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Family Caregivers' Perspectives on Establishing Hospice Care in Belize

Rachael Florita Battle
Walden University

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Walden University

College of Health Sciences

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Rachael F. Battle

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Review Committee

Dr. Raymond Thron, Committee Chairperson, Health Services Faculty

Dr. Jeanne Connors, Committee Member, Health Services Faculty

Dr. Frazier Beatty, University Reviewer, Health Services Faculty

Chief Academic Officer

Eric Riedel, Ph.D.

Walden University

2019

Abstract

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by

Rachael F. Battle

MAT, School of Education, North Carolina Central University, 2003

BS, Sewanee, The University of the South, 1999

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Health Services

Walden University

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Abstract

End-of-life (EOL) care decisions present a challenge for family caregivers. Despite the increasing number of terminally ill patients in need of pain management and comfort care, there is limited qualitative data about how populations in the developing world can access culturally appropriate resources and EOL support. In this phenomenological study, 17 Garifuna family caregivers in southern Belize were interviewed about their experience caring for terminally family members. The conceptual frameworks were Kübler-Ross's hospice approach and Watson's theory of human caring. The two theories were selected based on their significance to this process: Kübler Ross's hospice approach and its impact on the family system during the end stage of life and Watson's theory of human caring for its emphasis on the impact of the importance of meeting the basic needs of individuals. NVivo 12 was used to code and generate themes for further analysis.

Caregivers who said they would not utilize support outside of the home were those who were committed not do so at the request of the patient. Caregivers who cared for their family member and those who could financially afford to hire caregivers in their home to assist with their relative said they would not utilize nonfamily support. All others, regardless of relationship to the patient, indicated they would have accepted care if the environment were safe, caring, and culturally sensitive. Additionally, the caregivers saw their needs as secondary and insignificant compared to the comfort and care of the patient. This study may contribute to positive social change by revealing strategies and services that could be included in the design of a health services delivery system to meet the needs of individuals facing EOL decisions.

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Dedication

This dissertation is dedicated to three people:

My late father Mr. Edlin Leslie Sr., a Belizean fisherman who lost his battle with prostate cancer in 2007. His foresight, vision, and final wish to establish hospice services in Belize and my promise to fulfill his wish have sustained me throughout my dissertation journey.

My husband, The Very Rev. Michael Battle PhD., whose unwavering support has propelled me to my program's completion.

My three beautiful children, my pride and joy, Sage Battle, Bliss Battle, and Zion Battle, whose love and understanding throughout my dissertation journey have been a blessing.

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Chapter 1: Introduction to the Study

Hospice organizations throughout the world provide palliative care for the physical pain of dying patients and emotional support for their families. (Dy et al., 2015). Despite the value of those services to hospitals and nursing homes, as well as to the patients and families, many developing countries lack end-of-life (EOL) medical support for the terminally ill. The purpose of this study was to identify and understand the needs of family caregivers when caring for a terminally ill family member in Belize, a developing country with a limited health care system.

Palliative care has been largely overlooked by government health departments, particularly in developing countries lacking necessary medicine for palliative care and large populations in need of those services (Bazargani, Ewen, de Boer, Leufkens, Mantel-Teeuwisse, 2014). Belize, as one such country, has a poorly organized health care system and attracts few medical practitioners. The foundation of the country's health system was accidental and arose from the need to provide medical care not for the inhabitants itself but for transient seamen from Great Britain, of which Belize (then called British Honduras) was a colony (Herrmann, 1985).

Although a history of hospice use and philosophy of care is well established in the United Kingdom and the United States, previous research has suggested there are significant gaps in how to assess the needs and evaluate programs for hospices in multicultural societies in developing countries such as Belize (Washington, Bickel-Swenson, & Stephens, 2008). In light of the problems of health disparities in underdeveloped countries, the World Health Organization (WHO; as cited in Bruera, De

Lima, Wenk, & Farr, 2004) advocated for a call to action for government and health care systems to establish a continuum of care for dying patients. The need for an established continuum of care is critical and will require committed medical practitioners to develop and maintain. Belize could lead Central America by providing patients with quality, dignified, and compassionate care and support for both patients and their families.

Belize has seen significant demographic shifts since its independence in 1981 (Woods, Perry, & Steagall, 2001). In light of demographic changes and mass immigration in Central America, it is important to understand how knowledge of best practices and meaningful training and support systems that are available in Belize could provide a model to support both patients and family caregivers (Vroman & Morency, 2011). According to the WHO, 50% of new cancer cases around the world occur in developing nations (Webster P.C., 2011). and at the time of diagnosis, more than 80% of those new cases are late-stage and incurable. This condition alone indicates a need for EOL care and access to palliative services. The WHO has sought to form policies to enforce national health care regulations in regions impacted by the rapid increase in noncommunicable diseases (Malloy et al., 2014).

A global analysis supported the need for hospices in 234 countries (Lynch, Connor, & Clark, 2013). Although there is a growing awareness of the need for hospice care in Belize, the capability and commitment of the nation's leaders to develop sound policy and intergenerational health care remain a problem. Belize is one of 23 countries in the capacity-building phase, and one of 74 countries whose service provisions of hospice care are disconnected from established systems (Lynch et al., 2013). The

Ministry of Health (MOH; 2014) in Belize lacks established policies on advanced directives and surrogate decision making, but there are policies in place governing patient rights and responsibilities related to health care decisions (MOH, 2014).

Understanding the evolution of hospice care is important, and drawing from lessons learned from a global perspective might help stakeholders identify key elements in models that can be applied to diverse cultural and socioeconomic contexts (Higginson et al., 2013). The importance of alleviating pain and suffering for the dying is central to the philosophy of hospice or EOL care (Ferrell & Coyle, 2008). The time necessary to build trust is critical to understanding a patient's needs. This trust gives the patient peace of mind and reduces or eliminates uncertainty, which is critical to the patient's comfort (Ferrell & Coyle, 2008).

Practices in five Latin American countries—Argentina, Brazil, Cuba, Mexico, and Peru—support the belief that standards of care vary widely, even in countries classified as developing by the United Nations. Vigil, Aday, De Lima, and Cleeland (2007) examined the inability to both access and afford care were critical predictors of conditions of advanced cancer in Latin America. The differences in attention and expectations of care for terminally ill patients are important because knowing what is missing and what patients need or expect does not necessarily mean that a caregiver must be physically present with the patient (Vigil et al., 2007). The complexity in identifying or formulating a model for hospice in Belize stems from the absence of policies and procedures governing EOL care within the country. The lack of infrastructure creates a complex problem with multiple gaps in ways to provide services (MOH, 2014).

Family Caregivers

According to Stroebe, M. & Boerner, K. (2015), in too many cases caregivers face challenging issues of depression without support for bereaved family members. Nurses who have had personal experiences with death can better guide the family through the dying process (Seno, 2010). Although they may be better prepared to support families, following the intensely emotional settings they are part of, caregivers also need ongoing support that reminds them of their value and shows them that the care they provide is meaningful (Adelman, Tmanova, Delgado, Dion, Lachs, 2014). Information gleaned by family caregivers may provide insight into the socioeconomic challenges, spiritual needs, and family structure necessary to provide care for terminally ill family members.

Professional Caregivers

Critical to the establishment of hospice is the need to establish strategic partnerships and maintain effective lobbying at nearly every level of the health care spectrum, but there is also the critical need for capacity building (Moran et al., 2014). If a local population becomes dependent on outside sources for leadership and does not play a central, sustained role in creating policy and legislation, the local stakeholders will lack the capacity for self-determination (Maiese, 2005). Thus, a goal must be community-based self-determination for creating and maintaining hospice services. Widespread participation in efforts can lead to a stronger civil society and a more responsible government and engender pride in the population and more trusting relationships (Maiese, 2005).

Professionals and paraprofessionals alike can benefit from instruction in providing EOL care. Moran et al. (2014), found in their literature review a strong emphasis on education and training in rural communities. Most of those receiving EOL training shared their skills and knowledge with other caregivers. This sharing of competencies is essential in the quest for capacity building and empowering those who do not have finances to seek the education and training necessary to provide quality EOL care. Unlike the unexpected way the first hospitals in Belize came about—to treat British seamen—hospice care must be deliberate and strategically planned, created, structured, and established (Herrmann, 1985).

Patient Care and Needs

Terminally ill patients have specific, personal needs when faced with EOL decisions. Doctors must provide honest communication with the patients regarding their condition. (Cook & Rocker, 2014). To this end, uniformity is needed in determining that all involved—patient, family, and medical staff—understand the concept of EOL so that policies and systems of care can be implemented globally. Having a common language and approach to EOL care also supports worldwide hospice care (Shipman et al., 2008). With diverse attitudes toward and beliefs about death and dying, understanding the context in which a hospice is established is critical to work efficiently with that population (Fraser et al., 2017). Some of the greatest challenges of creating hospice care in developing countries include the availability of opioid medication, capacity building, and human resources reflecting a critical mass medical professionals (Fraser et al., 2017).

Problem Statement

Myriad circumstances have caused Belize to experience significant emigration and immigration patterns after its independence from Great Britain in 1981. These settlement patterns have had a profound impact on the ethnic diversity in the country (Woods et al., 2001). As a result of these settlement patterns, EOL care in Belize is a complex issue both medically and culturally, involving sensitive matters of death and dying (Valentine, 2002). Ranging from the sociopolitical, sociocultural, and socioeconomic factors, religious beliefs, and geographic location, the complexities of hospice establishment remain a problem in Belize in particular and Central America in general (Valentine, 2002). Identifying community needs as well as establishing protocol on compassionate, dignified approaches to addressing those facing EOL decisions is important for each person facing such challenges.

