator who has experience in rigorous translation procedures. All translated study materials were cross-checked by a staff member bilingual in English and the relevant local language(s) at the clinical care sites. Translations were discussed locally at each site to ensure their initial meaning had not been distorted to thereby affecting cultural validity.

Pre-testing of data collection tools

The study questionnaires were pre-tested with relevant experts from both countries for face and content validity, and with at least 6 patients in each clinical site, with revisions made based on this experience. The data from the 6 patients was not included in the study sample. These revisions included the grading of disease stages for cancer and CVDs – for later categorisation, although sampling was conducted irrespective of disease stage – and deciding on the most common types of diagnoses for cancer, cardiovascular and chronic respiratory diseases and diseases that could be listed in advance, in order to facilitate data management. It was also agreed that space should be provided for the data collection teams to specify types of diagnoses not listed. The list generated was based on country-specific data on the most common type of diagnoses for the conditions. The validated outcome measures were not altered in any way.

Training of research assistants

Data was collected by experienced research assistants trained and supervised by in-country research coordinators and an overall research coordinator based at APCA. The research assistants received two days of training, and one day of close supervision following the first day of data collection. Training included: 1) extensive discussion of specific job duties; 2) detailed discussion and understanding of the study questions and instructions; 3) definition of the study design, study population and study techniques, and; 4) common questions and answers.

Following the above training and orientation to the study, the local research assistants travelled to each clinical care site to establish the typical clinic outpatient attendances and the anticipated rate of accrual to the study. Based upon this information, a time-scale for data collection at each site by the individual researcher was calculated.

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[64] Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1977; 1: 385-401.

[65] Myer L, Smit J, Liezel LR, Parker S, Sein DJ, Seedat S. Common mental disorders among HIV-infected individuals in South Africa: Prevalence, predictors, and validation of brief psychiatric rating scales. *AIDS Patient Care and STDs* 2008; 22: 147-158..

[66] Nakasujja N, Skolasky RL, Musisi S, Allebeck P, Robertson K, Ronald A, Katabira E, Clifford DB, Sacktor N. Depression symptoms and cognitive function among individuals with advanced HIV infection initiating HAART in Uganda. *BMC Psychiatry* 2010; 10;10: 44.

DATA MANAGEMENT & ANALYSIS

DATA MANAGEMENT

Data entry and validation

To ensure data quality, weekly Skype meetings were held among research assistants and the research coordinator to review the data collection process, check data completeness, and resolve any logistical or methodological issues. Data quality was monitored in the field by the in-country study coordinators using a series of checklists and control forms to ensure questionnaire completeness and consistency. All questionnaires were checked by the study coordinator. After completion, the questionnaires were sent to the APCA office in Uganda by courier.

Data was double entered into a pre-designed EPI INFO delete database with logic and consistency checks followed by validation in two rounds of data entry and cleaning. The cleaning was undertaken by manually checking the questionnaires supplied to resolve any inconsistencies.

DATA ANALYSIS

Analysis was undertaken at multiple levels:

- Descriptive analysis was performed to profile the sample of patients in both countries by socio-demographic and basic medical metrics, including functional performance data. Continuous data was summarized by means and standard deviations and categorical data was summarized by proportions.

- (The intensity of palliative care related-problems was determined by computing the proportions of patients reporting varying levels of intensity for each of the APCA African POS items (questions 1-7) on the 0-5 scale.

- The total APCA African POS score was computed and items 1, 2, and 3 were reversed so in all instances higher scores were associated with less palliative care-related problems (possible range 0-35).

- Symptom burden was determined by tabulating each of the symptoms of the MSAS–SF, with patients reported presence of each of the symptoms presented by frequency and percentage. Symptom associated distress was also analysed descriptively for each of the symptoms.

- Regression analysis was used to establish the correlates of symptom distress. To test for associations with eight key explanatory variables, one multivariable linear regression model was generated for each of the two scores namely; physical and psychological symptom distress. The model included the explanatory variables: sex, country, education, co-morbidities, sero status, diagnostic category, age in years and KPS of functional performance scores. No model selection procedures were used for these models; instead the associations were estimated simultaneously so that potential confounding effects would be automatically accounted for. Model assumptions were checked and found to be satisfactory.

- Qualitative data from the open-ended question on patients' self-reported main pressing problems in living with their diagnosis were typed out in pre-designed Word templates. The responses were then read by two people followed by the development of themes. These themes were compared for consistency and discrepancies resolved through discussion. The themes were presented as textual summaries.

RESULTS

RESULTS

Data were collected between 15 April - 15 May 2015 in Malawi and 14 May - 29 June 2015 in Namibia. A total of 457 patients participated in the study: Malawi (207); Namibia (250). Twenty four refusals were recorded in Namibia (response rate: 90.4%); three refusals in Malawi (response rate: 98.6%).

Characteristics of the study population

Detailed information on the study population is set out in Tables 3 and 4. Over half of respondents were female (58.9%; n=269), with the mean age being 48 (SD: 15.7). Just under half 45.5% (n=208) had attained secondary education. Primary diagnoses included 28.4% (n=130) with CVDs (of whom, 69.7% [n=86] had hypertensive heart disease, 10.6% [n=13] had ischemic heart disease); 32.2% (n=147) with cancer; 16.0% (n=73) with CRD (of whom, 80.6% [n=54] had persistent asthma); and 23.4% (n=107) with diabetes (Tables 3 and 4). Additionally, 43.8% (n=200) reported having co-morbidities, and 17.9% (n=82) reported a positive HIV sero-status. For the two selected countries combined the median KPS functionality score was 90 (IQR: 80-100). The median number of dependents was 4 (IQR: 2-6), with three-fold differences in average expenditure for medication- and laboratory-related costs reported between the two countries.

Table 3: Baseline characteristics of the study participants

VARIABLE	MALAWI *(n=207)*	NAMIBIA *(n=250)*	OVERALL *(n=457)*
Age			
Mean (sd)	50.16 (14.6)	46.35 (16.4))	48 (15.7)
Gender			
Male	80 (38.7%)	108 (43.2%)	188 (41.1%)
Female	127 (61.4%)	142 (56.8%)	269 (58.9%)
Education			
None	25 (12.1%)	12 (4.8%)	37 (8.1%)
Attended primary	101 (48.8%)	70 (28.0%)	171 (37.4)
Attended secondary	73 (35.3%)	135 (54.0%)	208 (45.5%)
Diploma /degree or higher	8 (3.9%)	33(13.2%)	41 (9.0%)
Primary diagnosis			
Cardiovascular diseases	63 (30.4%)	67 26.8%)	130 (28.4%)
Cancer	83 (40.1%)	64 (25.6%)	147 (32.2%)
Chronic respiratory diseases	17 (8.2%)	56 (22.4%)	73 (16.0%)
Diabetes	44 (21.3%)	63 (25.2%)	107 (23.4%)
Does patient have co-morbidities?			
Yes	92 (44.2%)	108 (43.2%)	200 (43.8%)
No	115 (55.6%)	142 (56.8%)	257 (56.2%)

