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.

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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 noncommunicable diseases[2]—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.,

downtown, shopping centers, malls, etc.) were identified for recruitment in the central business district of Windhoek. Participant sampling entailed approaching every 10th person passing the researcher (with the inclusion criteria being aged 18 years and older and of Namibian nationality), alternating the approaches between men and women, and inviting their participation in the study. If the 10th person approached was the same gender as the preceding participant, the next person of an appropriate gender was approached.

Following screening of potential participants against the inclusion criteria, the interviewers determined the potential participant's language preference to be used (i.e., English or Afrikaans) and subsequently explained the details of the study and sought verbal consent. The interviews, conducted between November and December 2010, were undertaken by two African researchers with experience in end-of-life care research who had been involved in the piloting of the survey tool.

Data Collection Tool

Respondents were asked about their care preferences and priorities if faced with a serious illness (e.g., cancer) and were likely to have less than one year to live. Researchers read aloud a brief questionnaire to participants who provided verbal responses recorded by the researcher. Sociodemographic items included age, gender, level of education, religious affiliation, and tribe. These were adapted from a European Commission–funded cross-sectional survey carried out in more than 32 European countries (i.e., European Social Survey, with most from the European Social Survey Round 4),[15] and 12 PRISMA study questions, adapted via piloting to ensure that they were culturally sensitive to the Namibian context.

The PRISMA questionnaire, which was used in Europe as part of a telephone survey,[12] was subsequently adapted to the Kenyan context and used in a street setting in the country's capital.[14] The final study questionnaire covers the following main areas: preferences for place of death, symptoms and problems, preferences for information and involvement in decision making, and priorities for end-of-life care.

Data Analysis

Data were double entered into SPSS® v. 15 (SPSS Inc., Chicago, IL), cleaned, and validated. Descriptive analysis was conducted using STATA10® (StataCorp LP, College Station, TX), with cases with missing data excluded and data described as proportions for all items in the questionnaire. Additionally, the following variable transformations were performed: for the question of how patients ranked keeping a positive attitude at the end of life—which was based on a four-rank order ranging from "1" for important to "4" for least important—we recategorized the data into two rankings: first rankings were categorized as "yes" (i.e., keeping a positive attitude is considered most important), and second, third, and fourth rankings were categorized as "no" (i.e., keeping a positive attitude is not considered most important). The variable of age was categorized into four groups (≤20, 21–25, 26–30, and ≥31), given that it was not normally distributed.

Those symptoms or problems reported, from a predetermined list of nine items, as most concerning by participants were ranked according to the sums of scores given by individuals to each item, with higher scores meaning a higher priority.

Participants preferring a hospital death were compared with those preferring to die elsewhere (i.e., home, hospice) on a number of sociodemographic factors—age group, highest level of education, gender, other end-of-life care preferences, being personally diagnosed with serious illness, having had a close relative or friend diagnosed with a serious illness, preferred end-of-life focus of care, and a high level of concern for keeping a positive attitude at the end of life—using the chi-squared statistic (χ^2) and Fisher's exact test for those instances where cell counts were less than five.

At the multivariate level, binary logistic regression was used to examine factors associated with a preference for a hospital death. Only variables significant at a statistical level of 0.2 in bivariate analysis were selected for multivariate logistic regression analysis,[16] with odds ratios and 95% CIs estimated in the final model. Other independent variables included gender, highest level of education, experience of a serious illness, and concern about improving quality of life at the end of life vs.

extending life. All tests were two tailed, and $P < 0.01$ was deemed significant in the final models to allow for multiple testing.

Ethics

The survey was approved by the Namibian Ministry of Health and Social Services' Research Ethics Committee (Ref: 17/3/6).

Results

Participants' Sociodemographic Characteristics

A sample comprising 200 respondents was recruited, with a response rate of 91%. Table 1 presents the characteristics of the sample. The mean age was 27 years (SD 7.5; range 18–69), with nearly half ($n = 94$; 47%) of the respondents unemployed and nearly all ($n = 199$; 99.5%) expressing a religious affiliation. These figures are broadly comparable to those of the wider population, where the median age is 22.1 years, unemployment among youth (aged 15–24 years) is 41.7%, and religious affiliation is expressed by all (Christian 80%–90%, with at least 50% Lutheran, and indigenous beliefs at 10%–20%).[17] Nearly 6% ($n = 11$) of the respondents had been diagnosed with a serious illness in the last five years, and 55.3% ($n = 109$) had had a close relative or friend diagnosed with a serious illness over the same time period. The majority of respondents ($n = 127$; 64.5%) had experienced the death of a close relative or friend, and 50.5% ($n = 98$) had cared for a relative or friend in the last months of life.