Although the United States and Great Britain have well-established hospice health care services, little is known about sustainable hospice models in developing countries. Emerging research suggests that there are significant gaps in assessing the needs of establishing hospices in multicultural societies and developing countries (Washington et al., 2008). Without the reference point of successful sustainable hospices in developing countries, knowledge of best practices and recommendations is limited. Information on culturally sensitive models from hospice experts' professional experiences can provide valuable information to help to fill the gap in the establishment of hospices in multicultural societies. Therefore, identifying best practices and models used globally

may eliminate some barriers and encourage the creation of more hospices in developing countries tailored to the needs of families who provide direct care to the dying.

Hospice models are constructed to meet the physical, social, psychological, cultural, and spiritual needs of populations facing EOL. (Fraser et al., 2017). Such models are designed to identify the knowledge and expertise of hospice experts to determine what is needed and models for successful sustainable palliative programs in Kenya and Uganda (Fraser et al., 2017). This knowledge may be used to inform health care professionals and strategic partners of ways to eliminate barriers and establish the means to achieve sustainability of hospice and palliative care services in developing countries. According to sources at the MOH (2014) in Belize, the only available document related to patient care and EOL care is the Bill of Rights and Responsibilities. Given the complexity of this problem, I used a phenomenological approach to investigate the problem and seek knowledge of family caregivers who can provide information that would enable the design of models of hospice care in Belize.

Purpose of the Study

The goal of this qualitative, descriptive phenomenological study was to determine how to meet the needs of family caregivers in Belize. Family caregivers, for the purpose of this research, referred to individuals who had provided their terminally ill family members with at least 2 weeks of direct care in Belize. During the analysis phase, I used the caregivers' responses as the foundation for my study. I analyzed the responses and sought to identify emerging themes and concepts. Based on the information revealed, I wrote a narrative based on the findings. I intended to learn from family caregivers their

primary needs, resources, and insights on overcoming barriers to establishing hospice care in Belize. The results were expected to provide a compelling argument for countries with limited resources to consider supportive care in the form of hospice care for the terminally ill, as well as emotional support for their families.

I used a purposeful sample of 17 participants and a phenomenological reflection to understand the perspectives of family caregivers (Patton, 2015). According to Patton (2015), this approach facilitates exploration of the meaning, essence, and structure of an individual's experience or the experience of groups of people. This research provides insight into services that may be offered to support family caregivers and patients at the end of life in Belize. The results of the interviews may lead to a set of best practices of ways to support family caregivers (Strommen, Fuller, Sanders., & Elliott, 2018).

This research formed the foundation for the establishment of hospice care policy in Belize guided by valuable information provided by family caregivers. This study could significantly affect the spectrum of care for terminally ill patients and their caregivers in the country. Understanding caregiver needs within the context of the hospice philosophy and policies could serve to sensitize medical professionals throughout the country. Moreover, these outcomes may be used to inform the establishment of context-specific hospices in developing countries such as Belize with the goal of using a culturally sensitive model. This could enhance the body of literature by providing a framework for caring for the dying in other developing countries with limited resources. Services that follow the hospice philosophy and policies might increase the awareness of medical professionals in Central America, in particular, and lead to additional services for

caregivers who provide palliative care and family support. In doing so, the extent of services and priorities that are given to caring for the dying and their families could enhance a country's commitment not only to health care but to the comfort of all patients and their families.

Reviewing models of care and how hospices have historically established and sustained services, as well as models used by modern-day hospices, addressed how to form the foundation and proceed with the groundwork for hospice care in a country that has no formal hospice services (Alonso et al., 2016). Identifying the best ways to care for patients from diverse spiritual, economic, and cultural backgrounds is a meaningful contribution on steps needed to establish hospice services and contributes to the literature, to the community in which such a hospice is established, and to developing countries needing EOL care services (Alonso, et al., 2016). The results of the interviews with family caregivers can be used to support family caregivers and can be used to discern best practices for dignified hospice care in Belize (see Guo & Jacelon, 2014).

Establishing a context-specific hospice in a developing country with an emphasis on personal dignity and relational dignity is important (Guo & Jacelon, 2014). The genius of hospice is that there must be care for the whole person and family systems. Investigating family caregiver needs when caring for patients from diverse spiritual, economic, and cultural backgrounds could be a significant contribution toward establishing hospice care, contributing to the literature, and supporting the community (Guo & Jacelon, 2014).

The call to action by the WHO in 2014 required dedication and commitment to providing dignified care to ease pain and suffering in the face of the rapidly increasing numbers of serious illness due to noncommunicable diseases in developing countries. Although the WHO recognized the barriers to effective reporting of patients with noncommunicable diseases, recognizing the challenges faced by family caregivers and medical professionals to alleviate pain and suffering with effective palliative care medication was also important (Ferrell & Coyle, 2008).

This study provides insights from hospice family caregivers with experience in providing care for their terminally ill relatives in Belize. The focus of this research was to learn about the needs of family caregivers, expressed patient needs, and ways that this population of care providers can be supported during the EOL process. I used interviews to identify the core needs of Garifuna family caregivers in the town of Dangriga in southern Belize. The Garifuna population are descendants of West African captives and Arawak Indians and represent the most marginalized populations in Belize (Cayetano, 1974).

Research Questions

I answered the following research questions (RQs) from the perspectives of hospice experts I interviewed.

RQ1: What are some barriers to quality end of life care, with an emphasis on caring for and meeting the basic needs of Garifuna patients in Belize?

RQ2: What services and support systems would be most helpful to family caregivers of Garifuna patients for acceptance of the patient's passing and throughout the grieving process?

Conceptual Framework

Hospice care is a critical need for people facing EOL decisions (Janecka, 2009). EOL care is not only a reflection of the health care system, it is a societal and family issue (Janecka, 2009). The absence of a comprehensive system of care for the rapidly growing population of elderly citizens reflects a health care system that does not adequately serve or protect the community (Janecka, 2009). People and their families need options for the type and extent of the care the person chooses to have at the EOL. In the United States and many other parts of the world, programs exist that enable humane treatment after patients have lost the ability to care for or make decisions for themselves (Janecka, 2009). These programs also protect their caregivers or relatives from having to make decisions about the way the person's last days or hours are spent such as appointing a health proxy or healthcare power of attorney and completing (Janecka, 2009).

The purpose of developing a model for an efficient service delivery system of EOL care is to educate, direct, and provide a comprehensive spectrum of care for patients facing EOL decisions. This study is grounded in Kübler-Ross's hospice approach and Watson's theory of human caring. According to Watson and Kübler-Ross, these theories underpin the needs, options, and decisions related to the hospice approach as well as the concept of human caring to help better understand the choices people make about their EOL needs.

The Kübler-Ross Hospice Approach

This qualitative study was grounded in Kübler-Ross's (Kübler-Ross, Wessler, & Avioli, 2010) theory of hospice approach as well as Watson's (2010) theory of human caring. Kübler-Ross's approach comprises five stages of grieving: denial, anger, bargaining, depression, and acceptance (Kübler-Ross et al., 2010). This approach also takes into account the need to understand the voluntary separation by the patient from family members and caregivers and why caregivers respond as they do (Kübler-Ross et al., 2010). For example, caregivers of terminally ill patients in hospitals take approximately 11 minutes longer to respond to their patients' call button (Kübler-Ross et al., 2010). This is not an indication of negligence; instead, it is an indication of the emotional challenges faced by caregivers and their way of coping with losing their patients (Kübler-Ross et al., 2010). Kübler-Ross's hospice approach addresses the importance of caring for the patient as well as drawing attention to the emotional difficulties faced by all in that community (Kübler-Ross et al., 2010).

Watson's Theory of Human Caring

Published as a textbook for undergraduate nursing students in 2010, Watson's theory of human caring expanded to include the essential elements of nursing theory to reinforce the need for human components of care and compassion for those studying to care for the sick (Ravi & Nair, 2018). Watson's caring theory was also used as a general guide for nursing practice (Ravi & Nair, 2018) The caring theory emphasizes the importance of basic human needs for food, nutrition, shelter, comfort, clothing, and other essential elements as critical to a healthy, trusting healing environment (Ravi & Nair,

2018). Watson included three additional conceptual components. The first, *caritas*, which means “cherishing or appreciating,” describes the way nurses should treat their patients (Ravi & Nair, 2018). Another component of *caritas* includes seeking and finding creative ways of healing that may be unique to the patient and may bring about healing in a manner that traditional means might not provide (Ravi & Nair, 2018). Among these is artistic expression, a concept that promotes encouraging the patient to express their feelings through sound or visual images (Ravi & Nair, 2018) and supporting that patient by doing whatever is needed to help the patient through the process of healing (Ravi & Nair, 2018). An additional element of Watson’s caring theory was the importance of developing an authentic, trusting relationship with each patient (Ravi & Nair, 2018). That means more than going through the motions of physical care; it means creating opportunities for personal growth for the patient (Ravi & Nair, 2018). Teaching and learning are also important in the healing process and include the healing of body, mind, and spirit (Ravi & Nair, 2018)

The second component of Watson’s transpersonal caring-healing relationships considers the emotional health of the patient while seeking to make a deeper connection through the spiritual realm (Ravi & Nair, 2018) The final component, the caring moment, is characterized by sharing unique experiences that can result in a profound connection between the nurse and the patient, leading to a spiritual connection that may bring about deep healing (Ravi & Nair, 2018). According to Watson (2007), following and practicing the elements of the caring theory can bring about positive emotional, physical, spiritual, and social outcomes. The MOH in Belize (2014) has recognized the importance of the

interconnectedness of the community, interpersonal and intrapersonal relationships, and organizational factors.

