

Original Article

Public Priorities and Preferences for End-of-Life Care in Namibia

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Abstract

Context. Although quality end-of-life care provision is an international public health issue, the majority of evidence is not generated in low- and middle-income countries that bear a disproportionate burden of progressive illnesses.

Objectives. To identify the priorities and preferences of the Namibian public for end-of-life care.

Methods. Using a cross-sectional study design, data were collected in the country's capital, Windhoek, from November to December 2010.

Results. In total, 200 respondents were recruited. The mean age was 27 years (SD 7.5; range 18–69), with nearly all ($n = 199$; 99.5%) expressing a religious affiliation. Being in pain was reported as the most concerning of nine common end-of-life symptoms and problems ($n = 52$; 26.1%), and the most important care-related aspect was having as much information as wanted ($n = 144$; 72%). The majority (64%) would want their end-of-life care to focus on improving their quality of life rather than extending it, with 40% not wanting to know if they had limited time left to live. Hospital ($n = 96$; 48%) and home ($n = 64$; 32%) were the most preferred places of death. The most important end-of-life priority was keeping a positive attitude ($n = 128$; 64%). Having had a close relative or friend diagnosed with a serious illness was associated with a 2.3 increase in the odds of preference for a hospital death (odds ratio = 2.34, $P = 0.009$, 95% CI 1.23–4.47).

Conclusion. This study identified a number of areas that need to be pursued in future research to explore factors that may affect patient preferences and priorities in end-of-life care in Namibia. *J Pain Symptom Manage* 2014;47:620–630. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Key Words

Namibia, Africa, end of life, terminal, cancer

Introduction

A conservative estimate that each death affects five other people in terms of informal caregiving and bereavement suggests that 300 million people (5% of the world population) are affected each year by death.¹ Consequently, addressing end-of-life care is increasingly an international public health issue. The vast majority of global deaths—projected to increase from 57 million in 2002 to more than 74 million in 2030, with a significant shift in demographic profile from younger to older aged people and in causation from communicable to non-communicable diseases²—occur in developing countries.

Sub-Saharan Africa is characterized by a significant disease burden. By 2011, 23.5 million people in sub-Saharan Africa were living with HIV/AIDS, 69% of the global disease burden.³ Cancer is an emerging public health problem in the region.⁴ In 2008, there were an estimated 715,000 new cancer cases and 542,000 cancer-related deaths in Africa,⁵ with cancer rates on the continent expected to grow by 400% over the next 50 years.⁶ Approximately 36% of cancers in Africa are infection related, twice the global average.⁷

As part of an integrated, comprehensive palliative care service, public consultation is needed to ensure that care is person centered and that policies and service organizations respond to the preferences of those who will use end-of-life care services. Defining end-of-life care is complex; it is a diffuse term that can vary by culture and setting and predominates in academic rather than practitioner, patient, and family dialogue. The U.K. National Institute of Health State-of-the-Science Conference on Improving End-of-Life Care reported that “there is no exact definition of end-of-life; however, the evidence supports the following components: 1) the presence of a chronic disease(s) or symptoms or functional impairments that persist that may also fluctuate; and 2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death.”⁸

However, although for some end-of-life care is conflated with terminal care in the last few days or weeks of life, others define it as the period preceding the very end of life, and others include the last year of life.

Despite the disease burden in sub-Saharan Africa, there is a dearth of evidence on the nature of appropriate end-of-life care.^{9,10} Indeed, although a body of data has been generated in high-income countries, no data currently exist on end-of-life priorities and preferences in African countries to inform policy and service development. However, understanding these preference and priorities is a prerequisite to improving and optimizing care provision, given the limited resources available, taking into consideration local social, cultural, and economic contexts, where differences in meaning and priorities can exist.^{10,11}

This study sought to address that research gap and replicate work conducted in this area as part of the three-year European Commission—funded collaboration, PRISMA (www.prismafp7.eu), which aimed to inform best practice and harmonize research in end-of-life care for cancer patients across Europe that included work in Africa,^{9,12,13} by identifying the priorities and preferences of the Namibian public with regard to end-of-life care.

Methods

Study Design

The study used a street survey methodology, a novel method that has been developed and piloted in Nairobi, Kenya.¹⁴ To ensure that the questionnaire was understandable in a local context, the tool was piloted among 10 people of mixed gender in Windhoek, the capital of Namibia; their responses were omitted from the final sample data set. No issues were raised regarding question clarity and sensitivity that necessitated alterations to the survey instrument.

Sampling and Recruitment

Using two researchers in a mutually supportive “buddy” system, eight “streets” (e.g.,

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