VARIABLE	MALAWI (n=207)	NAMIBIA (n=250)	OVERALL (n=457)
Patients' HIV sero-status by self-report			
Positive	50 (24.2%)	32 (12.8%)	82 (17.9%)
Negative	134 (64.7%)	154 (61.6%)	288 (63.0%)
Unknown	23 (11.1%)	64 (25.6%)	87 (19.0%)
Median (IQR) KPS score (range)	80 (70-90)	90 (80-100)	90 (80-100)
Median number of dependants (range)	5 (3-7)	3 (1-6)	4 (2-6)
Average cost of round trip journey to health facility (median, IQR)	$1.8 ($1-$3.6)	$3 ($2-$6)	NC
Average expenditure of medicines in the previous 30 days prior to the survey (range)	$3.6 ($1-$8.9)	$15 ($5-$40)	NC
Average expenditure on laboratory investigations in the previous 30 days prior to the survey (range)	$6.0 ($1.8-$27.5)	$18.5 ($0-$60)	NC

NC: Not computed

Table 4: Diagnosis by disease group

DIAGNOSIS	n	&
Chronic respiratory diseases (n=73)a		
Persistent asthma	54	80.6%
Occupational lung disease	8	11.9%
Pulmonary hypertension	4	6.0%
Chronic obstructive pulmonary disease	1	1.5%
Cardiovascular diseases (n=130)b		
Hypertensive heart disease	86	74.8%
Ischemic heart disease	13	11.3%
Rheumatic heart disease	9	7.8%
Other (Congestive heart failure, cardiomyopathy, heart valve disease)	4	3.5%
Inflammatory heart disease	3	2.5%
Cancer (n=147)c		
Karposis sarcoma	37	27.8%
Cervix	31	23.3%
Breast	27	20.3%
Leukaemia	7	5.3%
Liver	7	5.3%
Other cancers (kidney, stomach, myleloma, lung, Bronchogenic carcinoma, spinal humour, oral)	8	6.0%
Oesophagus	5	3.8%
Prostate	4	3.0%
Lymphomas	3	2.3%
Colon	2	1.5%
Thyroid	2	1.5%

Note: a 6 missing values , b 15 missing values , c 14 missing values

Time since diagnosis and time under care by type of diagnosis

In Malawi, there were no statistically significant differences between the four diagnostic groups in terms of mean time since diagnosis, which ranged from 9.11 years – 10.65 years. In terms of mean time under care, CRD patients had been under care longer than other diagnostic groups, and this difference was statistically significant (F=5.44, P=0.0013).

In Namibia, diabetes patients had the longest mean time since diagnosis (12.22 years), and this difference was statistically significant (P=<0.001). Diabetic patients had also been in care longer than any of the other diagnostic groups (5.98 years) and all the differences were also statistically significant (P<0.001, P=0.0037) (See Table 5 for further details on the foregoing).

Table 5: Time since diagnosis and time under care by type of diagnosis

	Time since diagnosis (years)		Time under care (years)	
Malawi[a]	mean (SD)	F statistic , P value	mean (SD)	F statistic , P value
Cardiovascular (n=56)	9.30 (4.5)		4.9 (6.6)	
Cancer (n=77)	10.11 (4.13)	F=1.03, P=0.381	2.21 (3.6)	F=5.44, P=0.0013+
CRDs (n=15)	10.65 (4.28)		7.58 (9.82)	
Diabetes (n=43)	9.11 (3.8)		3.34 (3.61)	
Namibia[b]				
Cardiovascular (n=58)	7.58 (4.70)		3.37 (4.11)	
Cancer (n=60)	10.44 (5.9)	F= 9.44, P<0.001+	2.34 (3.34)	F=4.62, P=0.0037+
CRDs (n=45)	9.57 (4.9)		4.88 (5.94)	
Diabetes (n=57)	12.22 (4.66)		5.98 (8.20)	

a 16 missing values, b 30 missing values, + statistically significant

Palliative care-related problems as measured by the APCA African POS

The worst patient self-reported palliative care problems were defined as the worst two intensity scores in the APCA African POS scale categories for each patient. The three palliative care-related problems discovered on this basis. One was shared feelings (i.e., not at all/not very often). The proportions reporting high intensity were 28% CVDs, 23% CRDs, 22% cancer and 21% for diabetes. Second was help and advice (i.e., none/very little): 28% cancer, 26% CVDs, 22% diabetes, and 16% CRDs. Worry (i.e., most/all the time): 27% cancer, 18% CVDs, 18% diabetes and 14% CRDs (See Table 6 for full details).

Table 6: Intensity of palliative care-related problems as measured by the APCA African POS (N=457)

POS ITEM	RATING	CANCER (N=147)		CARDIO-VASCULAR DISEASES (N=130)		CHRONIC RESPIRATORY DISEASES (N=73)		DIABETES (N=107)	
		n	%	n	%	n	%	n	%
Pain	No pain at all	26	18%	38	29%	17	23%	29	27%
	Slight pain	17	12%	26	20%	22	30%	16	15%
	moderate pain /severe	79	54%	53	41%	28	38%	41	38%
	very severe /worst/ overwhelming	25	17%	13	10%	06	08%	21	20%
Other symptoms	no, not at all	48	33%	45	35%	11	15%	31	29%
	slightly	31	21%	36	28%	17	23%	31	29%
	moderate /severe	61	41%	43	33%	37	51%	35	33%
	very severe /worst/ overwhelming	07	5%	06	5%	08	11%	10	9%
Worry	not at all	31	21%	34	26%	14	19%	30	28%
	very occasionally	20	14%	15	12%	14	19%	18	17%
	some/a lot of the time	57	39%	58	44%	35	48%	40	37%
	most /all the time	39	27%	23	18%	10	14%	19	18%
Shared feelings	not at all/not very often	32	22%	37	28%	17	23%	22	21%
	occasionally/fairly frequently	65	44%	41	32%	19	26%	30	28%
	often	26	18%	17	13%	10	14%	15	14%
	yes freely talked	24	16%	35	27%	27	37%	40	37%
Life worthwhile	Not at all/not very often	20	14%	16	12%	05	07%	14	13%
	occasionally/some of the time	40	27%	31	24%	18	25%	24	22%
	most of the time	38	26%	23	18%	8	11%	29	27%
	All of the time	49	33%	60	46%	42	58%	40	37%
Felt at peace	not at all/not very often	32	22%	22	17%	06	08%	18	17%
	occasionally /some of the time	53	36%	43	33%	19	26%	31	29%
	most of the time	34	23%	25	19%	16	22%	26	24%
	All of the time	28	19%	40	31%	32	44%	32	30%
Help and advice	none/very little	41	28%	34	26%	12	16%	24	22%
	for a few /several things	39	27%	29	22%	23	32%	32	30%
	for most things	48	33%	25	19%	15	21%	15	14%
	as much as wanted	19	13	42	32%	23	32%	36	32%