Health Care in Belize

The increased prevalence of HIV, diabetes, and cancer places an immense burden on the health services system in Belize. Tables 1 and 2 show the growth in the number of hospitals, health centers, and health posts between 2005 and 2009. While a current comprehensive list of health centers is not available, I obtained a partial 2019 list from the office of epidemiology representative for 2019, the latest years for which data are available. Data on the current status of health posts are not currently available. Also shown is a geographical list of the countrywide locations of the government and private hospitals as well as health centers and the number of posts available at each health center. To address the disparity created in the concentration of human resources for health (HRH) among health regions, primarily in the urban setting, technical cooperation agreements exist between the Belize, Cuban, and Nigerian governments, where HRH (mainly volunteer general practitioners) are deployed to work in the rural areas. About 14% of Belize's health care providers were from these two countries in 2005.

Table 1

Health Centers and Health Posts by District in Belize

District	<u>2005</u>		<u>2006</u>		<u>2007</u>		<u>2008</u>		<u>2009</u>	
	H C	HP	H C	HP	H C	HP	H C	HP	H Cs	HP
Corozal	6	7	6	8	6	8	6	8	6	7
Orange Walk	6	7	5	8	5	7	5	7	6	9
Belize	7	3	12	11	12	16	12	11	18	1
Cayo	4	7	4	7	4	6	4	6	6	6
Stann Creek	7	7	8	7	8	7	8	7	4	9
Toledo	7	12	5	19	7	12	7	12	7	17
Total	37	43	40	60	42	56	42	51	47	49

Note. HC = health center; HP = health post. Adapted from “Health Abstract 2009” by Belize Ministry of Health, Office of Epidemiology, Belmopan, Belize.

One of the goals of the current decade in HRH development is for countries to become more self-reliant in being able to produce sufficient numbers of HRH health care providers to meet their needs. Without a medical school, Belize is expected to continue to remain dependent upon physicians recruited from abroad (Pan American Health Organization, 2010). According to the 2012 HRH Goal #4, the qualified ratio of nurses to physicians would reach a 1:1 ratio by 2015 (Pan American Health Organization, 2010). The primary objective was to enhance health service efficiency and reduce cost of service. However, the ratio was less than 1:1, which was attributed to two possible factors. The first factor that may have impacted this ratio was that an increased number of general practitioners arrived from Cuba and/or the migration of nurses from Belize to

other countries.. Additionally, recruitment and retention of nurses in general may have affected this decline of 14% from baseline (Castillo, 2013).

Table 2

Number of Registered Hospitals by District

District	<u>2005</u>		<u>2006</u>		<u>2007</u>		<u>2008</u>		<u>2009</u>	
	Gov.	Priv.	Gov.	Priv.	Gov.	Priv.	Gov.	Priv.	Gov.	Priv.
Corozal	1	0	1	0	1	0	1	0	1	0
Orange Walk	1	1	1	1	1	1	1	1	1	1
Belize	1	2	1	2	1	2	1	2	1	2
Cayo	2	1	2	1	2	1	2	1	2	2
Stann Creek	1	0	1	0	1	0	1	0	1	0
Toledo	1	0	1	0	1	0	1	0	1	0
Total	7	4	7	4	7	4	7	4	7	5

Note. Gov. = government, Priv. = private *Note.* Adapted from “Health Abstract 2009” by Belize Ministry of Health, Office of Epidemiology. Belmopan, Belize.

Table 3

Health Centers and Health Posts by District in Belize

District	Public health	Public polyclinic	Public health center	Other	Total
Corozal	1	2	6		9
Orange Walk	1	0	4		5
Belize	1	3	8	BDF Hospital	13
Cayo	2	0	4	Palm View MH Hospital	7
Stann Creek	1	2	6		9
Toledo	1	1	9		11
Total	7	8	37	2	54

Note. Provided by the Belize Ministry of Health (E. Nah, personal communication, February 8, 2019). *Note.* Provided by the Belize Ministry of Health (E. Nah, personal communication, February 8, 2019). Additionally, the primary distinguishing factor is that Health Centers are staffed with at least one nurse stationed at each location. Meanwhile, Health posts are staffed by community health workers with limitations to their scope of service. Health post staff offer consultation and referral services and treat minor ailments. (E. Nah, personal communication, April 16, 2019).

Even with the limited human resources in Belize, the country was able to meet the target of recruitment and retention of nurses of the Health Ministries of the Americas, the minimum standard required by the WHO. The existing model for Belize's health system service delivery and the literature provide valuable insight into the formulation of a new model offering support for employees, practical solutions to the provision of services, and improved productivity and efficiency. The current model described in the paragraph below consists of the government minister at the top, followed by the chief executive officer and the director of health services.

Based on the existing model of Belize's health system, seven units report directly to the chief executive officer of the MOH: the finance officers, administrative officers,

central medical supplies, National Engineering Maintenance Center, National Drug Abuse Control Council, Belize Health Information System, and the project management unit. The director of health services has two deputy directors and one director who reports to the director of Health Information System. The first deputy director is responsible for licensing and accreditation, including the Department of Mental Health, pharmacy, radiology/imaging, nursing and dental health. The second is in charge of epidemiology and surveillance, which includes environmental health, maternal and childbirth, vector control, health education and community participation bureau, nutrition, and central medical laboratory.

Nature of the Study

Phenomenology in qualitative studies aims to reveal the lived experiences of the population (Creswell, 2017). I conducted in-depth interviews of family caregivers in the Garifuna communities in Belize using purposeful sampling from a database of caregivers within the research partner database. This study was focused on an analysis of the needs of family caregivers, which may be used to support family caregivers in the homecare setting as well as inform hospice models of care that can be established in Belize to meet the needs of hospice patients. The criterion for participation in this study was family caregivers who had cared for their relatives for at least 2 weeks. I used descriptive phenomenology to identify the lived experiences of family caregivers and help to identify meaningful relations and patterns manifested through identified themes (see Creswell, 2013). In qualitative studies, descriptive phenomenology can provide new perspectives

on the needs of family caregivers and ways that can improve understanding of family caregiver needs and inform hospice model design in resource poor countries.

Definition of Terms

For the purpose of this research, I defined these terms as follows:

Caregiver: The designated family member caring for the patient in the home (Ortega-Galán et al., 2018).

Consent: Permission by a patient or close relative to provide medical services and treatment of illness (Russell, 2018).

Continuity of care: Continuous care from referral to the time of death, which reduces feelings of insecurity and abandonment (Liu et al., 2018).

Hospice: A philosophy of care. According to Medicare guidelines, hospice is services for those who have less than 6 months to live and their families (Liu, et al., 2018).

Hospice experts: Family caregivers in Belize in the absence of hospice services.

Palliative care: Providing pain relief and relief for both patient and family from distress without hastening or postponing death (Clark & Kaufer, 2018).

Assumptions and Limitations

This study filled a gap in the literature highlighted by WHO in 2004, which suggested further research was needed about the services for increasing numbers of people dying in developing countries as a result of noncommunicable diseases. In developing countries, the lack of policies and protocols safeguarding such programs create barriers to the establishment, support, and sustainability of these programs.

Continuous education, training, and community service projects, as well as national EOL care training, can serve to educate the public of the importance of hospice care.

I assumed that, despite the many barriers, establishing a sustainable hospice in a developing country is both necessary and possible. Most notably, I assumed that family caregivers have insights that could lead to successfully establishing hospice models in developing countries and that the results of the interviews with family caregivers were comprehensive and provided valuable information. I also assumed that participants or caregivers were invested in the need for increased services for the populations of developing countries and had sufficient knowledge to thoroughly answer all questions truthfully. As a limitation, the participants in this study were caregivers of Garifuna people. Caregivers of patients of other ethnic groups were not included in this study. Therefore, the findings of this study may not be generalizable to the broader population of non-Garifuna patient caregivers.

Significance of the Study

The need is urgent for hospice care in developing countries for the terminally ill and their families (Lynch et al., 2013). Based on interviews with family caregivers, this study was designed to identify the barriers to supporting patients at end of life and determine best practices and strategies for establishing a support system for caregivers and potentially expanding hospice in Belize (see Cook & Rocker, 2014). This research could create positive social change because it illustrated how developing countries can provide quality care for terminally ill patients even with limited resources and lack of access to palliative medication (see Lynch et al., 2013). The cultural component of the

caregiver's decision making regarding the care for their terminally ill Garifuna relative plays a vital role in the caregivers' decision about a care plan for their relative. The correlation between the caregivers' knowledge of the Garifuna culture and decisions regarding a care plan for the patients has far reaching implications. The findings of this study demonstrate a gap in knowledge of the Garifuna culture and thereby represents a need for education so that caregivers' decisions reflect the cultural needs of the patient.

Establishing a context-specific hospice facility that follows the hospice philosophy and policies could also inform and sensitize medical professionals in the developing world to the need for this service for patients and their families as an adjunct to treatment. Extending the services and priorities given to caring for the dying could enhance the country's commitment to care and comfort. The objective of caring for indigent patients and others from diverse spiritual, economic, and cultural backgrounds could be a significant contribution to the literature and the community.

The MOH in Belize, in partnership with nongovernmental organizations, has decided to join with and expand the spectrum of care for cancer patients, including the alleviation of patients' pain and suffering and reduced health care costs for their families (see Lynch et al., 2013).

Commitment from the government of Belize, particularly the MOH, is imperative for the development and sustainability of hospice programs and policies in Belize (see Lynch et al., 2013).

