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THE EMOTIONAL AND SPIRITUAL
WELLBEING OF HOSPICE PATIENTS IN BOTSWANA
AND SOURCES OF DISTRESS FOR THEIR CAREGIVERS

Master's Thesis
Submitted to the Faculty
Yale University School of Nursing

In Partial Fulfillment
of the Requirements for the Degree
Master of Science in Nursing

Psyche Linnea Philips

May 15, 2013

This thesis is accepted in partial fulfillment of the requirements for the degree Master of Science
in Nursing.

J. Mark Lazenby, PhD, MSN

Date _____

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ABSTRACT

THE EMOTIONAL AND SPIRITUAL WELLBEING OF HOSPICE PATIENTS IN BOTSWANA AND SOURCES OF DISTRESS FOR THEIR CAREGIVERS

Background: Little regional data exists on the distress of people nearing the end of their lives and their caregivers. **Objective:** The purpose of this study was to describe the quality of life and the emotional and spiritual wellbeing of people at the end of life and the sources of distress for their primary caregivers in Gaborone, Botswana, in order to inform current and limited hospice resources and services. **Design:** This study employed a qualitative design. **Setting/Subjects:** Twenty-eight primary caregivers who cared for an adult who passed away fewer than 14 months prior to the interview date and were in the care of a non-governmental hospice (NGH) in Botswana were interviewed between June and August 2012. **Measurements:** Semi-structured interviews and the Quality of Death and Dying (QODD) questionnaire were used. **Descriptive analysis and qualitative content analysis** was performed. **Results:** Quality of life of decedents was poor. Emotional and spiritual distress persists at high rates even for those receiving support from an NGH. Caregiver distress arises from practical concerns, including lack of food, clothing, and shelter, and from emotional and spiritual concerns. **Conclusions:** The practical, emotional, and spiritual needs of people at the end of life in Botswana and their caregivers are not being fully met, with poor overall quality of life among the dying. More research is needed to explore how hospice and home health services and the services of spiritual leaders can be expanded to meet their needs.

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CHAPTER I: BACKGROUND

Botswana is a land-locked, southern African country just shy of two million inhabitants (Botswana Central Statistics Office, 2012). Similar to its neighbors in sub-Saharan Africa, Botswana has a high mortality rate and limited provision of hospice and palliative care (Grant, Downing, Namukwaya, Leng, & Murray, 2011; Gysels, Pell, Straus, & Pool, 2011; World Health Organization, 2008). Botswana has one of the highest levels of HIV prevalence in the world (World Health Organization, 2011a), and noncommunicable diseases continue to impact Botswana's mortality rate. It was estimated that 31% of all deaths in Botswana in 2008 were from noncommunicable diseases (World Health Organization, 2011b). The World Health Organization conservatively estimated that 1 in 56 Botswana (the people of Botswana) need end-of-life care associated with a death from HIV/AIDS or cancer each year (World Health Organization, 2004).

With a health infrastructure unable to match the demand for end-of-life care, the responsibility of caring for the sick and dying often falls on family members, friends, and neighbors (Ama & Seloilwe, 2011; Harding & Higginson, 2005; Kang'ethe, 2010; Shaibu, 2006). The overwhelming need for palliative care in Botswana has prompted the formation of non-governmental hospice (NGH) programs. A recent review of global palliative care development found that there are just four palliative care services in Botswana that attempt to provide care for the country's population of nearly two million (Lynch, 2012). This shortage of end-of-life care may contribute to the distress experienced by people with life-limiting illnesses and those who care for them.

To date, little regional data exists on the distress of people nearing the end of their lives and their caregivers (Gysels et al., 2011; Harding et al., 2008). The overall purpose of this study

was to describe the quality of life near the time of death among hospice patients and sources of distress among their caregivers in Gaborone, Botswana. The specific questions addressed in this study were: What was the overall quality of life of decedents? What was the emotional and spiritual wellbeing of decedents? What were the sources of distress experienced by caregivers and their dying loved ones?

The findings in this thesis represent a subset of results from a larger study which investigated topics including caregivers' understanding of hospice care, perceived barriers to hospice and palliative care, the reasons for choosing home death over hospital death, and the benefits of and need for end-of-life care in Gaborone. Those findings are beyond the scope of this paper and will be submitted for publication at a later date.