Symptom prevalence and associated distress as measured by the Memorial Symptom Assessment Schedule (SF)

The most prevalent physical symptoms were: pain, reported by 78% (n=115) of cancer patients, 68% (n=89) of CVD patients, 68% (n=49) of CRD patients and 73% (n=78) of patients with diabetes. This was followed by lack of energy, reported by 63% (n=93), 55% (n=71), 68% (n=50) and 74% (n=79) of cancer, CVD, CRD and diabetes patients, respectively. Cough was common (68%; n=50) in patients with CRD, while dry mouth, numbness and hunger were more common in diabetic patients, with a prevalence of 61% (n=77), 64% (n=68), and 70% (n=75), respectively. Difficulty sleeping was more common in patients with CRDs (60%; n=44) and diabetes (53%; n=57). Weight loss was more common in cancer patients (58%; n=85). Worry was the most common psychological symptom, reported by 73% (n=107) of cancer, 65% (n=84) of cardiovascular, 77% (n=56) of CRD and 72% (n=77) of diabetic patients. Feeling irritable was more common in cancer patients (52%; n=77) (Table 7).

Table 7:Physical and psychological symptom prevalence in the previous 7 days

	CANCER (N=147)		CARDIOVASCULAR DISEASES (N=130)		CHRONIC RESPIRATORY DISEASES (N=73)		DIABETES (N=107)	
Symptom	Prevalence N (%)	% reporting high distress	Prevalence N (%)	% reporting high distress	Prevalence N (%)	% reporting high distress	Prevalence N (%)	% reporting high distress
Difficulty concentrating	70 (48%)	27%	64 (49%)	25%	35 (48%)	26%	51 (48%)	38%
Pain	115 (78%)	52%	89 (68%)	38%	49 (68%)	33%	78 (73%)	56%
Lack of energy	93 (63%)	35%	71 (55%)	25%	50 (68%)	36%	79 (74%)	37%
Cough	61 (42%)	16%	43 (33%)	19%	50 (68%)	56%	42 (39%)	19%
Changes in skin	53 (36%)	37%	16 (12%)	25%	6 (8%)	17%	21 (20%)	29%
Dry mouth	54 (37%)	24%	34 (26%)	21%	35 (48%)	23%	65 (61%)	32%
Nausea	59 (40%)	24%	23 (18%)	4%	28 (38%)	7%	32 (30%)	34%
Feeling drowsy/ tired	87 (59%)	24%	80 (62%)	26%	46 (63%)	33%	82 (77%)	49%
Numbness/tingling in hands or feet	65 (44%)	37%	63 (48%)	24%	19 (26%)	11%	68 (64%)	46%
Difficulty sleeping	72 (49%)	40%	59 (45%)	44%	44 (60%)	39%	57 (53%)	58%
Feeling bloated	45 (31%)	24%	32 (25%)	31%	25 (34%)	44%	34 (32%)	44%
Problems urinating	29 (20%)	38%	16 (12%)	38%	4 (5%)	20%	31 (29%)	42%
Vomiting	33 (22%)	27%	7 (5%)	29%	10 (14%)	0%	10 (9%)	40%
Shortness of breath	28 (19%)	21%	38 (29%)	39%	55 (75%)	64%	28 (26%)	25%
Diarrhoea	26 (18%)	22%	12 (9%)	25%	5 (7%)	0%	27 (25%)	25%
Sweats	44 (30%)	43%	31 (24%)	29%	17 (24%)	6%	63 (59%)	43%
Mouth sores	14 (10%)	36%	12 (09%)	8%	2 (3%)	0%	16 (15%)	26%
Problems with sexual interest / activity	48 (33%)	57%	30 (23%)	60%	19 (26%)	47%	42 (40%)	40%
Itching	42 (29%)	20%	23 (18%)	17%	10 (14%)	20%	28 (26%)	50%
Lack of appetite	63 (43%)	21%	41 (32%)	38%	23 (32%)	22%	31 (29%)	39%
Dizziness	57 (39%)	25%	55 (42%)	25%	23 (32%)	39%	59 (55%)	34%
Difficulty swallowing	24 (16%)	44%	8 (6%)	0%	8 (6%)	0%	7 (7%)	26%
Changes in way food tastes	42 (29%)	33%	20 (15%)	30%	15 (21%)	20%	37 (35%)	27%
Weight loss	85 (58%)	35%	41 (32%)	14%	33 (45%)	18%	50 (47%)	32%

	CANCER (N=147)		CARDIOVASCULAR DISEASES (N=130)		CHRONIC RESPIRATORY DISEASES (N=73)		DIABETES (N=107)	
Symptom	Prevalence N (%)	% reporting high distress	Prevalence N (%)	% reporting high distress	Prevalence N (%)	% reporting high distress	Prevalence N (%)	% reporting high distress
Hair loss	35 (24%)	43%	1 (1%)	0%	1 (1%)	0%	6 (6%)	50%
Constipation	34 (23%)	31%	22 (17%)	18%	13 (18%)	16%	29 (27%)	31%
Swelling of arms or legs	46 (31%)	27%	39 (30%)	31%	07 (10%)	14%	27 (25%)	26%
I don't look like myself	62 (42%)	29%	28 (22%)	11%	16 (22%)	25%	30 (28%)	23%
Sores or lumps in private parts*	18 (12%)	44%	3 (2%)	100%	1 (1%)	0%	8 (7%)	13%
Discharge from private parts*	31 (21%)	35%	3 (2%)	33%	1 (1%)	0%	4 (4%)	25%
Bad smell or odour*	32 (22%)	44%	3 (2%)	33%	0 (0%)	0%	8 (7%)	38%
Difficulty moving*	37 (25%)	0%	34 (26%)	41%	11 (15%)	0%	34 (32%)	50%
Difficulty walking*	61 (42%)	34%	55 (42%)	38%	21 (29%)	14%	41 (38%)	63%
Muscle aches*	70 (48%)	20%	55 (42%)	29%	23 (32%)	17%	43 (40%)	30%
Difficulty seeing well, poor vision*	39 (27%)	23%	61 (47%)	30%	19 (26%)	6%	68 (64%)	57%
Difficult hearing, poor hearing*	20 (14%)	25%	22 (17%)	18%	4 (5%)	0%	22 (21%)	36%
Hunger*	60 (41%)	38%	43 (33%)	35%	21 (29%)	20%	75 (70%)	44%
Feeling sad	93 (63%)	24%	64 (49%)	33%	40 (55%)	35%	57 (53%)	39%
Worrying	107 (73%)	39%	84 (65%)	43%	56 (77%)	29%	77 (72%)	50%
Feeling irritable	77 (52%)	22%	45 (35%)	31%	31 (42%)	32%	43 (40%)	40%
Feeling nervous	47 (32%)	34%	54 (42%)	35%	28 (38%)	29%	42 (39%)	29%

*Note: High distress is defined as patients reporting 'quite a bit' or 'very much' for physical symptoms / 'frequently or almost constantly' for psychological symptoms, expressed as a percentage of those with the symptom. * African items*

Symptom distress

MSAS-SF items and associated symptom distress

The MSAS-SF items that had the greatest associated symptom distress in our findings were as follows (see also Table 7):

Cardiovascular

Problems with sexual interest (60%), difficulty sleeping (44%), shortness of breath (39%), pain, problems urinating, lack of appetite and difficulty walking (all 38%). The most distressing psychosocial symptoms were: worry (43%) and feeling nervous (35%).