Family caregiver outcomes can play a significant role in the establishment of EOL support programs using the hospice philosophy and policies. This information could

serve to sensitize medical professionals throughout the country while providing support for family caregivers. In addition to supporting family caregivers, the information gleaned from this study may be used to inform a context-specific hospice in a developing country, with the goal of using a culturally sensitive model. Establishing a facility that follows the hospice philosophy and policies might increase the awareness of medical professionals in Central America in particular and lead to additional facilities providing palliative care and family support. In doing so, the extent of services and priorities that are given to caring for the dying and their families could enhance a country's commitment not only to health care but to the comfort of all patients and their families.

A deeper understanding of the cultural needs, basic care needs, family support needs, and other aspects of EOL care may provide the foundation for programs and services that may be beneficial to family caregivers in the interim while formal hospice services and policies are being developed to address the needs of specific populations. While the outcome of this research may point to a specific system of care that is needed, exploring the individual results of each interview can potentially address issues that could go unnoticed such as the understanding of the presence or absence of the individual and collective knowledge and application of the role of culture in addressing systemic changes to meet the needs of homogenous communities.

Learning from the needs of family caregivers during the EOL transition and through the literature review from hospice experts how hospices have historically established and sustained services, as well as models used by modern-day hospices, helps fill the knowledge gap of how to form the foundation and proceed with the groundwork

for services in a country that has no formal hospice services and only limited caregiver support services (Heyland et al., 2006; Payne et al., 2010). Identifying the needs of caregivers and patients in the Garifuna community increased the understanding of the spiritual, economic, and cultural contexts.

The call to action by the WHO in 2014 required dedication and commitment to providing dignified care to ease pain and suffering in the face of the rapidly increasing numbers of serious illness due to noncommunicable diseases in developing countries (see Ferrell & Coyle, 2008). Though the WHO has recognized the barriers to effective reporting of patients with noncommunicable diseases, recognizing the challenges faced by medical professionals to alleviate pain and suffering with effective palliative care medication is also important (Ferrell & Coyle, 2008).

This study provides insights from family caregivers of terminally ill Garifuna patients with at least 2 weeks of providing care for the patient. The focus of this research was to learn the strategies, services, and continuums of care essential to meeting the needs of the population. I used interviews to identify the core needs of family caregivers in southern Belize (see Goodrick & Rodgers, 2015).

Summary

This chapter addressed the background of hospice or EOL care, the problem statement, the purpose statement, the research questions, and the conceptual framework. I used a phenomenological approach to learning caregivers' perspectives of the primary needs of family caregivers. Additionally, in Chapter 1, I provided the operational definitions of key terms as well as the assumptions, delimitations, limitations, and scope

of the study. Finally, I presented the significance of the study and its potential social change implications. Education, resources, and continuous staff development are critical to providing necessary support for family caregivers and for the foundational work for future hospice services in developing country. Based on the responses of family caregivers on ways to support patients' family caregivers at EOL, I intend to eventually design such a program in Belize.

Chapter 2 contains a literature review focusing on the history of hospice care, systems theory, Kübler-Ross's (2010) theory of hospice approach, Watson's (2010) theory of human caring, best practices in hospice, and barriers to establishing hospices in developing countries.

Chapter 2: Literature Review

Introduction

The purpose of this study was to determine how to provide hospice care in Belize. While hospice models exist globally, there were few available studies of what might be required to support hospice patients in countries like Belize as well as neighboring Latin American countries (World Palliative Care Alliance, 2014). The literature review provides examples of hospice models from around the world that focus on successes in advocacy, volunteerism, training, policy issues, palliation, services, and hospice barriers. I also analyzed research related to hospice care, the origin of hospice, important considerations when establishing a hospice, and culturally relevant issues in this chapter, as well as the background, significance, and origin of the problem. Additionally, the literature review includes the importance of the caregiver being present during EOL suffering; meeting family caregiver needs in regard to bereavement; identifying and meeting patient needs; understanding what matters most at EOL; and understanding spirituality in EOL care. In this chapter, I present the strategies used for the literature search, justify the research methodology, and summarize the major themes that emerged from the literature.

Literature Review Strategy

In keeping with Walden's literature review criteria, I used Walden's online library to search peer-reviewed, full-text articles published between 2013 and 2018. I also used other relevant articles that were within 2 years of the required dates. Key words used in search engines such as PubMed, Academic Search Complete, MEDLINE, Nursing and

Allied Health, CINAHL and Science Direct, EBSCOhost, SAGE Pub Premier, Google Scholar included *hospice origin, family caregivers, family caregiver needs, hospice models, hospice barriers, hospice and culture, hospice and ethnicity, Hospice and spirituality, hospice care in Belize, hospice in the English-speaking Caribbean, hospice and developing countries, hospices in Latin America and Central America, hospice education, hospice definition, hospice foundation, Dame Cicely Saunders, hospice care, palliative care, definitions of hospice and palliative care, hospice in developing countries, hospice and pain management, end-of-life care and access to medication, hospice resource-poor communities, family caregivers experiences, hospice and volunteers, hospice models of care, immigration and immigration in Belize, hospice in Belize, and global map of hospices*. The articles generated through these searches were all found in peer-reviewed, evidence-based journals. Inclusion and exclusion criteria included qualitative research studies.

An extensive and exhaustive empirical review of the terms *hospice care* and *palliative care* conducted by Hui et al. (2013) suggested confusion between the two terms, and they are sometimes used interchangeably. However, differences in the use of the terms, the stages of the disease in which the terms are used, and the phases of implementation based on disease prognosis are a few of the areas that are clearly defined. Hospice care is more generally associated with late-stage disease prognosis and palliative care with comfort care. The empirical data search showed that hospice is a philosophy, a system, a program, or a facility. Palliative care is also used interchangeably with

palliative medicine and is defined as comfort care, which focuses on life quality throughout the course of the disease (Hui et al., 2013).

World Health Priority for Hospices in Developing Countries

Illnesses such as cancer and infections from HIV are two of the most difficult health challenges in developing countries (Bekker et al., 2018), and the need for hospice and palliative care in these regions is critical. As early as 2008, Africa reported approximately 22 million persons affected by HIV/AIDS, or 67% of the global infection rates that year (Ddungu, 2011). The current concerns to maintain such gains is threatened by decreasing support for human rights, thus halting health programs (Bekker et al., 2018). Although the number of new HIV infections has decreased and deaths as a result of AIDS have decreased since the peak of the epidemic, reducing the number of new infections over the past decade has not been significant. This trajectory may likely result in a resurgence of increased HIV infections (Bekker et al., 2018). Additionally, the WHO also emphasized the need for cancer control programs in developing countries. The evidence of late stage diagnosis of cancer in developing countries resulting from a lack of infrastructure and essential resources for early detection has become a critical public health issue (Ddungu, 2011). As a result of disease trajectories such as these, and the lack or limited knowledge of palliative care and hospice care, the WHO recommended a public health approach in developing countries (Ddungu, 2011). This approach is designed to integrate the services into government policy, educate the population, and acquire opioid medication for pain management. Recognizing the lack of policies governing palliative care in developing countries and the urgency of the need for

palliative care at early stages during the span of the diseases, the WHO recommended a public health approach to palliative care should be provided as soon as possible (Ddungu, 2011).

Hospice Global Expansion

Since hospice care was developed in the United Kingdom and later introduced in the United States in 1972 by Dame Cecily Saunders, hospice programs have grown each year exponentially (Lynch et al., 2013). A global map showing the trajectory of countries with varying degrees of hospice programs consists of 234 countries. Countries fall within one of the six categories of hospice care development:

1. Group 1 has no palliative care activity.
2. Group 2 lacks hospice or palliative care services; however, networking, capacity building, and a range of programs geared towards program development have been in effect.
3. Group 3a has random activities of hospice and palliative programs funded by donors and led by groups with small home-based programs with limited pain medication and support.
4. Group 3b consists of federal areas of hospice development with consistent funding, morphine, and more than two independently operated hospice locations.
5. Group 4a are countries with a variety of hospice services that are integrated into the health care system, multiple pain relieving medications including morphine are available, education services are provided by various

organizations, and there is a concept of a national palliative association in that country.

6. Group 4b has a critical mass of hospice and palliative activism and a variety of services that have been integrated into the system, extensive education training, full awareness of palliative care, multiple medication options, and organizational advocacy (Lynch et al., 2013).

Barriers to Hospice Care in Developing Countries

The WHO advocates for the inclusion of hospice and palliative care services into health care delivery systems (Lynch et al. 2013). Additionally, for hospices to be integrated into a health care plan, three provisions must be made. The services must be recognized as substantially beneficial and essential (Lynch et al. 2013). Being recognized means that governments will then need to allocate funds for the services and include the programs in their national budget that facilitates the policy process (Lynch et al. 2013). The responsibility for and sharing of resources pose the challenge. Second, education and training on the meaning of palliative care and linking training of cancer control protocols and HIV transmission is critical (Bekker et al., 2018). Finally, pain control is a barrier due to the limited availability of opioid medication necessary for the alleviation of chronic pain during the terminal phase of some illnesses (Bekker et al., 2018). Each barrier poses significant challenges, as they require a system to change policies, change mindset through education, and share a limited morphine supply (Bekker et al., 2018).

Previous studies have explored caregivers' perception of caregiving in Belize. Vroman and Morency (2011) focused on feedback from caregivers in Belize, a country

with more than 45% of its population living below the poverty line. Caregivers reported that they did not think the role was burdensome. On the contrary, many caregivers took pride in their duty and caring for their loved ones. Yet, caregivers often lived in substandard housing and lacked basic equipment to improve mobility. Vroman and Morency (2011) mentioned some of the cultural barriers to hospices, although through education and the changing family systems in Belize, the mindset could change. Information gleaned from a pilot study of health risk factors in caregivers of terminally ill family members suggests caregivers are significantly affected on a physical, psychological, and emotional level (Cora, Partinico, Munafò, & Polomba, 2012). The stressors of caregiving can have a lasting negative and even fatal impact on elderly caregivers (Cora et al., 2012). In light of a paucity of published literature on hospice care in Belize specifically, it is difficult to determine the extent to which caregivers' health is affected.