Operational Definitions

An adult in this study is considered to be a person 18 years of age or older. Batswana is the local term for the people of Botswana. For the purposes of this research, the terms "hospice care" and "palliative care" will be used interchangeably. Palliative care is defined by the World Health Organization as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual, (World Health Organization, 2012).

CHAPTER II: RESEARCH METHODS

Design

This cross-sectional study employed a qualitative design. The data analyzed in this paper represent a subset of responses from a larger study exploring caregiver and decedent needs.

Participants

Respondents were primary caregivers 18 years of age and older who cared for a dying family member or loved one who passed away within the 14 months prior to the interview. Subjects interviewed were recruited on a voluntary basis through key informants within two NGH organizations in Botswana: Holy Cross Hospice in the capital city of Gaborone and Pabalelong Hospice in the nearby village of Metsimotlhabe.

Setting

Holy Cross Hospice was founded in 1994 and provides home-based care, adult day care, and a variety of other support services such as food assistance and transportation to clients and their families in urban Gaborone. Pabalelong Hospice is a 12-bed inpatient hospice opened in 2010 that provides both inpatient and home-based care from their facility in the town of Metsimotlhabe, eighteen kilometers northwest of Gaborone. Both hospice organizations are funded largely through donations and their respective sponsoring religious communities, and focus on providing services to those who cannot afford to pay for private care.

Procedures

Interviews were conducted using open-ended questioning and the quantitative Quality of Death and Dying Questionnaire (hereafter, QODD; University of Washington). Thirty interviews were conducted by the primary author (PP) from June through August 2012, with two interviews excluded from analysis. One interview was excluded because the respondent chose to

end the interview before completion; another respondent had a family member who took his own life, thus it was deemed inappropriate to investigate hospice and palliative care needs during the period preceding death. In total, 28 interviews were included in analysis.

Human subjects committee approval was obtained from Yale University and the Botswana Ministry of Health, and verbal and written informed consent was obtained from all participants.

All interviews were audio recorded. Interviews took place in the respondent's home and lasted between 30 and 90 minutes. An employee of Holy Cross Hospice was present at all interviews. The semi-structured qualitative interview began with basic demographic data about the respondent and decedent. Once basic data was obtained, open-ended questions explored the caregiver's experience, patient and caregiver needs, and types of hospice and medical care received during the period leading up to the death of their loved one.

Measures

The 33-item QODD questionnaire is a validated instrument that assesses the death and dying experience of a person who has passed away through directed questions answered by a primary caregiver (Hales, Zimmermann, & Rodin, 2010; Patrick, Engelberg, & Curtis, 2001). If the decedent was able to speak to the caregiver in an understandable way in the last seven days of their life, questions were asked about those seven final days. If the decedent was not able to speak to the caregiver during their last seven days, questions were asked about the last thirty days of the decedent's life.

Qualitative interview questions were generated based on common caregiver experiences that were not addressed in the QODD. The semi-structured, open-ended questionnaire was reviewed and modified based on feedback from faculty members from the Yale School of

Nursing, Yale School of Medicine, and Yale School of Public Health. Questions in the qualitative interviews focused primarily on the caregiver experience and met vs. unmet needs.

Analysis

For the purposes of this study, a subset of questions specifically related to emotional and spiritual wellbeing, caregiver and decedent needs, and quality of death were extracted from both the open-ended interview and the QODD for analysis.

Quantitative QODD responses and demographic data were organized using Microsoft Excel 2010. Analysis was completed using Microsoft Excel 2010 and SOFA Statistics version 1.3.2 (Paton-Simpson & Associates Ltd, Auckland, New Zealand). Qualitative interview transcripts were systematically reviewed for content pertaining to sources of caregiver distress of an emotional and spiritual nature. These transcript excerpts were then labeled and grouped according to theme. Line-by-line coding and determination of categories were completed by Psyche Philips and Mark Lazenby, with 100% agreement reached.

CHAPTER III: RESULTS

Sample Characteristics

Of 28 total respondents included in the analysis, 16 (57.1%) completed the seven day version of the QODD and 12 (42.9%) completed the thirty day version. Eight (28.6%) of the caregivers interviewed were male, none of whom cared for someone who died at home. The average age of caregivers was 35.8 (SD = 14.7) years (Table 1).

The average age of decedents was 50.1 (SD = 16.2) years. Sixteen (57.1%) of the decedents passed away in an acute inpatient hospital setting; four (14.3%) died in inpatient care in an NGH; and eight (28.6%) died at home (Table 2).

