

POLICY BRIEF



A high burden of complex symptoms and concerns among ambulatory patients diagnosed with cancer, diabetes, chronic respiratory and cardiovascular diseases.

A case study of two countries in Southern Africa

Key findings

The three palliative-care-related problems with the highest intensity were: shared feelings (not at all/not very often); help and advice (none/very little); and worry (most/all the time). The most prevalent physical symptoms across the range of diseases being considered were pain and lack of energy. Cough and difficulty sleeping were common in patients with CRD, while dry mouth, numbness, difficulty sleeping and hunger affected diabetic patients. Weight loss was most common in cancer patients. Worry was the most common psychological symptom, reported across the range of patients, although feeling irritable was more common in cancer patients. Qualitative data also revealed the economic burden of NCDs from the patient's perspective. Costs related to transport and medication were a common theme.

Policy recommendations

- There is an urgent need to scale up access to palliative care for patients with non-communicable diseases to promptly identify and treat complex symptoms and concerns they experience
- Mental health is also a concern in this population, care providers should be equipped with relevant skills to make mental health integral to the palliative care service package.
- Palliative care should be recognised as part of the response strategy to NCD pandemic in the African region.

Introduction

There is a growing recognition in Africa of the importance of addressing non-communicable diseases (NCDs) and advancing palliative care service provision for NCD 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.

Summary of research

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 (expanded); and the Center for Epidemiologic Studies Depression Scale.

Research findings

A total of 457 patients participated in the study, from Malawi (207) and Namibia (250), and data from those patients was collected in May/June 2015. Just 27 of those approached refused to take part.

Slightly more than half of respondents were female, and the mean age of all participants was 48 (standard deviation, SD: 15.7). Just under half of respondents ($n=208$) had attained secondary education. Primary diagnoses included 28.4% ($n=130$) with CVDs (of whom 69.7% [$n=86$] had hypertensive heart disease and 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. Additionally, 43.8% ($n=200$) reported having co-morbidities, and 17.9% ($n=82$) reported a positive HIV serostatus.

The three palliative-care-related problems with the highest intensity were: shared feelings (not at all/not very often); help and advice (none/very little); and worry (most/all the time). The most prevalent physical symptoms across the range of diseases being considered were pain and lack of energy. Cough and difficulty sleeping were common in patients with CRD, while dry mouth, numbness, difficulty sleeping and hunger affected diabetic patients. Weight loss was most common in cancer patients. Worry was the most common psychological symptom, reported across the range of patients, although feeling irritable was more common in cancer patients.

Qualitative data also revealed the economic burden of NCDs from the patient's perspective. Costs related to transport and medication were a common theme

Conclusions

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 multidisciplinary 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 of 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 that 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.¹ Integration of palliative care with other care settings (eg, 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,² 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 patients receiving adequate palliative care.

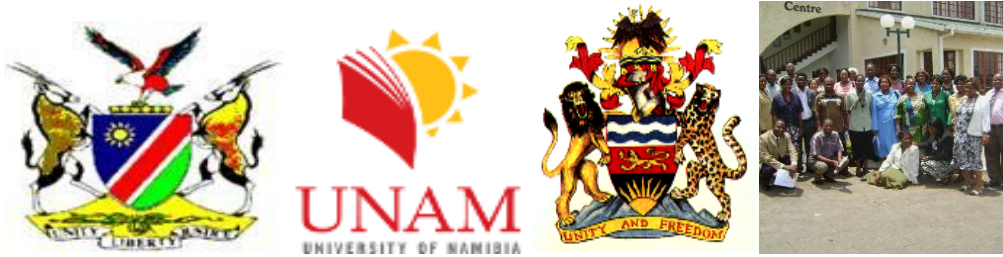
Please see full report here

https://www.africanpalliativecare.org/images/stories/pdf/NCD_REPORT.pdf

¹ Hospice and Palliative Care Association of South Africa. *Guidelines for Providing Palliative Care to Patients with Tuberculosis*, 2011. Available at www.inpracticeafrica.com/~media/Guidelines/SA_HPCA_TB_Palliative.pdf.

² Pastrana T, Eisenclas J, Centeno C, De Lima L. "Status of palliative care in Latin America: looking through the Latin America Atlas of Palliative Care", *Curr Opin Support Palliat Care* 2013; 7: 411–416.

In country partners



Ministry of Health and Social Services –Namibia
Faculty of Medicine University of Namibia
Ministry of Health Malawi
Palliative Care Association of Malawi

Contact

Dr Emmanuel BK Luyirika

emmanuel.luyirika@africanpalliativecare.org

Eve Namisango

eve.namisango@africanpalliativecare.org

<https://www.africanpalliativecare.org/>