Foundations of Hospice Philosophy

Hospice care may have originated several thousand years ago, so the concept of caring for the dying or terminally ill is not new. Hospice today is a philosophy of care and a place where people die well (Thoresen, Wyller, & Heggen, 2011). This concept was developed and expanded by Dame Cicely Saunders, who developed the hospice philosophy, cared for patients, and built the first hospice in London based on her beliefs. (Baines, 2013).

Saunders was a pioneer who introduced the idea of hospice in the United States in 1963 during a presentation at Yale University (Himmel & Smith, 2013).

Despite similarities in care between the United States and the United Kingdom since 2009, there are fundamental differences in policies and operational definitions, treatments, duration of hospice stays, legal issues, and funding. Research conducted by De Roo et al. (2013) focused on quality indicators with measurable outcomes that can be used to improve the quality of services and programs.

In the developed world, access to hospice services is on the continuum of care for all dying patients, and financial support is readily available, specifically through Medicare or Medicaid in the United States. Many countries in need of hospice services do not have access to palliative medication or hospice services for terminally ill patients (Malloy et al. 2014).

Hospice Service Models

Some needs of patients at EOL are universal. The one certainty is that the patients will die, yet, partially due to cultural beliefs, among other factors, medical practitioners delay the news or understate the severity of the patient's prognosis in some instances to keep the patient positive and hopeful (Malloy et al. 2014). Some similarities in patients on a global scale include physical, emotional, psychological, social, and spiritual needs (Malloy et al. 2014). Given the diversity in hospice models, hospice services pose different challenges from one country to another, as well as inter- and intraculturally (Higginson et al., 2013). Those who explore hospice service models in developed countries must consider how services in developing countries will likely serve a marginalized population of low socioeconomic status facing significant hardship in receiving quality EOL care (Higginson et al., 2013). While Hospice care has evolved

globally, including diversified models of care, and exists in many countries around the world following many different models (Higginson et al., 2013), the central focus on compassionate, patient-centered care has not changed.

Home Care Model

While home care is preferred in Japan, it is difficult to determine how effective end of life care is and what related factors best influence quality EOL care. Lgarashi et al. (2015) examined the three-pronged approach to home care services provided through agencies and found that it is difficult to determine the effectiveness of home-care nursing, home health and care management on quality of end of life care. According to Aslakson (2014, many patients prefer to die at home; however, because of inadequate training of care providers and access to skilled care, patients often return to the hospital or to the intensive care unit (ICU). Some programs are often marked by inconsistencies in supportive care, inadequate skilled care, difficulty caring for a loved one, caregiver lack of sleep, exhaustion, and anxiety (Aslakson, 2014). The knowledge gap as it relates to the provision of hospice care is significant.

Residential Care

Residential care programs are often characterized by the support of an interdisciplinary team of professionals (Sherwen, 2014). Such care includes support for the physical, spiritual, psychological and emotional needs of the patients and families. An interdisciplinary team is important in meeting the needs of both the patient and family members. Long-term care provides the kind of services that goes beyond a short stay. Such care provides opportunities for patients and caregivers to establish relationships and

get to know each other (Sherwen, 2014). While the bonding time is important, the transition from life to death makes the loss much more difficult for the caregivers who have had the opportunity to get to know the patients and build a relationship (Sherwen, 2014). Short-term care can range from a few weeks to a few days. This service is offered to patients who have a short time to live based on their existing health prognosis by a certified physician. Some hospices only offer respite care, others offer long-term care, and others offer both options (Sherwen, 2014). Riffin et al. (2014) noted that whether care is short term or long term in a residential facility, the team of medical professionals along with the support of family members often work collaboratively to ensure that the patient is comfortable regardless of the lack of knowledge, availability of medicine, and limited staff.

Day Care Model

In her study on day hospice service models, Swetenham (2014) explored day hospices in New Zealand, Canada, and the United Kingdom. Swetenham observed day hospice service models to determine their effectiveness as well as the feasibility of establishing such a program in South Australia. The day hospice programs in both New Zealand and Canada were similar, operating one to three sessions weekly and lasting for three to four hours each session. The patients favored the patient-centered approach within an interdisciplinary team. Additionally, they reported the aspects of social, psychological, and spiritual components of the program that emphasized social interaction (Swetenham, 2014). The opportunity for the patients to build relationships, reduce social isolation, have emotional connections, and decide on their treatment plans

and planning for their final days were important aspects of these. Although the program resembled the day hospice program in the United Kingdom, the UK is more focused on a rehabilitation model with some strong social elements (Swetenham, 2014). These services are possible in day hospice programs because the patient population is not actively dying, and the patients have a sense of purpose and identity but cannot fulfill the demands of family expectations (Swetenham, 2014). In all programs, food and hospitality are central to the social interaction of the patients. New Zealand and Canada include the cost of food in their operational expenses, while the UK charges a small fee for the consumed food (Swetenham, 2014).

Hospice Caregivers' Perspectives

The literature review revealed a lack of previous qualitative research on family caregiver needs in Central and Latin America. Thus, a qualitative investigation using a phenomenological approach is warranted. Descriptive phenomenology is the proposed research method in order to learn the lived experiences of family caregivers. Husserl (as cited in Shosa, 2012) developed the theory of phenomenology in his quest to understand everyday social phenomena, and phenomenology is often used in health care to learn about individual experiences.

Rationale for Phenomenological Research

Two of the approaches in data analysis are content analysis and thematic analysis (Vaismoradi, Turunen, & Bondas, 2013). Additionally, phenomenology is used in qualitative research to understand the meaning and lived experiences of people and reveal insights into such experiences (Shosha, 2012). The two components of phenomenology

are (a) descriptive, developed by Husserl; and (b) interpretive or hermeneutic, developed by Heidegger (Shosha, 2012). I used descriptive phenomenology to learn more about the lived experiences of family caregivers who provided the knowledge and understanding of family caregiving that would be applicable to EOL care in Belize.

To determine the kinds of data to be collected and for what purpose, the researcher must decide whether to use oral interviews, printed material, or electronic media collected from a variety of formats and sources (Hsieh & Shannon, 2014). As such, I conducted face to face interviews with family caregivers with at least 2 weeks of experience caring for a terminally ill Garifuna family member.

Summary

Knowing the history of health care in general and hospice care and the hospice movement is important when seeking ways to support those who care for terminally ill family members. Previous research as well as the current status of hospice care in Belize by the International Hospice of Palliative Care Association, as well as the WHO, can volunteerism; however, it also highlights the need for content-specific models based on diverse needs and limited resources. Identifying needs of individuals and their families can best be discerned through the expressed needs of those involved in the day-to-day care of the patients. The importance of family caregivers cannot be overstated. Based on the expressed needs in a particular culture, appropriate models can be identified, infrastructure and resources can be assessed, and a vision and plan can be developed and implemented. Ad hoc community care groups can provide care in good faith; however, it

is imperative to understand the ramifications of inconsistent care and the negative impact on the patient and the family.

Chapter 3: Research Method

Introduction

The purpose of this qualitative, phenomenological descriptive study was to explore the needs of family caregivers in Belize, which could eventually lead to the establishment of hospice care in the country. EOL care in developing countries is a complex health care issue that usually involves personally and culturally sensitive matters of death and dying (Valentine, 2002).

Uniformity is needed in determining human needs at the EOL so that policies and systems of care can be implemented globally, share a common language, and stress culturally sensitive approaches (Higginson et al., 2013). In this chapter, I discuss the research design and rationale for this study, the research questions, the role of the researcher, methodology, participant selection logic, instrumentation, procedures for participation and data collection, data analysis plan, issues of trustworthiness, and ethical procedures. I conclude with a summary.

Research Design and Rationale

Past research on various hospice care models included no studies of residential hospice models suited to the unique demographics and socioeconomics of Belize. Because quantitative approaches use deduction and are dependent upon numerical data rather than personal intention (Creswell & Poth, 2017), I did not choose this approach for my study. According to Creswell & Poth (2017), the five types of qualitative research include grounded theory, ethnography, narrative research, case studies, and phenomenological research. For this study, I used a descriptive phenomenological model,

a technique used when the goal is to explore the lived experiences, meaning, and personal perceptions of participants who know the subject under study (Creswell & Poth, 2017). A researcher can develop a deeper understanding of the lived experiences through the personal knowledge and expertise of participants (Moustakas, 1994).

The aim of the two research questions was to identify family caregivers' needs and explore ways to apply this knowledge for practical implementation of a model in Belize using descriptive phenomenology, a process developed by German philosopher Husserl (as cited in Shosha, 2012). The approach is designed to gain a deeper understanding of the research problem.

RQ1: What are some barriers to quality end of life care, with an emphasis on caring for and meeting the basic needs of Garifuna patients in Belize?

RQ2: What services and support systems would be most helpful to family caregivers of Garifuna patients for acceptance of the patient's passing and throughout the grieving process?

Role of the Researcher

I was the researcher and the data collection instrument and conducted, recorded, and transcribed the interviews. I was aware of and noted any nonverbal communication clues such as body language and facial expressions of each participant. I did my best to put aside preconceived notions of the participants and their beliefs and practices in order to gain their candid perspectives (see Sorsa, Kiikkala, & Astedt-Kurki, 2015) I disclosed all relevant information regarding my potential bias, whether it was personal, cultural, religious, or through collaborative partnerships (see Goodrick, & Rodgers, 2015). As the

researcher, I secured signatures on all participant forms required by Walden University, including informed consent, the method of communication, and interview protocols.