Table 1
Caregivers' Demographic Characteristics

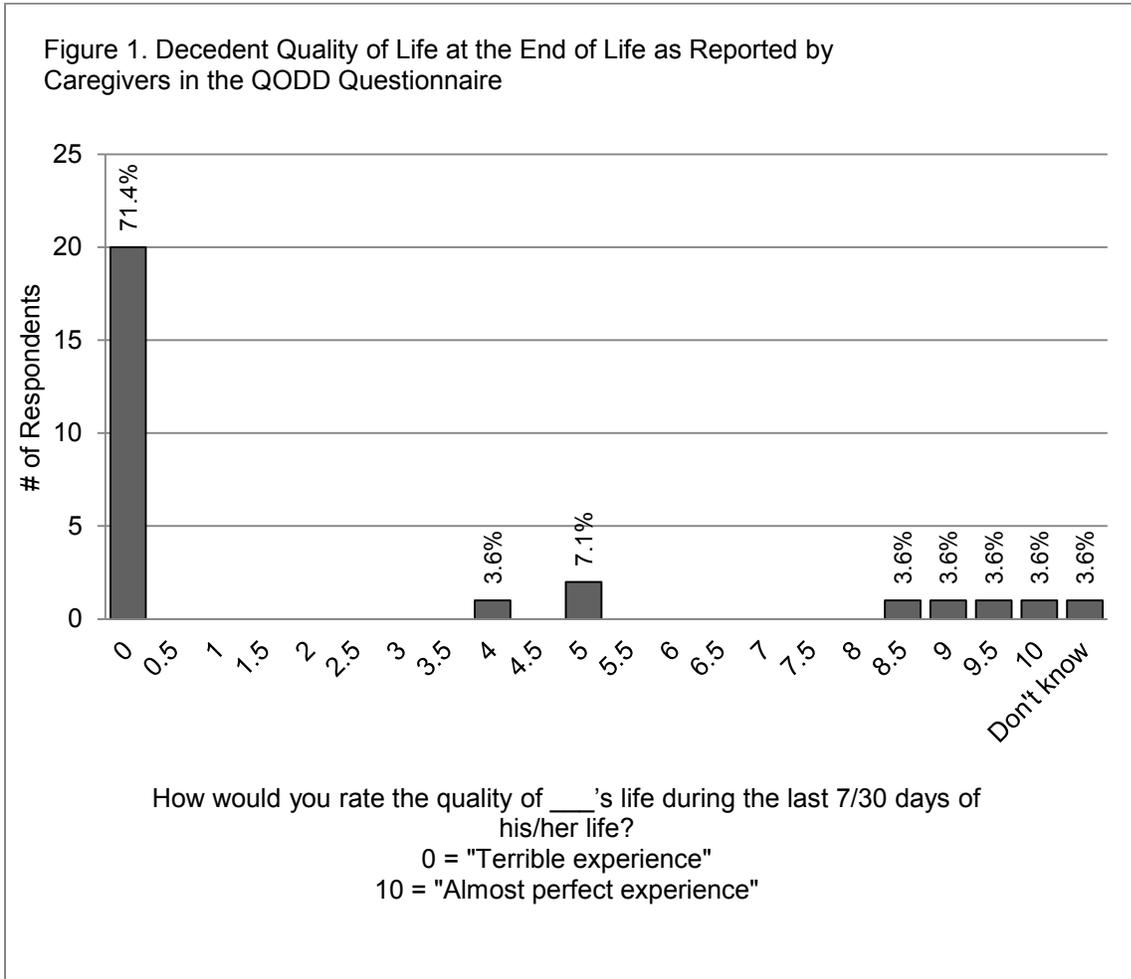
Characteristic		n (%)
Sex	Male	8 (28.6)
	Female	20 (71.4)
Marital Status	Single	24 (85.7)
	Widowed	2 (7.1)
	Married	1 (3.6)
	Engaged	1 (3.6)
Age (Years)	Range	18-82
	Median	32
	18-25	6 (21.4)
	26-35	13 (46.4)
	36-45	4 (14.3)
	46-55	2 (7.1)
	56-65	1 (3.6)
	66+	2 (7.1)
Job Status	Not Working/Unemployed	15 (53.6)
	Privately Employed	6 (21.4)
	Government Employed	3 (10.7)
	Self-Employed	2 (7.1)
	Student	2 (7.1)
Education Level (Highest)	No Formal Education	3 (10.7)
	5 Years or Less	10 (35.7)
	Some High School	2 (7.1)
	Completed High School	6 (21.4)
	Some College	6 (21.4)
English Fluency	Fluent	11 (39.3)
	Some English	11 (39.3)
	None	6 (21.4)
Religion	Christian	13 (46.4)
	None	9 (32.1)
	Apostolic	3 (10.7)
	Other	3 (10.7)
Relationship to Decedent	Child	11 (39.3)
	Sibling	8 (28.6)
	Parent	3 (10.7)
	Spouse	2 (7.1)
	Other	4 (14.3)
Source	Holy Cross Hospice	19 (67.9)
	Pabalelong Hospice	9 (32.1)
		N = 28