Table 1
Sample Sociodemographic Characteristics

Variable	n (%), $N = 200$
Male	100 (50)
Female	100 (50)
Namibian nationality	200 (100)
Mean (SD), in years	26.99 (7.5)
16–29	145 (72.5)
30–39	45 (22.5)
40–49	5 (2.5)
50–59	3 (1.5)
60–69	2 (1)
Unemployed	94 (47)
With a religion or denomination	199 (99.5)
Seriously ill in the last five years	11 (5.6)
Relative/friend seriously ill in the last five years	109 (55.3)
Death of relative/friend in the last five years	127 (64.5)
Cared for relative/friend in the last months of life	98 (50.5)
Highest level of education	
Primary education	13 (6.5)
Secondary education	134 (67)
Bachelor's degree	53 (26.5)
Level of urbanization where participant lives	
Urban	189 (94.5)
Peri-urban	4 (2)
Rural	7 (3.5)
Ethnic group	
Ovambo	80 (40)
Herero	36 (18)
Damara/Nama	26 (13)
Kavango	19 (9.5)
Caprivian	16 (8)
Other	22 (11)
Missing	1 (0.5)

For the majority of respondents ($n = 134$; 67%), the highest level of attained education was secondary, again comparable to official school life expectancy among the population of 12 years,[17] whereas 26.5% ($n = 53$) studied to the undergraduate level. An overwhelming majority ($n = 189$; 94.5%) lived in urban areas. All respondents reported being Namibian citizens, with only one white person included. Forty percent ($n = 80$) of the participants reported being from the Ovambo ethnic group (which, at the time of the pre-independence last recording of ethnicity in 1989, accounted for 49.8% of the country's population),[18] and 18% ($n = 36$) were Herero.

Information Preferences

The vast majority of respondents said that they would always like to receive information on the available care options ($n = 196$; 98%) and also on the symptoms and problems they might experience ($n = 186$; 93%) (Table 2). Two-fifths ($n = 80$; 40%) of respondents reported not wanting to know if they had limited time left to live.

Most Concerning Symptoms and Problems

As Table 3 shows, being in pain was reported as the most concerning of nine common end-of-life symptoms and problems ($n = 52$; 26.1%), followed by having no energy ($n = 31$; 15.6%) and being unable to get their breath ($n = 26$; 13.1%).

Preferences for Decision Making

Table 4 shows that around half ($n = 106$; 53%) of the respondents would want to be involved in making decisions about their care

Table 2
Information Preferences

Variable	*n* (%), *N* = 200
Options available for care	
Yes, always	196 (98)
Yes, but only if asked	0 (0)
No	4 (2)
Symptoms and problems one might experience	
Yes, always	186 (93)
Yes, but only if asked	2 (1)
No	12 (6)
Limited time left	
Yes, always	112 (56)
Yes, but only if asked	8 (4)
No	80 (40)

when they have the capacity to do so. Similarly, 57% ($n = 114$) of the patients, in a scenario of full mental capacity, would like to involve their family. However, in a scenario of lost capacity, there was a 10% point drop in the proportion of people who wanted doctors to make decisions for them and a 21% greater proportion wanting their family members to make decisions on their behalf.

Most Preferred Place of Death

Forty-eight percent of respondents ($n = 96$) preferred to die in a hospital but not a palliative care unit (defined as a place with specialized care and beds for dying patients); their own home was the second most preferred place of death ($n = 64$; 32%) (Table 5).

Least Preferred Place of Death

For the majority of respondents ($n = 130$; 65%), home (either their own home or the home of a relative or friend) was the least preferred place of death, followed by a hospital but not a palliative care unit ($n = 44$; 22%) (Table 5).

Table 3
Most Concerning Symptoms and Problems

Symptom/Problem	Rank Score
Being in pain	First: 343
Having no energy	Second: 286
Being unable to breathe	Third: 271
Changes in the way you look	Fourth: 265
Being a burden to others	Fifth: 263
Being worried and distressed	Sixth: 262
Being alone	Seventh: 257
Having no appetite	Eighth: 230
Feeling as if wanted to be sick	Ninth: 211

The nine symptoms and problems were ranked based on the sum of scores given by 200 individuals representing their level of concern with that specific symptom and problem. Higher scores mean higher priority.