Methodology

I recruited participants were recruited based on the following predetermined criteria: (a) they lived in close proximity to the patient for at least 2 weeks, (b) they were currently caring for a terminally ill family member or cared for a terminally ill family member or a combination thereof. Participants were family caregivers who had cared for their relatives at the end of life. I used purposeful sampling to identify and recruit 20 to 25 participants for my research study and five to participate in a pilot study to test the trustworthiness and validity of the interview questions within the family caregiver community of terminally ill Garifuna patients in southern Belize (see Creswell & Creswell, 2018). Due to the low response rate of the participant pool provided by the research partner, it was necessary to use the snowballing technique in order to seek additional participants (see Creswell & Creswell, 2018). To begin the process of identifying participants for the study, my research partner invited family caregivers who had cared for their relatives to participate in this study. Upon verifying their EOL caregiving experience, I used the prospective participants' contact information to communicate directly with the participant. I delivered the invitation letter, a copy of the consent form, and a map with written directions to the interview location. I then asked potential participants to take part in a face-to-face interview. I obtained permission to audio record each interview for future reference and transcript generation. Based on Creswell & Poth (2017) and Goodrick and Rodgers (2015), I expected all themes would

emerge with a sample of five to 25 participants (Creswell & Creswell, 2018). However, saturation occurred at 12 participants. The convenience sample provided by my research partner yielded 12 participants who met the criteria, but I used the snowball method to identify five additional participants. I entered the data collected on each interview question from each participant into NVivo. I sorted the data into categories and labeled them. I identified the codes from within the data. After deeper reflection on the data, I identified patterns that emerged across participants responses and themes (see Goodrick, and Rodgers, 2015).

Participant Selection Logic

I used phenomenological reflection to understand the perspectives of the purposeful sample (Patton, 2015). According to Patton (2015), a reflective researcher asks the meaning, structure, and essence of the lived experience of this phenomenon. I interviewed caregivers of Garifuna patients to understand the cultural, spiritual, and socioeconomic challenges of these patients. Only family caregivers of Garifuna patients participated in this study. The Garifuna population are descendants of West African captives and Arawak Indians and are the most marginalized population in Belize. The information gained from this study can serve as a guide to establishing a hospice model or models that could be effective in serving this population in Belize.

Instrumentation

The primary data collection technique was interviews using a self-designed questionnaire to answer the two research questions. The interview questions, developed using the descriptive phenomenological approach to inquiry, focused on the conceptual

framework of the study (Moustakas, 1994). The survey questions were designed to provide data to answer the two research questions. The interview questions were constructed to reveal participants' perceptions of the patient and caregiver needs and their application in Belize. I continued to interview participants until no new information was forthcoming and saturation was achieved. Prior to the actual interview with the participants in the study, a pilot group of five participants tested the survey questions to determine if the interview questions effectively provided data to answer the research questions (see Creswell & Creswell, 2018). The participant pool included current or former caregivers of families with terminal cancer, HIV, or diabetes who had received services through the Dangriga Cancer Center in southern Belize. Caregivers were identified based on the criterion outlined in this study: caring or a terminally ill Garifuna family member for at least 2 weeks. I made initial contact with the caregivers, providing the purpose of the communication and written request to caregivers to participate. All subsequent steps were followed according to the methodology outlined in this study.

Data Analysis Plan

The data collection and analysis in descriptive phenomenological studies consist of an interview protocol along with the following steps. First, during personal interviews each participant was invited to an office space in Dangriga and was asked a series of questions. Each participant was given up to 30 minutes to review the consent form and ask any clarifying questions before signing the consent form. Participants were reminded of the purpose of the interview and their right to end the interview at any time. As the researcher, I conducted each interview. Each participant was asked all survey questions.

Each participant was given time to respond to each interview question and ask clarifying questions. Responses to the entire interview ranged from 5 minutes to 35 minutes. All responses were audiotaped and transcribed. Next, I transcribed each completed interview and attached the notes from observations of participants during the interviews. I then reread all interview transcripts and handwritten notes. I conducted coding systematically, and after deeper reflection of participant responses, themes emerged and were further categorized. I reviewed NVivo themes and statements for accuracy (Goodrick & Rodgers 2015). Transferability was achieved by selecting a research sample that could represent a cohort of participants who meet the criteria of knowledge and experience in hospice care in Belize. Following this protocol ensured the research would apply to other resource-poor countries seeking to establish hospices that are unique to their cultural contexts.

Issues of Trustworthiness

In qualitative studies, the researcher aims to achieve trustworthiness of the study by ensuring credibility, transferability, dependability, and confirmability of the study (Goodrick & Rodgers, 2015). Of the four components, credibility is most critical in establishing trustworthiness (Goodrick & Rodgers, 2015). Credibility depends in large part on the alignment of the research question and the research findings with reality (Goodrick, & Rodgers, 2015), which supports the internal validity of the study. I sought to ensure trustworthiness of the study by asking the same questions and following the same interview format with each participant. However, prompts and probes were used to further understand participants' responses to the interview questions.

Following the sequential bracketing steps in a phenomenology study is important to avoid personal bias (Chan, Fung, & Chien, 2013). A researcher should be aware of bracketing throughout the entire proposal stages rather than only during the data collection phase (Chan et. al, 2013). Reflexive bracketing requires that the researcher continuously remain aware of ways that they may set aside their own thoughts, understanding, and values in order to create a clean slate for new information and new ways of understanding a person's lived experiences (Chan et al., 2013).

The dependability of the study was augmented by explaining thoroughly to each participant how the study was conducted. The process was documented in a way that assures another researcher could repeat it (Goodrick & Rodgers, 2015). I achieved confirmability by my written disclosure of any research bias that could potentially arise at any stage of the research process, including my personal and professional associations with research participants (Goodrick & Rodgers, 2015).

Ethical Procedures

Before I conducted any aspect of data gathering, I sought the approval of the Walden University Institutional Review Board approval number (03-19-18-0201853). I also had secured written consent from each participant and gave each the interview protocol. I confirmed with each participant that they had received, read, and understood the consent and interview protocols. For participants who wished to review the transcripts and receive the results of the study, I will e-mail, personally deliver, or air mail a two- to three-page summary of the results after Walden University approves the completed dissertation. Each participant took part of their own free will and was not paid to

participate. Reimbursements for travel expense was provided upon request. Participants could withdraw from participating at any time. All written notes and audiotapes will be stored in a locked safe for 5 years, after which I will shred all written notes and will destroy all audiotapes.

Summary

Chapter 3 included the research questions and purpose of this study, my role in the research process, and my rationale for using a qualitative, descriptive phenomenological research method. I also presented the important components of methodology, which included purposeful sampling, snowballing, criteria for participant selection, development of interview questions, and the process for informed consent and interview protocol. The chapter also included data collection procedures and analysis and measures to improve trustworthiness.

Chapter 4: Results

Introduction

This dissertation was designed to examine family members' experiences of caring for their terminally ill relatives. In this chapter I present the results. This chapter begins with a discussion of the sample and data collection method, followed by the demographic profile of the participants and an analysis of the findings.

Sampling Logic

Thirty-six individuals were included in the participant pool in a purposeful sample provided by the research partner. Of the 36 prospective participants, 12 qualified participants were located and interviewed. Five additional participants were recruited using the snowballing technique. I interviewed 10 women ranging from 44 to 55 years of age and seven men aged 39 to 73 who resided in the Stann Creek District in Belize. I subsequently coded and analyzed the data. Although the findings cannot be generalized to all terminally ill patients in Belize, it is conceptually feasible to identify common themes across cultures for individuals facing EOL decisions with similar needs. The degree to which transferability may be applicable to others outside of this population can be determined using a formula to determine transferability.

Data Collection

Thirty-six prospective participants were identified by the research partner as potential participants during the summer of 2018. Locating participants was challenging because of complications involving phone numbers and addresses. Of the 36, I was able to locate 10 by phone and 10 by the address they provided. With further work I was able

to locate seven of the remaining 16 potential participants, for a total of 17 possible interviewees. Of the 17 participants who agreed to participate, four showed up for the interviews on the first attempt; 13 did not attend and were rescheduled. On the second attempt, three appeared for the interviews. Of the remaining 10, a second and third attempt resulted in five more interviews for a total of 12. Upon consulting with my dissertation chair, I met with the remaining five participants in their homes to better meet their needs, and the remaining interviews were successfully completed without any further cancellations or delays.

Data were collected using a self-designed interview protocol that included six demographic questions as well as open-ended questions. A complete list of the interview questions approved by the Walden Institutional Review Board can be found in Appendix A. Each interview lasted between 5 and 30 minutes. With each participant's consent, all interviews were audio recorded.

To determine the feasibility of the study, the first five participants agreed to participate in a pilot study to test the questions. Each participant in the pilot study was asked all questions on the survey. Each participant was given time to respond and elaborate on their responses. Based on the outcome of the pilot study, inquiries were made to clarify all potential research participants home location for travel purposes to the research location. This was done due to conflicting travel locations requiring additional travel cost to be paid to one participant in the pilot study. Based on the pilot study, I also made adjustments in the full study, including to read the questions to the participants more than once if necessary. I made notation of which questions may require

reading multiple times. Additional time was provided for each participant in the pilot study to ask clarifying questions and to determine when a participant would require the question to be read to them more than once. The data from the pilot study, as indicated in the methodology, were included in the full study. During both the pilot study and the full study, I asked probing and clarifying questions. All participants received hand-delivered invitation letters. To comply with my inclusion criteria, I first verified that each participant met the basic requirements of having cared for a terminally ill Garifuna family member for a minimum of 2 weeks. I reached data saturation after 17 interviews. No new themes emerged after 12 interviews were conducted. Interviews were conducted from early April through late June 2018.