Table 2
Decedents' Demographic Characteristics

Characteristic		n (%)
Sex	Male	13 (46.4)
	Female	15 (53.6)
Age (Years)	Range	23-82
	Median	48
	18-25	1 (3.6)
	26-35	5 (17.9)
	36-45	6 (21.4)
	46-55	6 (21.4)
	56-65	5 (17.9)
	66+	5 (17.9)
Residence	Urban Gaborone	19 (67.9)
	Town or Rural Area	9 (32.1)
Occupation	None	11 (39.3)
	Construction/Manufacturing/Mining	6 (21.4)
	Agriculture	5 (17.9)
	Other	6 (21.4)
Place of Death	Hospital	16 (57.1)
	Home	8 (28.6)
	Inpatient Hospice	4 (14.3)
Living Children at Time of Death	Yes	25 (89.3)
	No	3 (10.7)
Living Spouse/Partner at Death	Yes	14 (50.0)
	No	14 (50.0)
		N = 28

Quality of Life at the Time of Death

Nearly three-quarters (71.4%) of respondents ranked their loved one's overall quality of life in the last days or weeks of life as zero on a scale of zero to ten, with zero being "terrible experience" and ten being "almost perfect experience." One question of the QODD addressed the decedent's overall quality of life (Figure 1).



Decedent Emotional and Spiritual Wellbeing

Decedents' emotional and spiritual wellbeing was identified through seven questions on the QODD (Table 3, Table 4).

Table 3
Frequency of Emotional/Spiritual Concerns of Decedents at the End of Life as Reported by Caregivers in QODD Questionnaire

In the last 7/30 days of ____'s life, how often did he/she ...	None of the time	A little bit of the time	Some of the time	A good bit of the time	Most of the time	All of the time	Don't know
	n (%)						
... appear to have control over what was going on around her/him?	14 (50.0)	3 (10.7)	4 (14.3)	3 (10.7)	2 (7.1)	1 (3.6)	1 (3.6)
... appear to feel at peace with dying?	5 (17.9)	1 (3.6)	1 (3.6)	0 (0)	3 (10.7)	16 (57.1)	2 (7.1)
... laugh and smile?	7 (25.0)	1 (3.6)	5 (17.9)	2 (7.1)	2 (7.1)	11 (39.3)	0 (0)
... appear to be worried about strain on his/her loved ones?	7 (25.0)	1 (3.6)	1 (3.6)	1 (3.6)	2 (7.1)	14 (50.0)	2 (7.1)
... appear to keep her/his dignity and self-respect?	12 (42.9)	0 (0)	3 (10.7)	1 (3.6)	5 (17.9)	6 (21.4)	1 (3.6)

Table 4
Emotional/Spiritual Concerns of Decedents at the End of Life as Reported by Caregivers in QODD Questionnaire

In the last 7/30 days of ____'s life, did he/she . . .	Yes	No	Don't know
	n (%)		
. . . appear to find meaning and purpose in her/his life?	14 (50.0)	11 (39.3)	3 (10.7)
. . . clear up any bad feelings with others?	11 (39.3)	15 (53.6)	2 (7.1)

Emotional wellbeing. Fourteen respondents (50%) indicated that their loved ones did not appear to have control over what was going on around them in the last days/weeks of life (Table 3). The majority (16 respondents, or 57.1%) responded that their loved ones appeared to feel at peace with dying all of the time. Of the eight decedents who passed away at home, six of their caregivers (75%) indicated that they were at peace with dying all of the time, while half of the 16 decedents who passed away in the hospital were at peace with dying all of the time. Half of respondents indicated that the decedent appeared to be worried about strain on her/his loved ones all of the time. In terms of keeping their dignity and self-respect, responses were split; 12 (42.9%) indicated their loved one kept their dignity and self-respect none of the time, while 11 (39.3%) thought their loved one maintained their dignity and self-respect most of the time or all of the time. Fifteen decedents (53.6%) did not clear up bad feelings with others, according to caregivers (Table 4). Half of respondents indicated that their loved ones appeared to find meaning and purpose in their lives at the end of life.