Table 4
Decision-Making Preferences

Preference	*n* (%), *N* = 200
Self	
Capacity	106 (53)
Lost capacity	14 (7)
Family	
Capacity	114 (57)
Lost capacity	156 (78)
Friends	
Capacity	24 (12)
Lost capacity	6 (3)
Doctor	
Capacity	106 (53)
Lost capacity	86 (43)
Others	
Capacity	4 (2)
Lost capacity	0 (0)

Factors Influencing Preferred Place of Death

Age, highest level of education, and previous exposure to a serious illness were not associated with the preference for a hospital death at the bivariate level. At the 0.2 statistical level of significance, there was an association between a high level of concern for keeping a positive attitude at the end of life, having experienced the death of a close relative, and having had a close relative or friend diagnosed with a serious illness, and preference for a hospital death; these variables were entered into the multivariate model (Table 6).

In the final multivariate model, 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

Table 5
Preferences for Place of Death

Location	*n* (%), *N* = 200
Most preferred place of death	
Hospital but not palliative care unit	96 (48)
Own home	64 (32)
Hospice or palliative care unit	22 (11)
Home of a relative or friend	8 (4)
Care home	6 (3)
Somewhere else	4 (2)
Least preferred place of death	
Own home	112 (56)
Home of a relative or friend	18 (9)
Hospice or palliative care unit	8 (4)
Hospital but not palliative care unit	44 (22)
Care home	6 (3)
Somewhere else	12 (6)

Table 6
Univariate Associations Between Participants' Characteristics and Preference for a Hospital Death

Variables[a,b]	Preference for Hospital Death, *n* (%)		χ^2 (Fisher's Exact Test for Cell Counts Less Than Five)	*P*-Value
	Yes	No		
Gender				
Male	51 (49.00)	49 (51.00)	1.318	0.251[c]
Female	42 (57.14)	56 (42.86)		
Age group (years)				
≤20	18 (55.00)	22 (45.00)		
21–25	27 (52.63)	30 (47.37)	0.110	0.991
26–30	25 (52.63)	30 (47.37)		
≥31	22 (52.17)	24 (47.83)		
Highest level of education				
Primary education	4 (69.23)	9 (30.77)		
Secondary education	62 (53.03)	88 (46.97)	1.444	0.486
Completed a bachelor's degree	26 (50.94)	31 (49.06)		
High level of concern for keeping a positive attitude at end of life				
Yes (ranked first)	54 (42.52)	73 (57.48)		
No (ranked second, third, or fourth)	40 (54.79)	33 (45.21)	2.804	0.094[c]
Preferred focus of care at the end of life				
Improve the quality of the remaining life	58 (48.74)	61 (51.26)	1.1390	0.566
Extending life	11 (37.93)	18 (62.07)		
Both are equally important	22 (57.9)	16 (42.1)		
Personally diagnosed with serious illness				
Yes	4 (36.36)	7 (63.64)	0.6278	0.428
No	90 (48.65)	95 (51.35)		
Experienced death of a close relative				
Yes	66 (51.97)	61 (48.03)	2.5911	0.107[c]
No	28 (40)	42 (60.00)		
Has had a close relative or friend diagnosed with a serious illness				
Yes	60 (55.05)	49 (44.95)		
No	54 (61.36)	49 (38.64)	5.2553	0.022[c]

Missing data include "don't know," refusals.
[a]Sums may not always amount to the total sample number because of missing values on variables.
[b]There were two missing values for gender, age group, and highest level of education, 14 for high level of concern for keeping a positive attitude, four for personally diagnosed with serious illness, and three for has had a close relative or friend diagnosed with serious illness.
[c]Variables selected for multivariate analysis.

(odds ratio = 2.34, $P = 0.009$) (data not shown).

Most Important Goals at the End of Life

For the majority of respondent ($n = 128$; 64%), the first most important goal was keeping a positive attitude and the second was making sure relatives and friends were not worried or distressed ($n = 40$; 20%) (data not shown).

Most Important Care-Related Aspects at the End of Life

Having as much information as wanted was the most important care-related aspect ($n = 144$; 72%) reported by respondents, followed by choosing who makes decisions about their care ($n = 34$; 17%).

Preferred Focus of Care at the End of Life

The majority of respondents ($n = 128$; 64%) thought that improving quality of life would be more important than extending life. Less than a fifth thought that extending life would be the preferred focus of end-of-life care ($n = 32$; 16%). Both quality and quantity of life were equally important for 20% ($n = 40$) of the sample.