Before I started each interview, I reviewed the consent form in its entirety, obtained the signature of the participants, and provided them a copy of the form. Additionally, before starting the interview, I reviewed the purpose of the study and obtained permission to audio record the interview. I reminded each participant that the participant was free to withdraw at any time for any reason.

Only once did a participant say she had “nothing” to say to one of the 20 interview questions. Of these 20 questions, six were demographic questions, and three were close variations of other questions on the list, allowing each participant multiple opportunities to respond to a question or give them time to think about it more deeply. The remaining 11 questions focused on the lived experiences of the caregiver and supports needed in order for them to provide the best care for the patient. I relied on the recording and was attentive during each interview. If I had questions, I asked them

immediately and made only minor notes when needed. Three participants were confused when I asked about their ethnicity. They responded with their gender. If they paused, I immediately said, “Garifuna? Creole?” If they were confused with the word *gender*, I asked if they were male or female.

Each interview was recorded in its entirety, and all responses to each question were transcribed. All transcribed data, audio recordings, consent forms, and anecdotal notes are stored in a locked safe on a flash drive and on a secured folder on my personal computer. For the purposes of easy identification, I labeled each participant with their first initial, last initial, and a number. I used a dictation app to assist with transcribing the interviews. I used a headphone to listen to the interviews and spoke into the app. The interview transcription was e-mailed directly from the app to my e-mail. I downloaded and deleted each e-mail after every download. Further listing and editing were required, given the issues with some word recognition.

Demographic Profile of Participants

Table 3 indicates the profile of the participants. Seven Garifuna males and 10 Garifuna females from the Stann Creek District in southern Belize participated. Males ranged from age 39 to 73 years and females from ages 44 to 75. All were caring for or had cared for a terminally ill family member for more than 2 weeks.

Research Questions

The goal of this qualitative, descriptive phenomenological study was to determine how to meet the needs of family caregivers in Belize. Family caregivers, for the purpose of this research, referred to individuals who had provided for their terminally ill family

members with at least 2 weeks of direct care in Belize. During the analysis phase, I used the caregivers' responses as the foundation for my study. I analyzed the responses and sought to identify emerging themes and concepts. I wrote a narrative based on the findings. I intended to learn from family caregivers their primary needs, resources, and insights on overcoming barriers to establishing hospice care in Belize. The results were expected to provide a compelling argument for countries with limited resources to consider supportive care in the form of hospice care for the terminally ill, as well as emotional support for their families.

Table 3

Demographic Characteristics of the Sample

Participant number	Gender	Age group
1	Male	45-50
2	Female	65-70
3	Female	60-65
4	Male	65-70
5	Male	55-60
6	Female	75-80
7	Female	45-50
8	Male	35-40
9	Female	50-55
10	Female	40-45
11	Female	55-60
12	Male	50-55
13	Female	50-55
15	Female	55-60
16	Female	65-70
17	Male	70-75
18	Male	55-60

Note. The ethnicity of all participants and patients was Garifuna.

RQ1: What are some barriers to quality end of life care, with an emphasis on caring for and meeting the basic needs of Garifuna patients in Belize?

RQ2: What services and support systems would be most helpful to family caregivers of Garifuna patients for acceptance of the patient's passing and throughout the grieving process?

Data Analysis

I used NVivo 12 as the coding tool to extract data and identify themes. I subsequently analyzed themes to determine the depth and breadth of the findings. Each participant interview was transcribed immediately while the information was on hand and easily accessible, decreasing opportunities for data loss. I uploaded each file into NVivo 12 software, and I created a word cloud using the "word frequency query" to identify most frequently used words in the interview responses. This word cloud provided insight into word frequency and assisted with the development of parent nodes. The data were initially coded by each question. Using information gleaned from this initial data, nodes were created using a combination of word frequency queries along with the research questions. Upon further analysis of the nodes created, child nodes were determined using similar subtopics to create a dynamic node structure. Further analysis revealed the following parent themes listed as four general themes: Cultural Understanding, Financial Support, Training and Support, and Garifuna Worldview. Each general theme has supporting contextual themes as indicated in the sections below. Although I originally planned to interview 20 to 25 participants, after 12 participants were interviewed, no new

themes were evident. I continued with five additional participants and confirmed no new themes emerged (see Saunders et al., 2018)

Evidence of Trustworthiness

Credibility

The validity of this study depended on the honest responses of each participant. Authenticity coupled with a comprehensive response to each question was important to the strength of the validity of this study. As the researcher, I abstained from interjecting during the participants' answers to each question and provided clarification only when asked. I remained neutral throughout the interview, remaining cognizant of my body language such as posture and facial expression in particular. Participants were not prompted by positive or negative feedback during the interviews. I ensured that bracketing of my personal thoughts, opinions, and actions was maintained throughout the interview. I provided an environment where participants could speak freely, openly, and honestly without fear of direct or indirect negative consequences (see Miles & Huberman, 2014).

Transferability

As a result of the small, purposively selected homogeneous sample, the findings of this qualitative phenomenological study cannot not be generalized to the entire Belizean population. However, the findings may be transferable to similar homogeneous groups of Garifuna family caregivers should the application of the findings meet the needs based on the demographics of the participants and the setting of the study (Patton, 2015).

The intention of the purposive sampling strategy used in this study was to include caregivers of terminally ill Garifuna patients with the intent to learn as much as possible about the lived experiences of the caregiver and patient needs (Patton, 2015). The demographics of the study, the setting, and inclusion and exclusion criteria provided a foundation for exploration of transferability and the readers ability to discern the validity and extent of transferability (Noble & Smith, 2015).

Dependability

Dependability in this research study was supported by participants granting consent to the researcher to audio record the interview, enhancing the dependability of the study. All interviews were clearly audible and clarifying questions were asked immediately following the interview, ensuring I fully understood the responses.

Confirmability

I was keenly aware and deliberate in my line of questioning. I avoided leading questions when clarifying questions became necessary and ensured that the clarifying questions were similar, if not exactly the same, as preceding questions.

Themes

Themes Related to Research Question 1

RQ1: What are some barriers to quality end of life care, with an emphasis on caring for and meeting the basic needs of Garifuna patients in Belize?

Answers to the interview questions covered a broad spectrum of needs and concerns of what was most important to the Garifuna culture. Some responses applied to both research questions. Other responses provided a deeper understanding of the

presenting issues as well as cultural beliefs on death and dying within the Garifuna culture. The need to understand the culture is regarded as central to providing services and support with the community.

General Theme 1. Cultural understanding. When asked about the unique needs of the Garifuna patient, four caregivers spoke of Garifuna spirituality and the Garifuna worldview. Five participants referenced Garifuna spiritually more than five times across all interview questions. Three spoke of the importance of the traditional Garifuna food, and the remaining 10 participants referred to Garifuna unique needs as basic supplies needed for the patient, such as adult diapers, chux pads (used to protect the beds), wipes, nutrition, and food, as well as wheelchairs and ramps for homes. Three referred to all of the above. Although participants were not asked specifically about general or basic needs, it was evident that the basic needs for quality EOL care were a pressing barrier and needed attention. The participants were equally passionate in their responses and particularly what they referred to as “Garifuna unique needs”: programs to support terminally ill patients and their recommendations for organizations that may want to provide support in the Stann Creek District. When participants were asked about their recommendations for programs and services based on the needs of a Garifuna patient, responses were focused on the importance of caregivers having a comprehensive understanding of the Garinagu people—more specifically, Garifuna spirituality, food, diet, and medication—as well as nontraditional remedies preferred by the elders, in particular. Also emphasized were access to treatment abroad, especially radiation, traditional Garifuna food, and cleanliness of the patient and their physical surroundings.

Other participants emphasized the importance of exercise and finding a facility where the less fortunate can have a clean, safe place to take their loved ones instead of leaving them alone without proper care. Emphasis was also placed on the importance of having a place in the Stann Creek District that would be easily accessible to patients who need care and caregivers needing support to care for the patient. The need for training of caregivers focusing on role playing caregiver roles for a terminally ill patients, such as bathing, feeding and changing the patient. Caregivers also recommended that financial support should be available to individuals who would like to keep their patients at home and care for them there. Participants emphasized an EOL program should take into consideration the beliefs and worldview of the patients, which may involve a bath and mass for the ancestors, and pardoning. The importance of understanding the visions often experienced by individuals who are near death. Additionally, those caregivers who know of existing programs by the ministry encourages caregivers to participate in those programs to better equip themselves to care for their family members. Several contextual themes are associated with each general theme as they relate to the research questions.

Contextual Theme 1: Cultural beliefs. Those who expressed the importance of the Garifuna cultural understanding and worldview were prolific and passionate about their responses. Based on the responses of the participants, the ancestral spirits play a significant role in the maintenance of harmony between individuals and the external world; however, responses addressed possibilities rather than providing definitive responses. It is not clear whether the Garifuna believe that the dying patients are being punished by the ancestral spirits for evil that they have done or whether the spirits

intervene to protect the individual from the trauma inflicted by the external world. Throughout the interviews, participants who spoke of their ancestors did so with reverence rather than out of fear. The relationship between harmony, the external world, and the ancestors plays an important role in the Garifuna culture, particularly as it relates to death.

Participant 5 described a component of cultural understanding as follows:

There is the aspect of cultural belief that family members or caregivers, professionals, and medical professionals probably need to understand or to be able to work with the family members regarding the treatment. Although it might be a terminal condition, in our culture it's also believed that it could be some damage being done by haters, and or by ancestors as a matter of punishment for disbelief in certain aspects of the culture. So, that to me would be some kind of resolve or need to consult and understand how both mesh, mix or fit to be able to eliminate one or the other.