Spiritual wellbeing. Thirteen respondents (46.4%) indicated that their loved one had one or more visits from a religious or spiritual advisor in the last days or weeks of their life (Table 5). Half (n=4) of those who died in the hospital and one third of those who died at home

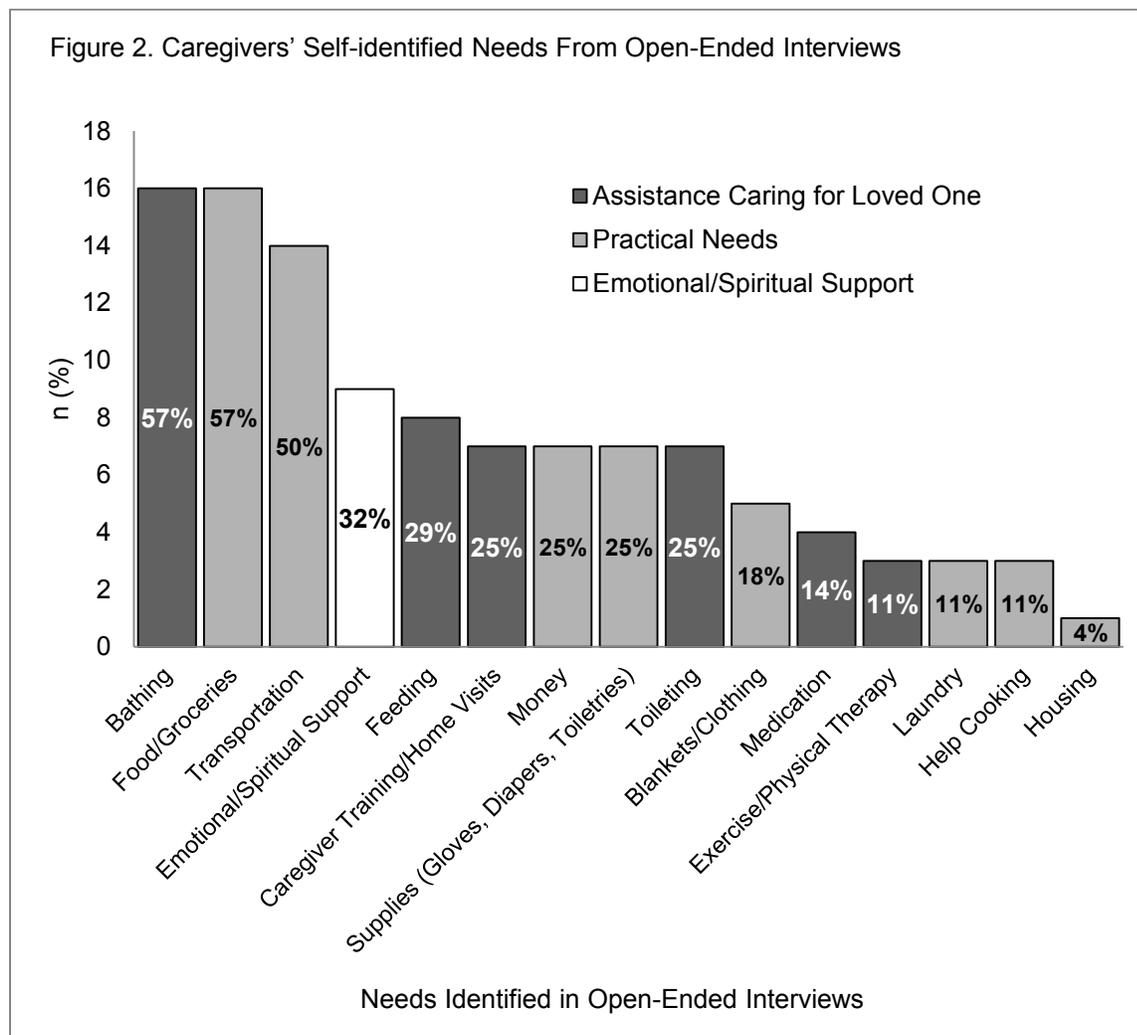
(n=5, or 31.3%) had a visit from a spiritual advisor, while all four decedents who died at the inpatient hospice reported having a religious visit. The majority (12 out of 13) respondents who said the decedent had a visit from a religious advisor in the time preceding death ranked the experience as either a nine or ten on a scale of zero to ten, with ten being “an almost perfect experience” (Table 5). All 15 respondents who replied that the decedent did not have a visit from a spiritual advisor ranked the experience as two or lower, with zero being “a terrible experience.”