Discussion

This study had a number of limitations. Specifically, it largely determined the views of an urban-based, physically mobile, young, educated, and healthy sample for a hypothetical scenario, recognizing that choices can change when confronted by real-life situations. Given its exploratory nature, the study also had no formal sample size calculation. However, despite these limitations, the survey revealed six important findings: 1) for nearly two-thirds of the participants, improving quality of life is considerably more important than extending

life itself in a scenario of advanced illness; 2) the vast majority of people (more than nine of 10) would always like to receive information on the available care options and the symptoms and problems they might experience; 3) being in pain would be the most concerning symptom and problem; 4) most people want to be involved in decisions about their care and to involve their family in that process, particularly in a scenario of personal incapacity; 5) a significant percentage of people (four of 10) do not want to know if they have limited time to live; and 6) a home death was less preferred to the one in hospital.

Improving Quality of Life Rather Than Extending Life

The majority of the Namibian public place more value on the quality of the time they have left to live in this scenario, with 64% ($n = 128$) wanting to improve the quality of life they hypothetically had left, compared with only 16% ($n = 32$) who reported wanting to extend it. This finding should be used to address the specific current emphasis of the country's global health initiative on the prolonged survival of persons living with HIV/AIDS[19] and augment the National Health Policy Framework, 2010–2020's strategy to expand and promote the delivery of accessible, sustainable, and equitable quality health care through an integrated, multisectoral, primary health care model.[20]

Information on the Available Care Options and Symptoms and Problems Possibly Experienced

The study demonstrates a high preference for information without having to ask for it, particularly around care options, symptoms, and problems. The finding concurs with the results from previous research from Africa.[21] Openness in communication and providing adequate information is an underlying principle in the delivery of end-of-life care to patients and their carers,[22] with medical care satisfaction influenced by the level of information patients and carers receive.[23]

Pain: The Most Concerning Symptom

Currently, concerns remain regarding the prevalence, under-recognition, and undertreatment of pain.[24,25] In addition to having their personal pain and discomfort relieved, keeping a positive attitude was foremost in end-of-life priorities. Consequently, a step change in the way policy makers and clinicians perceive end-of-life care is needed, ensuring that people's priorities and preferences inform the planning and delivery of services. A change in the way health care professionals working with patients with advanced diseases (such as cancer) measure those issues that are important to patients and their families also is required. Although important, routine tests to investigate vital clinical indicators may ignore the effects of the illness on the person and their family. There is a need to focus on the assessment of symptoms, in conjunction with psychological, social, and spiritual problems, to ensure appropriate responses to patients' and families' preferences. Priority should be accorded to symptom control, emotional well-being, family support, choice of where to be cared for, and information needs, as these are some of the key determinants of a "good death."[26]

Shared Decision-Making Models

Maintaining a degree of choice and thereby control in the decision-making process was found to be important in this study, although the survey did not clarify to what areas of decision making this applied. Moreover, a significant proportion of respondents (78%) expressed a preference for families to be involved in decision making in a hypothetical scenario of lost capacity. Additionally, the findings show a significant shift in preferred decision making when the hypothetical scenario changes from one of patient capacity to one of incapacity, with an increased reliance on family members at the expense of the involvement of a doctor. However, despite patient preferences to involve family members in decision making, ways of helping families in this respect are limited. There is a need to prioritize the education and empowerment of families so that they can make informed decisions on behalf of the patients and the further training of health care staff in communication issues and family meetings.[27]

The findings suggest that a shared decision-making model centered on the patient and the family would address the preferences of the majority. However, this model poses complex

challenges that will need resolution, such as conflicting views, unrealistic expectations, lack of information, and the discussion of options.[28]

Not Knowing of the Limited Time to Live

It is notable that 40% of respondents reported not wanting to know if they had limited time to live. Lack of public openness about death may have negative consequences for the quality of end-of-life care, arising from fear of the process of dying, lack of knowledge of how to request and access services, lack of candid expression between close family members, and isolation of the bereaved.[29] The response could potentially echo the "denial of death thesis" often, although not without challenge over time,[30,31] used to characterize the contemporary Western society.[32] However, given the parameters of this study, additional research is needed to explore the actual reasons for the expressed desire of not wanting to know.