Cancer

Problems with sexual interest (57%), pain (52%), difficulty swallowing, sores or lumps in private parts and bad smell / odour (all 44%), sweats and hair loss (both 43%) and difficulty sleeping (40%). The most distressing psychological symptoms were worry (39%) and feeling nervous (34%).

Chronic respiratory diseases

Shortness of breath (64%), cough (56%), problems with sexual interest (47%), feeling bloated (44%), and feeling dizzy (33%). The most distressing psychosocial symptoms were: feeling sad (35%) and feeling irritable (32%).

Diabetes

Difficulty sleeping (58%), pain (56%), feeling drowsy (49%), numbness and tingling on hands and feet (46%), and feeling bloated (44%). The most distressing psychosocial symptom was worry (51%) and feeling irritable (40%) (Table 6). Among the MSAS African items, hunger (70%) and difficult seeing (64%) were the most common patient reported symptoms. Patients who reported having difficulty walking and seeing reported high symptom associated distress, 63% and 57%, respectively.

Symptom distress scores by diagnosis

Patients with CRDs reported a slightly lower mean number of total symptoms as compared to patients with CVDs, cancer and diabetes (9.8 vs 10.3, 10.2, 10.9, respectively) (F=6.19, P=0.0004) (Table 8). Cancer and diabetes patients reported higher psychological symptom distress scores (F=7.99, P=<0.001) compared to COPD and CVD patients, while diabetic patients reported higher global distress scores compared to the other diagnostic groups (F=4.26, P=0.005). There was no statistically significant difference in the physical symptom distress experiences by patients across the four diagnostic groups (See Table 8 for further details).

Table 8: Symptom distress scores by type of diagnosis (n=457)

	Cardio-vascular	Cancer	Chronic respiratory diseases	Diabetes	Statistical measure of association and P value
MSAS subscale					
Total number of symptoms	10.3 (4.9)	10.2 (4.9)	9.8 (4.7)	10.9 (4.6)	F=6.19, P=0.0004*
MSAS psychological distress index	0.78 (0.57)	1.07 (0.77)	0.93 (0.63)	1.18 (0.71)	F=7.99, P=<0.001*
MSAS physical distress Index	1.13 (0.90)	1.2 (0.8)	1.2 (0.81)	1.3 (0.95)	F=0.81, P=0.4885
MSAS global distress index	1.07 (0.74)	1.25 (0.70)	1.18 (0.69)	1.40 (0.7)	F=4.26, P=0.005*

* *Statistically significant differences*

Prevalence of depression symptoms by diagnosis

Of the 457 participants in the study, 17.9% (n=82) reported mild-to-moderate depression and 33.2% (n=152) had scores suggestive of possible major depression. More cancer patients reported mild-moderate psychological distress (31.7% vs 25.6% for CVDs vs 17.1% for CRDs vs 25.6% for diabetes) and more possibility of major depression symptoms (38.2% vs 23.0% for CVDs, vs 12.5% for CRDs vs 26.3% for diabetes (Table 9).

Table 9:Depression symptom scores by diagnosis (n=457)

	Cardio-vascular diseases (n=130) n(%)	Cancer (n=107) n(%)	Chronic respiratory diseases (n=73) n(%)	Diabetes (n=107) n(%)	Statistical measure of association and P value
No clinically significant psychological distress (<16)	74 (33.2%)	63 (28.3%)	40 (17.9%)	46 (20.6%)	223 (48.8%)
Mild-to-moderate psychological distress ≥16-20	21 (25.6%)	26 (31.7%)	14 (17.1%)	21 (25.6%)	82 (17.9%)
Possibility of major depression symptoms ≥21	35 (23.0%)	58 (38.2%)	19 (12.5%)	40 (26.3%)	152 (33.3%)

Correlates of symptom distress

At the multivariate level, we found a very high correlation between GDI and the number of symptoms (rho=0.845). Consequently, models using physical and psychosocial distress were considered useful for multivariate analysis.

Correlates of physical symptom distress

Significantly higher mean scores (difference=0.348, p<0.001) were seen in Namibia compared to Malawi, after adjusting for potential confounding among other variables. Male gender was associated with reduced physical symptom distress (difference=0.174, p=0.005). The presence of comorbidities was associated with increased physical symptom distress (difference=0.169, p=0.007), while increased functional performance was associated with lower physical symptom distress (coefficient=-0.017, p<0.001) (Table 10).

Table 10: Associations with physical symptom distress scores, derived from a multiple regression model

Variable	Level or change	Estimate	P value	95% CI
Sex				
	Male	(ref)		
	Female	0.174	0.005	(0.05, 0.29)*
Country				
	Malawi	(ref)		
	Namibia	0.348	<0.001	(0.21, 0.48)*
Education				
	Primary /None	(ref)		
	Secondary	-0.055	0.419	(-0.19, 0.08)
Sex				
	Tertiary	-0.101	0.380	(-0.33, 0.12)
Co-morbidities				
	Yes	(ref)		
	No	-0.169	0.007	(-0.29, -0.05)*
Sero status				
	HIV positive	(ref)		
	HIV negative	0.028	0.759	(-0.15, 0.20)
	Unknown	-0.030	0.781	(-0.24, 0.18)
Diagnosis				
	Cancer	(ref)		
	CVDs	-0.226	0.066	(-0.47, 0.01)
	CRDs	-0.047	0.725	(-0.31, 0.22)
	Diabetes	0.172	0.168	(-0.07, 0.42)
Age	per year	0.002	0.469	(-0.00, 0.01)
Functional performance	per unit increase	-0.017	<0.001	(-0.02, -0.01)*

** Statistically significant, CI confidence interval CRDs = chronic respiratory diseases , CVD = cardiovascular diseases*

Correlates of psychosocial symptom distress

In relation to factors associated with psychosocial symptom distress significantly higher mean scores (difference=0.234, p=0.011) were seen in Namibia compared with Malawi. Secondary education was associated with a 0.224 reduction in psychological distress, compared with primary education alone or no education at all (p=0.014). An absence of comorbidities was associated with a 0.202 reduction in psychological distress (p=0.016). Increasing functional performance was associated with reduced psychological symptom distress (coefficient=-0.014, p<0.001) (Table 11).