Table 5
Caregiver Perceptions of Religious/Spiritual Advisor Visits Preceding Death

		“Did ___ have one or more visits from a religious or spiritual advisor in the last 7/30 days of their life?”		
		Yes	No	TOTAL
	0	1	12	13
	1	0	1	1
	2	0	2	2
Rank this experience from 0 (terrible experience) to 10 (almost perfect experience)	3	0	0	0
	4	0	0	0
	5	0	0	0
	6	0	0	0
	7	0	0	0
	8	0	0	0
	9	1	0	1
	10	11	0	11
	TOTAL	13	15	28

Caregiver Distress

Sources of caregiver distress were assessed through open-ended interviews. Two main areas of distress were identified: practical concerns and emotional/spiritual concerns. Many caregivers also did not receive as much assistance physically caring for their loved one as they needed (Figure 2).



Practical Concerns

Sixteen caregivers (57%) identified the need for food and groceries as a source of distress. Half of all caregivers needed support with transportation. Eight of the 15 needs identified by caregivers fall into non-nursing, non-medical practical concerns (Figure 2): food, transportation, supplies, money, blankets/clothing, help with cooking, help with laundry, and housing.

Physical Caregiving Concerns

Sixteen caregivers (57%) needed help bathing their loved one. Eight (29%) needed help

feeding their loved one, while seven (25%) identified a need for home visits and caregiver training; the same number needed help toileting their loved one.

Emotional/Spiritual Concerns

Respondents commented on the emotional pain caused by the loss of their loved one and the suffering related to illness. The following comment by a caregiver is an example:

How can I say . . . losing a loved one . . . who went through many hard times, like this one this sickness the HIV one, is very painful. Very, very painful. ‘Cause sometimes you won’t know how he got it. You won’t know, ‘cause it, you just . . . you can just stay healthy not knowing that you have the virus. But it’s very painful losing a loved one who just got HIV and it’s very painful. That’s all.

Another caregiver remarked on the feeling she was left with after the loss of her family member: “My life, it is changed. I live by suffering.”

Some caregivers reported receiving emotional support during home visits from a hospice organization, although not with every home visit. When asked what was most helpful about home visits from the hospice organization, one caregiver said,

Sometimes I’ll be here with him [decedent], just the two of us, and then when they [hospice] come, that’s when we talk . . . I had that . . . how can I say it? How can I call it? They just come and, you know, give me some support. Like you know you are doing a great thing, and sometimes they help me with the cleaning of the house. But some of them just . . . come and check him and go, but some gave the love, gave that support . . .

Many of the caregivers who received home visits from a hospice organization had positive experiences with receiving emotional support while also receiving assistance with bathing, feeding, or toileting their loved one. “Okay, those people they are caring and loving people.

They can support you in each and every situation that you are in,” said one caregiver about the hospice staff.

One respondent remarked that her father received spiritual support in addition to the physical and nutritional support provided by adult day care services he received:

I see there are so many people whom I always see taken by this car, the hospice car, and after some months they are better. I’ve seen so many people . . . even my dad, he was one of them. When he was home, when they checked him home, he wasn’t getting fine, but when he was there, all day there, ah he was getting fine ‘cause he was getting all the support, the food, the support like spiritual support, and that love. He was getting that.

Others reported that family and friends provided some support, and a few mentioned visits from religious leaders as being helpful.

Overall, caregivers were appreciative of the emotional/spiritual support they received but felt that they needed more than what was available to them. Nine of the 28 caregivers interviewed (32.1%) said they needed emotional/spiritual support when caring for their loved one. The following exchange between the interviewer (PP) and an interviewed caregiver is an example of the need for emotional/spiritual support:

Interviewer (I): What things did you need the most while you were helping to take care of her?