Hospital Over Home as the Preferred Place of Death

Central to a good death is for a patient's preferred place of death to be honored; that is, individuals are to be respected and die with dignity and as comfortably as is possible, irrespective of who the individuals are, where they live, and the care setting. In this study, more than half of the sample preferred to die in a hospital, with only a third preferring to die at home. This contrasts with the findings from a large cross-national survey across seven European nations that found at least two-thirds of the people preferred a home death if they were to die with a serious illness, like advanced cancer, in all but one of the studied countries.[12]

Against a background of scarce health care facilities, difficulty in accessing available care facilities by the very ill, and the apparent preference for terminal care and death in the domiciliary setting,[26,33,34] most African governments promote home care. These expressed wishes can be the result of the potential myriad reasons,[27] not least of which in nonurban locations is geographic distance from (and hence inaccessibility of) hospitals, which can result in rural dwellers dying at home.[35]

In general terms, a preference for hospital care may indicate a resigned acceptance of the inevitability of inpatient care, a desire to save relatives and close friends (as part of the more resource-poor, informal health care structure) from the physical and financial burden of domiciliary care, a belief in better care being provided in acute care settings, or a refusal to admit that a cure is not possible, among other possible interpretations.[36] Additionally, this might arise from confusion between preferred location of care rather than death.

Over the last decade, the rate of urbanization has increased from 33% to 42% of the total population.[37] Although nearly 95% of this study population reported living in an urban area, we cannot assume that this location is always the capital, Windhoek. However, the city remains the predominant economic, service, manufacturing, and political center of the country, with better access to health services, as well as education, water, electricity, and employment opportunities.[38] The extent to which a return to familial rural areas for such internal migrants at the end of their lives is prohibited by dissolution of kinship ties—resulting in being labeled "Ombwiti" (one who has lost roots)—cannot be answered by this study.

Additionally, a specific potential impediment to home deaths in Namibia, and a potential explanatory factor underpinning hospital-based deaths, is the law that demands that death certificates have to be obtained within seven days of death.[39] This requirement can be problematic for those people living in more remote areas of the country, where death can occur in geographic isolation from the police officers or doctors required to obtain a death certificate within the stipulated time period, deterring people from dying at home.

Regardless, individuals who prefer to die in hospitals should be supported in having their wishes fulfilled (possibly around the model of hospital teams); the same holds for those who prefer to die at home, and obstacles to both should be addressed. This suggests a need to strengthen and integrate palliative care teams into the wider health care system so that end-of-life and other needs across the trajectory of life-limiting illnesses can be addressed.

Lastly, our findings show that men had a higher preference for a hospital death compared with women. The scarce evidence from studies that have examined the actual place of death in Europe shows that men are more likely to die at home than women.[40,41] As such, further research is needed in Africa to establish the common place of death and whether it is against patients' wishes.

Future Research

Raising public awareness of end-of-life care issues is just as vital as the policy and practice developments needed to address seemingly intractable problems in the care of the dying.[29] Indeed, this study's findings highlight six areas on which to focus future clinical studies: 1) pain control; 2) treatment of breathlessness; 3) interventions related to improving self-image; 4) interventions to promote function and patient independence; 5) interventions to support families; and 6) interventions to promote well-being (of patients and families at the end of life). These areas address issues that most concern the public in Namibia and suggest possible enhanced clinician training in areas such as symptom management and breaking poor prognostic news to patients and their families.

Additional nonclinical research is needed to investigate the *actual* (rather than hypothetical) views of the terminally ill and the extent to which they are met. Inclusion of rural areas outside the country's capital would allow an examination of the geographic and sociocultural variations in end-of-life preferences and priorities. Also, given the epidemiological transition from communicable to noncommunicable mortality causes and an increasing elderly population, future studies should investigate the views of the older generation. These studies should explore these issues in depth, investigating those factors (such as normative, attitudinal and cultural milieu) that can shape these expressed choices (be that for a home-, hospital- or hospice-based death); the importance of death location to patients; if and why patients may change their preferences according to the nature of their illness, disease progression, or the imminence of death; and how such decisions are made.[42]

Conclusion

This study, which confirmed the acceptability and feasibility of the street survey method as a means of investigating potentially sensitive end-of-life issues, contributes to the embryonic evidence base on public preferences and priorities for end-of-life care in Africa. The study also 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. Moreover, it prioritizes items for inclusion in clinical and research tools to measure end-of-life care outcomes to ensure both are responsive to the concerns, preferences, and priorities of the potential and actual users of care in the country.

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