Table 11: Associations with psychological symptom distress scores (n=457) derived from a multiple regression model

Variable	Level or change	Estimate	P value	95% CI
Sex	Male	(ref)		
	Female	0.044	0.596	(-0.12, 0.21)
Country	Malawi	(ref)		
	Namibia	0.234	0.011	(0.05, 0.41)*
Education	Primary / None	(ref)		
	Secondary	-0.224	0.014	(-0.40, -0.05)*
	Tertiary	-0.190	0.217	(-0.49, 0.11)
Co-morbidities	Yes	(ref)		
	No	-0.202	0.016	(-0.37, -0.04)*
Sero status	HIV positive	(ref)		
	HIV negative	0.004	0.972	(-0.23, 0.24)
	Unknown	-0.144	0.317	(-0.43, 0.14)
Diagnosis	Cancer	(ref)		
	CVDs	-0.111	0.498	(-0.43, 0.21)
	CRDs	-0.024	0.895	(-0.37, 0.33)
	Diabetes	0.064	0.703	(-0.26, 0.39)
Age	per year	0.001	0.911	(-0.01, 0.01)
Functional performance	per unit increase	-0.014	<0.001	(-0.02, -0.01)*

** p<0.05, CI confidence interval*

Patient self-elicited most pressing problems

Patients were requested to list their most pressing problems in living with their respective primary diagnosis. Patients expressed both physical and psychosocial thematic problems, and health-related costs incurred and discomfort with dietary restrictions were common problems that were evident across the diagnostic groups, to varying degrees (Table 12).

Table 12: Self-elicited issues that matter to patients with NCDs

Cardiovascular diseases	Cancer
▪ Physical symptoms ▪ Unhappy with dietary restrictions ▪ Reduced socialization ▪ Reduced physical activities ▪ Worry ▪ Agitation	▪ Physical symptoms ▪ Uncertainty about the future ▪ Very high transport costs to care centers ▪ Cannot afford the medication costs ▪ Fear of death ▪ Worry ▪ Loss of functional capacity
Chronic respiratory diseases	**Diabetes**
▪ Physical symptoms ▪ Not comfortable with dietary restrictions ▪ Worry about failing to breath ▪ Costly medication ▪ High transport costs to care centres ▪ Having to take medication for life ▪ Inability to engage in physical activities owing to shortness of breath ▪ Feeling depressed	▪ Physical symptoms ▪ Not comfortable with dietary restrictions ▪ Hunger ▪ Social exclusion; cannot engage in daily activities ▪ Medication is very expensive ▪ Lack of basic medical equipment and supplies for routine sugar level monitoring ▪ Cannot afford the cost of recommended diet

DISCUSSION

DISCUSSION

To our knowledge, this is the first study to assess the prevalence and correlates of palliative care-related problems among ambulatory patients with CVDs, CRDs and diabetes in sub-Saharan Africa. The mean age for the study population was 48 years; which has serious implications for developing economies given this is the most economically productive age group. There were also more women than men, and the plausible explanation for this finding is the documented disproportionate burden of NCDs in women,[67] which the WHO predicts is likely to increase in the next ten years.[68] Notable too is the significant prevalence of co-morbidities in this patient population (44%) and the self-reported prevalence of HIV (18%). The perennial problem of multi-morbidity ranging from patients having more than one NCD and the convergence between NCDs and communicable diseases is increasingly being recognized in resource-limited settings. [69] The need to orchestrate evidence-based responsive changes in policy and research that inform this situation cannot be overemphasised.

Challenging the common convention that patients with NCDs (except cancer) may not need palliative care, self-reported data from ambulatory patients with diabetes, chronic respiratory diseases and CVDs demonstrates they experience a high burden of physical and psychological symptoms. For three of the most prevalent physical symptoms – pain (68%-73%), lack of energy (55%-74%) and feeling tired (62%-77%) – the prevalence found in this study is higher than that reported among ambulatory HIV/AIDS patients (51.3% for pain, 60.3% for lack of energy and 61.9% for feeling tired).[70]

The most prevalent physical symptoms in patients with CVDs were pain, feeling drowsy, numbness / tingling in hands and feet and difficult sleeping. The most prevalent psychological symptoms were worry and sadness. The physical and psychological symptom prevalence reported in this study are lower than those reported in patients with advanced heart failure (New York Heart Association (NYHA) Functional Classification III / IV: pain 91.3%, feeling tired / drowsy 93.0%, worry 94.3%, feeling sad 93.0%).[71] A potential explanation for these differences is probably the comparative disease stage, as symptom burden has consistently been found to be associated with disease stage.

The most prevalent physical symptoms in cancer patients in our study were: pain, lack of energy and feeling sad. The common symptoms mirror those reported among patients attending palliative care services in Uganda and South Africa. Harding et al reported a higher prevalence of pain (87.5%), lack of energy (77.7%), feeling drowsy (72.3%), worry (69.6%) and feeling sad (75.9%).[72] The most distressing symptoms were: problems with sexual interest (57%), pain (52%) and difficulty sleeping (40%). The most plausible explanation for the differences is the likely association between high symptom burden and attending palliative care services. Patients most commonly attend palliative care services if they have a high symptom burden, and thus the sample from the palliative care services is biased towards higher symptom scores.

Whilst respiratory palliative care is receiving attention,[73] a dearth of evidence exists on it in resource-limited settings. To our knowledge this is the first study to assess palliative care-related problems in

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[68] World Health Organization. *Preventing chronic diseases: A vital investment.* Geneva: World Health Organization, 2005.
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[71] Lokker ME, Gwyther L, Magona P, et al. The prevalence and burden of physical and psychological symptoms in patients with advanced heart failure attending a South African public hospital. *Eur J Heart Fail* 2013; 12: S307.
[72] Harding R, Selman L, Agupio G et al. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. *Eur J Cancer* 2011; 47: 51-56.
[73] Bausewein C, Jolley C, Reilly C, Lobo P, Kelly J, Bellas H, Madan P, Panell C, Brink E, De Biase C, Gao W, Murphy C, McCrone P, Moxham J, Higginson IJ. Development, effectiveness and cost-effectiveness of a new out-patient Breathlessness Support Service: Study protocol of a phase III fast-track randomised controlled trial. BMC Pulm Med 2012; 12: 58.

patients with CRD in sub-Saharan Africa. Our sample was largely made up of patients with persistent / severe asthma, as asthma is the most common CRD in the region.[74] The four most common physical symptoms were shortness of breath (75%), pain (68%), lack of energy (68%) and cough (68%). The two most common psychological symptoms were worry (77%) and feeling sad (55%). Although mild asthma patients do not require palliative care, patients with persistent / severe asthma have limited therapeutic options, and remain at high risk of serious morbidity and mortality.[75,76,77] The significant overlap between persistent / severe asthma and COPD has also been noted in clinical practice[78] justifying the need for dialogue and more research on the palliative care-related problems of this patient group. CRDs have received less attention in most developing countries but our findings reveal a significant physical and psychological symptom burden that can lead to poor outcomes if not detected and managed in a timely manner. The most distressing symptoms were shortness of breath (64%), cough (56%) and feeling bloated (44%). The symptoms reported in this population mirror those reported in patients with advanced COPD, a disease that falls within the group of CRDs.