Respondent (R): I needed support.

I: Like emotional support, financial support . . .?

R: Emotional support, and spiritual.

I: And did you get that support?

R: No.

I: Where do you think it would have been helpful to get that support?

R: From family, from the community, from the hospice . . . from wherever.

CHAPTER IV: DISCUSSION

In this qualitative study we sought to describe the overall quality of life and the emotional and spiritual wellbeing of people dying in the care of a hospice in Gaborone, Botswana, and the sources of distress among their family caregivers. We interviewed 28 caregivers of loved ones who had died within 14 months of the interview. Overall, the quality of life of the decedent was ranked by decedents' caregivers as the lowest possible. About half of decedents experienced poor emotional and spiritual wellbeing at the time of death, according to caregivers, as witnessed by loss of control, concern about the effect of caregiving upon their family caregiver, loss of dignity and respect, an inability to find meaning and purpose, and the lack of a chance to clear up bad feelings. The importance of positive emotional and spiritual experiences has long been witnessed in other parts of the world. In the United States (U.S.), for example, a 1997 Gallup survey about dying revealed that Americans wanted to have the opportunity to say goodbye to loved ones and to make peace with their maker (George H. Gallup Institute, 1997). Numerous other U.S.-based studies about dying patients' perception of religion and spirituality suggest that up to 40% of patients report spiritual concerns (Otis-Green et al., 2012; Puchalski, 2004).

The caregivers of dying loved ones who received a visit from a religious or spiritual advisor in the final days of life reported the experience of the death as almost a perfect experience. This is consistent with findings elsewhere in Africa. Selman and colleagues (Selman et al., 2011) report that among 285 patients receiving palliative care in South Africa and Uganda, 21 to 58% reported poor spiritual wellbeing. However, the same patients judged feeling at peace and having a sense of meaning in life to be more important to them than physical comfort (Selman et al., 2012), indicating that in the sub-Saharan context spiritual distress is likely to have a particularly detrimental effect on quality of life. In studies from the USA and

Canada, neglect of patients' spiritual needs has been associated with reduced quality of life and satisfaction with care (Astrow, Wexler, Texeira, He, & Sulmasy, 2007; Clark, Drain, & Malone, 2003; Heyland et al., 2010) and increased healthcare costs at the end of life (Balboni et al., 2011). Based on caregiver responses, spiritual and emotional support can be effectively incorporated into home visits, and even a small amount of support is considered helpful for those who are at the end of life and also for caregivers.

Previous studies of needs among patients in hospice care in an African setting have identified practical needs, such as financial assistance and need for food, as a source of distress among 30% (Kikule, 2003) to 64% (Amery, Rose, Holmes, Nguyen, & Byarugaba, 2009) among adult and pediatric patients, respectively, and among 67% of caregivers. In our study, practical concerns weighed on upwards of 57% of caregivers and decedents.

The NGH organizations from which the participants of this study were drawn are largely dependent on private donations and volunteer labor. There are services being offered by the NGHs that help to meet the needs of patients and caregivers; however, these needs exceed the resources available at these NGHs. Non-governmental and governmental funding is needed to shore up the services offered by these NGHs and other home health care services.

Limitations

A focus group following the qualitative interviews was not used to validate findings due to the limited nature of time and resources available. Coding was performed by a single investigator, and therefore, was subject to the biases and interpretations of one individual. However, these limitations were mediated by confirmation by second author and expert review and advice from Yale School of Nursing and Holy Cross Hospice.

Conclusions

This study's results provide an in-depth description of the quality of life and emotional and spiritual wellbeing among hospice patients and the sources of distress among their caregivers in Botswana. The hospice patients at the end of life in our study in Botswana experience a poor quality of life. They and their caregivers experience unmet practical and emotional/spiritual needs. In order to provide focused, effective care, it is essential to examine the individual components that cause distress and address those issues from a holistic perspective. Hospice care initiatives that relieve the unmet practical, emotional, and spiritual needs of patients and families may reduce patient and caregiver distress and improve the quality of life of the dying. The success of hospice programs in Botswana hinges on the ability of the government and NGHs to provide support for those at the end of life and those who care for them. Future study is needed to explore how hospice and home health services can be expanded to meet their needs.

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