We present novel findings on the palliative care-related problems self-reported by diabetic patients. In countries where appropriate medication is available, diabetes can be managed effectively and in most cases patients may not require palliative care. However, it is important to address diabetes through the lens of palliative care alongside standard treatment where it is available in resource-limited settings. This is, first, because appropriate medicines are commonly unavailable and patients who may not be able to afford them can die from the disease or have to live with disease-related complications. Secondly, multiple morbidity is increasingly becoming a common phenomenon in health care. Typical palliative care patients (e.g., those with HIV/AIDS and cancer) are likely to live with multiple morbidity. The dialogue for a multi-disciplinary approach to care should therefore start sooner rather than later, given the complexity of patient needs. It is important that these symptoms are interpreted in the context of underlying conditions. The three most prevalent physical symptoms in this sample were: feeling drowsy (77%), lack of energy (74%), and pain (73%). The most common psychological symptoms were: worry (72%) and feeling sad (53%). No previous similar research has been undertaken in this patient population and therefore it was difficult to compare our findings with previous context-relevant research. It has, however, been noted that symptoms such as drowsiness, hunger etc., may point towards hypoglycaemia. The psychological morbidity is, however, worthy of comment, making the need for collaborative effort in managing patients with co-morbidities important.

Across the diagnostic groups, more than half of patients reported significant psychological distress. This points to the need for a comprehensive approach to care, which should be inclusive of good psychosocial components. Care should be taken to provide a comprehensive palliative care package for NCD patients, covering not only symptom control interventions but also mental and spiritual care and social support. The presence of comorbidities was associated with increasing symptom distress, including global, physical, psychosocial and the total number of symptoms. Other comorbidities are sometimes neglected or not well assessed in patients with NCDs but the current findings demonstrate the need to assess for the presence of this phenomenon across all diagnostic groups and interventions provided.

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[75] Global Initiative for Asthma. *Global strategy for asthma management and prevention.* NIH publication No. 02-3659. National Institutes of Health/National Heart, Lung, and Blood Institute, 2002.

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[79] Moens K, Higginson IJ, Harding R; EURO IMPACT. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *J Pain Symptom Manage* 2014; 48: 660-677.

As the APCA African POS has less commonly been used in patients with NCDs, an open question was posed to patients prompting them to list the most pressing challenges they face in living with their life-limiting or life-threatening condition. The most commonly occurring theme arising from this question was discomfort with proposed dietary restrictions and this is a pertinent issue that should be addressed. The issue of diet is important as it affects the prevention and treatment facets of the NCDs control strategy.[80] The key policy priorities for chronic disease prevention in many developing nations include diet. Studies have revealed a consistent relationship between unhealthy diet and the emergence of a range of chronic non-infectious diseases, including coronary heart disease, cerebrovascular disease, various cancers, diabetes mellitus, wdental caries, and various bone and joint diseases.[81] Local dietary assessment is an important starting point for the planning and implementation of favourable dietary interventions. As countries endeavour to establish cost-effective solutions to change unfavourable NCD trends, diet and physical activity should receive a major focus in public health policies in combating their emergence. It is recommended that users' preferences are addressed to improve compliance.

Qualitative data also revealed the economic burden of NCDs from the patient perspective, with costs as one of the main pressing problems for patients living with NCDs. Costs related to transport and medication were a common theme under the most pressing problems domain. Indeed in Malawi and Namibia, the total expenditure per capita on NCDs as a percentage of GDP is 11.4%; and 8.9%, respectively,[82] which is too low to meet medication and medical investigation costs. Evidence shows that despite advances made elsewhere in increasing access to medicines for NCDs in the developed world, access to medicines in low-income countries with weak health care infrastructures is a major barrier to controlling chronic diseases.[83] As such, patients have to pay for medications and investigations that cannot be provided within mainstream public health services and these costs are very high for a typical patient in a developing economy.

There is a need to think of models of care that achieve similar outcomes with affordable transport medical investigations and medication costs for patients. Potential options in this regards are investments in decentralised, community-focused services that are more rural based rather than predominantly urban with limited geographic coverage and empowering nurse practitioners to take on necessary additional roles as part of a task shifting agenda. These services could also make use of improved health technology. In this context, Powell et al proposed a chronic care model of service provision in partnership with other clinical providers in an integrated care continuum spanning prevention, early detection, diagnosis, treatment, survivorship and the end of life.[84]

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[82] www.who.int/countries/mwi/en/; www.who.int/countries/nam/en/
[83] International Federation of Pharmaceutical Manufacturers and Associations; www.ifpma.or.
[84] Powell RA, Ali Z, Luyirika E, Harding R, Radbruch L, Mwangi-Powell FN. Out of the shadows: Non-communicable diseases and palliative care in Africa. *BMJ Support Palliat Care* 2015 Sep 21. pii: bmjspcare-2014-000751. doi: 10.1136/bmjspcare-2014-000751. [Epub ahead of print].

RECOMMENDATIONS

RECOMMENDATIONS

Dealing with multiple co-morbidity is the mantra driving health service planning efforts globally. Many patients will continue to live with multiple morbidities, especially as they age, and understanding their palliative care-related problems is important to informing service development. The body of evidence on symptomatology in patients with NCDs is limited and has not been previously investigated in resource-limited settings. This is one of the barriers to assessing needs and to effective symptom control in this patient population. Our study demonstrates a high symptom burden in the ambulatory NCD population and shows evidence of their multidimensional needs. This complexity of needs for patients with NCDs and the common occurrence of co-morbidity demands a multi-disciplinary team approach to patient management. This can be achieved by increasing access to palliative care via the public health approach.

Unaddressed psychiatric symptoms could potentially affect adherence to medication, cause disability and result in poorer care outcomes. Given the apparent high levels psychological morbidity, palliative care professionals should be trained in mental health. This will equip them with skills to meet the psychosocial needs of patients living with life-limiting and life-threatening illnesses.

Diet, which was a cross cutting theme reported by patients, is an essential pillar for any NCD control strategy. Moreover, the fact that the patients in our study cited discomfort with dietary restrictions so often should be taken seriously given NCDs are chronic conditions. There is a need for context-relevant evidence on dietary assessment to inform dietary recommendations and this should be the starting point for planning and implementing favourable interventions.

To increase access to respiratory palliative care, the WHO recommends its integration with lung health programmes. Countries such as South Africa are already following these recommendations and other countries in the region could adopt this approach.[85] Integration of palliative care with other care settings (e.g., oncology for cancer patients and lung health programmes for CRD) is needed. This could follow different models: for example, liaison services associated with palliative care services, basic palliative care training for other health care specialities, specialist palliative care training for selected specialists in oncology, pulmonology etc. and other developments in integration.

There is also a need for proven and appropriate indicators. The universal health indicator (morphine equivalent per cancer death) has been a useful start, but better and more indicators are needed. The ALCP has introduced a set of 10 indicators,[86] but some of them may be difficult to assess and they are not suited for evaluation of the access to palliative care and the quality of palliative care at the patient level. For a meaningful evaluation of access and quality, a first step is to establish national registers for cancer and for other NCD diseases, which could then be used to calculate the percentages of the patients receiving adequate palliative care.

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APPENDICES

APPENDICES

Appendix 1: Information sheet

September 2014
Information Sheet

Palliative care needs among patients diagnosed with a non-communicable disease in two African countries

You are being invited to take part in a study. Before you decide, it is important for you to understand why the research is being done, and what it will involve.

Please take time to read / listen to this information carefully and discuss it with your health professional if you wish. Also, please ask us if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
We are trying to identify and measure the nature and severity of palliative care needs among patients diagnosed with a most prevalent non-communicable disease in two sub-Saharan African countries: Malawi and Namibia. To do this, we are interviewing patients attending this and other clinics in the country.

Why have I been chosen?
By talking to different patients, we hope to obtain information the particular palliative care needs of people diagnosed with a non-communicable disease, and this will help us advocate for services to meet those needs. In this way, you have been asked to take part because we would like to hear your story about your diagnosis and needs.

Do I have to take part?
No, you don't have to take part in the study if you don't wish to. If you decide to participate, you are free to withdraw from the interview at any time, and you don't have to give a reason. Taking part, withdrawing at any time, or a decision not to take part at all will not affect the standard of care you receive from this organization in any way.

***What will it involve*?**
If you do agree to participate, you will be given this information to keep and asked to sign a consent form to show that you have agreed to take part. A researcher who is working with the national palliative care association will then conduct a short interview with you.

The discussion will last no more than about 20 minutes, unless you wish to talk for longer. After these discussions there will be no more things for you to do with this study.

Will my taking part in this study be kept confidential?
All the information which we collect will be kept strictly confidential. None of the people who provide your care will be involved in the interviews or have access to the notes.

You will not be identified in any way, and your personal details (for example, your name) will be kept separately from the information you give. We will NOT let anyone have any information that could identify you. Any information you give us during the discussion will NOT be kept with anything that could identify you (like your name or address). You may withdraw your data from the project at any time up until it is used in the final report.

***What happens to the results of the research study*?**
We will use the interviews in which you participate to write up reports on the palliative care needs of people diagnosed with a non-communicable disease.

***Who is organizing the research*?**
This study is being organized by the Uganda-based African Palliative Care Association (APCA). The national ethics body of your country has reviewed this study and approved it for your protection.

***Who can I contact*?**
If you would like to talk to someone about the study, or get more information, please contact Eve Namisango, the Research Coordinator, on +256 414 266 251.

Appendix 2: Consent form

September 2014
Consent Form

Palliative care needs among patients diagnosed with a non-communicable disease in two African countries

Participant's Statement for Interviews:

- I confirm that I have read and understand the information sheet dated September 2014 for the above study and have had the opportunity to ask questions.
- I understand that if I decide at any other time during the research that I no longer wish myself to participate in this project, I can notify the researchers involved and be withdrawn from it immediately without my legal rights and care being affected.
- I consent to the processing of personal information about me for the purpose of this research study. I understand that such information will be treated as strictly confidential.
- I agree to take part in the above study.

_____ (name)

Signed or fingerprint: Date

---------- ----------

Researcher's statement:

I _____ (name)

Confirm that I have carefully explained the nature and demands of the proposed interview to the patient involved in this study.

Signed Date

---------- ----------

Appendix 3: Socio-demographic & clinical questionnaire

Patient ID

01	Date of Interview	____/____/____
02	Name of health facility Queen Elizabeth central hospital =1 Zomba central hospital =2 Kamuzu central hospital =3 Mzuzu central hospital =4	
	Question	**Answer**
P1	Please indicate the patient's gender Male =1 , Female =2	
P2	How old are you? (complete years)	
P3	What is the highest level of education you attended? None = 1 Attended primary = 2 Attended secondary = 3 Diploma = 4 Degree of higher = 5	
P4	Has the patient had a primary diagnosis of a non-communicable disease? Yes =1 no=2 *(If no please stop interview)*	
P4.1	If 'Yes': What is the PRIMARY diagnosis? (*for each please fill in the details of the diagnosis . please refer to patient files for details) if p4.1 =1 go to p4.2 , if p4.1 =2 go to p4.3 , if p4.1=3 go to p4.4* Cardiovascular diseases = 1 Cancer = 2 Chronic respiratory diseases = 3 Diabetes = 4	
P4.2	**Cardiovascular diseases** Rheumatic heart disease = 1 Hypertensive heart disease = 2 Ischemic heart disease = 3 Cerebrovascular disease = 4 Inflammatory heart disease = 5	
P4.3	**Type of Cancer** Breast = 1 Stomach = 2 Liver = 3 Colon = 4 Prostate = 5 Cervix = 6 Oesophagus = 7 Karposis scarcoma = 8 Other (please mention) ----------	
P4.4	**Chronic respiratory diseases** Occupational lung disease = 1 Pulmonary hypertension = 2	

P5	**Does the patient have any co-morbidities?** Yes =1 , No =2 *These are the presence of one or more additional disorders (or diseases) co-occurring with a primary disease or disorder, or the effect of such additional disorders or diseases.*	
P5.1	If yes in p5 please list the co-morbidities	
P6	Date when patient was diagnosed with primary NCD *(please use both self-report and patient records)* (For Unknown day =15, unknown month =06, unknown year enter 08/08/8888)	____/____/____
P7	Date when patient enrolled into this facility for NCD related care , treatment or support *(please use both self-report and patient records)* (For Unknown day =15, unknown month =06, unknown year enter 08/08/8888)	____/____/____
P8	What is the patient's HIV status? Positive =1 Negative =2 Not known =3	
P9	How many dependants do you have? (family members who are dependent on you including children)	
P10	How far is your home from this health facility (KMS)	
P11	How much money do you spend on transport to and from this health facility for a single visit?	
P12	On average how much did you spend on medication in the previous 30 days?	
P13	On average how much did you spend on laboratory and other investigation procedures in relation to this NCD treatment in the previous 30 days?	
P14	How many meals does your household have in a typical day? Three =1, two =2 one =3 none =4	
P15	Is food security a problem in your household? Yes =1 No =2	
	P16 What are your major challenges in living with this illness?	
P16	What language was the questionnaire/interview conducted in? English =1 Chichewa=2	

Appendix 4: Karnofsky Performance Scale (modified)

Patient ID

%	AMBULATION	AMBULATION AND EVIDENCE OF DISEASE	SELF CARE	IN TAKE	CONSCIOUS LEVEL
100	Full	Normal activity no evidence Of disease	Full	Normal	Full
90	Full	Normal activity some evidence of disease	Full	Normal	Full
80	Full	Normal activity with some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable normal job/ Work, some evidence of disease	Full	Normal Or reduced	Full
60	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full
50	Mainly sit or lie	Unable to do any work, extensive disease	considerable assistance required	normal or reduced	Full + /- Confusion
40	Mainly in bed	As above	Mainly assistance	Normal or reduced	Full or drowsy +/- Confusion
30	Total bed bound	As above	Total care	Reduced	As above
20	As above	As above	Total care	Minimal Sips	As above
10	As above			Mouth care only	Drowsy Or comma
0	Death				

How many minutes did it take you to conduct this tool with the patient?

Minutes

Appendix 5: APCA African POS

Patient ID

	POSSIBLE RESPONSES
ASK THE PATIENT	
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 7 days	0 (no pain) - 5 (worst/overwhelming pain)
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 7 days?	0 (not at all) - 5 (overwhelmingly)
Q3. Have you been feeling worried about your illness in the past 7 days?	0 (not at all) - 5 (overwhelming worry)
Q4. Over the past 7 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely)
Q5. Over the past 7 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time)
Q6. Over the past 7 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time)
Q7 Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted)
ASK THE FAMILY CARER	
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A
Q9. How confident does the family feel caring for _____?	0 (not at all) - 5 (very confident) N/A
Q10. Has the family been feeling worried about the Client over the last 7 days?	0 (not at all) - 5 (severe worry) N/A

How many minutes did it take you to conduct this tool with the patient?

Minutes.

Appendix 6: Memorial Symptom Assessment Schedule (SF – expanded)

Patient ID

Below is a list of symptoms. Ask the patient 'Have you had this symptom DURING THE LAST WEEK?' If the patient says 'Yes', please tick 'YES' for that symptom. If 'No', go on to the next item.

If the patient answered 'Yes', ask him/her 'How much has the symptom DISTRESSED or BOTHERED you?', providing the 5 options listed. Tick the answer the patient gives.

N.B. For each symptom row, there should either be 0 ticks (if no symptom in past week) or 2 ticks (if symptom).

Tick ALL the symptoms the patient had during the PAST WEEK	Yes ✓	If YES: How much did it DISTRESS or BOTHER the patient?				
		Not at all	A little bit	Somewhat	Quite a bit	Very much
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy/ tired						
Numbness/tingling in hands or feet						
Difficulty sleeping						
Feeling bloated						
Problems urinating						
Vomiting						
Shortness of breath						
Diarrhoea						
Sweats						
Mouth sores						
Problems with sexual interest/ activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Changes in way food tastes						
Weight loss						
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
Sores or lumps on private parts						
Discharge from private parts						
Bad smell/ odour						
Difficulty moving						
Difficulty walking						

Tick ALL the symptoms the patient had during the PAST WEEK	Yes ✓	If YES: How much did it DISTRESS or BOTHER the patient?				
Muscle aches						
Difficulty seeing well – poor vision						
Difficulty hearing well – poor hearing						
Hunger						
Please ask the patient and write in any other symptoms the patient has had during the past week:	**Yes ✓**	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
1.						
2.						
3.						
4.						
5.						

Below are other common symptoms. Ask the patient 'Have you had this symptom DURING THE LAST WEEK?' If the patient says 'Yes', please tick 'YES' for that symptom. If 'No', go on to next item.

If the patient answered 'Yes', ask him/her 'HOW OFTEN did you have the symptom in the past week?', providing the 4 options listed. Tick the answer the patient gives.

Tick ALL the symptoms the patient had during the PAST WEEK.	**Yes ✓**	If yes, how OFTEN did it occur?			
		Rarely	**Occasionally**	**Frequently**	**Almost constantly**
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Please tell me about me about any other symptoms that have been bothering over the past 7 days

How many minutes did it take you to conduct this tool with the patient?

Minutes.

Appendix 7: Center for Epidemiologic Studies Depression Scale

Patient ID_____

1. I was bothered by things that don't usually bother me.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

2. I did not feel like eating; my appetite was poor.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

3. I felt that I could not shake off the blues even with the help of my family or friends.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

4. I felt that I was just as good as other people.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

5. I had trouble keeping my mind on what I was doing.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

6. I felt depressed.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

7. I felt everything I did was an effort.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

8. I felt hopeful about the future.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

9. I thought my life had been a failure.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

10. I felt fearful.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

11. My sleep was restless.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

12. I was happy.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

13. I talked less than usual.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

14. I felt lonely.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

15. People were unfriendly.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

16. I enjoyed life.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

17. I had crying spells.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

18. I felt sad.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

19. I felt that people disliked me.

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

20. I could not get "going".

- ☐ Rarely or none of the time (<1 day)
- ☐ Some or a little of the time (1-2 days)
- ☐ Occasionally or a moderate amount of the time (3-4 days)
- ☐ Most or all of the time (5-7 days)

How many minutes did it take you to conduct this tool with the patient?

☐ Minutes.

ABOUT APCA

The African Palliative Care Association (APCA) is a non-profit making pan-African membership-based organisation which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004. Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, in collaboration with its members and partners, APCA provides African solutions to African problems, articulating them with what is the recognised regional voice for palliative care.

APCA's vision is to ensure access to palliative care for all in need across Africa, whilst its mission is to ensure palliative care is widely understood, underpinned by evidence, and integrated into all health systems to reduce pain and suffering across Africa. APCA's broad objectives are to:

- Strengthen health systems through the development and implementation of an information strategy to enhance the understanding of palliative care among all stakeholders;
- Provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa;
- Develop an evidence base for palliative care in Africa;
- Ensure good governance, efficient management practices and competent human resources to provide institutional sustainability;
- Position palliative care in the wider global health debate in order to access a wider array of stakeholders and to develop strategic collaborative partnerships, and;
- Diversify the financial resources base to meet APCA's current funding requirements and to ensure the organisation's future sustainability.

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