Participant 17 described the Garifunas' unique needs as follows:

I think that being a student of Garifuna spirituality, I think that it's a place where a person strayed away from our worldview. That might be a good place to encourage the person back so that the person can be as a way of the person finding peace. Garifuna spirituality is based on the idea of I for you and you for me. In Garifuna, we say "*au bu amu renu*," which means love and being at peace with the physical environment, being at peace with the social environment, being at peace with the spiritual environment. For us if one is at peace with each of

these manifestation or aspects of the environment there is harmony. There is peace, and I think the person can exit this life more comfortably and come to terms with his or her own situation.

The interviewee continued:

In our worldview, life does not end with death. Life continues after death, and there was a life before birth. So death is simply a transition, a door if you will, that you go to access the hereafter. Life after this world. In our rituals, for instance, we have three drums, together they symbolize life. The middle drum represents present life, which is where we are now. The drum to the left represents future life, the life that is not yet. and the drum to the right, or shall we say, left of the middle drummer represents those who have lived and moved on. In other words, past life and together the three drums symbolize life. So one transitions from not being born, not being here to being born and living in this state of existence, that's birth, and then one transitions from this life to the next and that's death, which is like I said, a transition or phase not state. So I think some comfort can be derived from the Garifuna person understanding that and that is how we think and the relationship between the spirits, the souls that are in each of those three phases of life continues. We have a relationship with those who are not yet born, and we have a relationship with those who have lived and moved on, and there are things that we do to emphasize that, or to remind ourselves of that or to assert that. So, I think that it would be useful for the caregivers of Garifuna people to understand that and to help bring people back to that, because they might have

strayed because of other non-Garifuna influences. You have all these other worldviews competing and staking their claim on our people and others, presenting themselves as the truth and seeing our view as idolatry as ill advised, but we need to come back to where we are before we exit this world, come back to what we are before we exit this life. The majority of the responses were focused on the importance of unity, familial support, basic supplies, medical equipment, handicap access.

Contextual Theme 2: Family and community support. The 17 participants focused on the importance of unity in the family unit and of shared responsibility rather than leaving the burden on one person. Regardless of what the issues are within the family members, according to the interviewees, one should put aside those issues and focus on caring for the terminally ill family member. One never knows when one will need help, too.

Interviewees spoke of abandonment. Advice to family members focused on the importance of not leaving the family member when he or she is in greatest need. The emphasis on compassionate care and the issues of financial burden were also prominent in the responses. Mental preparation for the inevitable culmination of life on earth is necessary if one is to have what is needed at the time of death to provide a proper burial.

Participant 9 expressed what would have been most helpful to her during the time she cared for her relative: "Family members coming together in every way. Sitting with her mother talking to her because I believe that unity is strength."

Participant 12 expressed gratitude to the attending physicians and relatives: “Just the presence of the physicians made me feel more encouraged, [along with] assistance from other family members.” Participant 15 said, “I needed help with him, especially to shower him. I couldn’t do it all by myself. Take him into the bathroom, put him in the tub, wash him, you know.” Participant 16 said, “Someone to come and help,” and Participant 1 answered, “Support from other family members.”

General Theme 2: Financial support. The prevailing theme that emerged in understanding barriers to quality EOL care was financial support. This theme was manifested in multiple ways, including lacking the resources to provide for the patient and the finances the necessary items needed for sustenance and support of the patient and caregivers.

Contextual Theme 3: Need for supplies and equipment. When participants were asked about their greatest need during the time they cared for their terminally ill family members participants responded with a variety of specific needs. Money was needed to purchase adult diapers, baby wipes, soap, medical equipment, proper bed, ramps, and access to treatment.

Participant 2 said, “I need Pampers, the one that you lie down on. I call it chux.” Participant 6 stated her needs, “I would have needed a bed that I could handle her in, but I would also need financial assistance. That would help me meet her needs.”

Contextual Theme 4: Proper nutrition. Participant 4 expressed the challenges faced in providing basic necessities, including Ensure and Pampers. She said these are needs, not wants.

Toilet tissue is needed, the vitamins and Ensure is needed for that specific reason it is needed. Vegetables are needed. In order that, vegetables are easier to consume than the flour or the rice. Those are what I would [call] needs. Also, you need to consider what you will need to consume in order that you can stand up and care for her. So in my case I have my children who supply my kitchen. We divide my kitchen. You responsible for this, I am responsible for that . . . until everything is in for the 2 weeks. After the 2 weeks, then we fill our kitchen again. Bills need to be paid and we divide it.

Participant 7 needed “money and support,” for food, fruits and vegetables while Participants 3, 4, and 12 mentioned having enough food, fruits, and vegetables.

General Theme 3: Training and support. Questions were decided to reveal whether the participants would use the opportunity if they were offered help by a caregiving team to assist them with the care of their terminally ill family member. Of the 17 participants, 12 stated that they would accept support as part of a caregiving team. Five said that they would not go anywhere outside of the home to be part of a team. The reasons for not accepting support were the pride of the patient, the obligation to the patient’s wishes, the inconvenience of moving the patient, and that the caregivers were being paid to care for their relatives. The caregivers who said that they would accept the support stated that they would do so in order to provide the best care for their loved ones, to learn more about the diseases affecting their relative so that they can help others later, and to get some relief and some skilled support at the most difficult time.

Of the seventeen participants, 14 said they received no EOL care training. One said all he knows is advice from his grandmother. Another participant considered EOL care “second nature” and that one should take care of a sick loved one. Three participants received formal training ranging from basic to advanced training. One participated in workshops offered by the MOH, one from workshops and other skilled training through various organizations, and one had training as a nurse.

Participant 1 stated, “No formal training. However, from my grandmother, I would take just the simple advice and then take it from there. So, no I had no formal training.” Participant 3 stated, “I guess it's just second nature if your husband is not well [that] you would have to do the things that would make him comfortable.” Participant 4 stated, “No, that was first experience, because both my parents died suddenly, so we never had that experience with them.”

Contextual Theme 5: Skill training. Some participants expressed the importance of spiritual and emotional support as an integral part of caring for the patient. Participant 11 stated that workshops are important because the trainings prepare him to take care of terminally ill patients. Participant 9 reinforced the importance of skill training, and reflected on her time in nursing school and the trainings received which prepared her to be a supportive and conscientious caregiver to her ill relative. Participant 18 stated, also shared the benefits of workshops and how the skills learned in the workshops prepares one for the caregiver roles and responsibilities.

All other participants said they had no training in caring for a terminally ill patient. Some participants offered recommendations for training and emphasized the

importance of the training for those caring now as well as for future generations.

Participant 9 stated,

They usually have programs, for example done by the Ministry of Human Development. I would advise that your love ones would go and learn more how to care for their love ones or any sick terminal form of patient or any patients for that sort. Because how would you care if you don't know, how to care for that person. You need to learn yourself so that whatever you have learned you can pass on what you have learned to do for that patient.

Ok, make sure they do their exercise. Don't just relax in that bed like that and don't do any kind of exercise, because they need the exercise. If they don't do no kind of exercise in that bed, then they are going down faster. Walk around in the house with them. Hold around their waist, a little walking and a few other exercises.

Contextual Theme 6: Spirituality and emotional support. Some participants expressed the importance of spiritual and emotional support as an integral part of caring for the patient. Participants emphasized the importance of Garifuna spirituality and the Garifuna worldview, while others spoke generally about their spiritual approach to coping. When participants were asked about unique cultural beliefs, what they needed the most, or recommended community service programs, they mentioned spiritual and emotional support, which could assist with the care as well of EOL transition of the patient and spiritual sustenance for the caregiver.

In response to the participants' greatest emotional and spiritual needs, Participant 8 stated, "I needed God the most." Participant 5 stated:

Just accept the fact as they are. We know that prayer is a powerful thing. We pray here, but we understand that it's a terminal situation. The prayer is not anymore that of begging God for survival. It's more for that transition period into the other world as we believe it.

Participant 9 said she needed "patience, wisdom, and faith." In responding to questions regarding the unique needs of the Garifuna culture, Participant 6 stated:

You have to learn how to handle them, how to change them and you have to learn how to keep them engaged. By that I mean they too to get discouraged or miserable and you cannot be miserable along with them. You have to show them that this is God's word and you have to accept it and always give them faith that everything is going to be all right.

Participant 15 stated,

So we gonna walk and when we finish walk I say am gonna pray so you can get heal, that's what I said to him and then he said, ok. . . . I pray my own prayers. I don't follow like the Garifuna, because we used to use like the "Our father" and "Hail Mary" and stuff like that so I don't do "Our Father." I pray "Our Father" yes, but I pray prayers that God could heal you know.

Participants were asked about their recommendations for programs and services to assist patients based on the needs of a Garifuna patient and recommendations for incoming programs aimed at supporting the community. Responses focused on the

importance of caregivers having a comprehensive understanding of the Garinagu people and, more specifically, Garifuna spirituality and emotional support. Participant 17 spoke of the importance of Garifuna spirituality as it relates to peace and harmony and the importance of acceptance and maintaining equilibrium:

This is a multicultural society. During life people are exposed to all sorts of things that would reshape them. I think that it is important to understand where the patient is coming from. The individual's background, how he and his people think and to factor that into the equation. In the case of Garifuna people, we came into this life just like everybody else. We are exposed to a particular culture. Our worldview, even though there are other competing views, some people might find that they are quite happy where they had diverted to and that might be enough for them. In other words, there are those who, like the evangelicals for instance, who believe that our spirituality is witchcraft. They don't know anything about it but they have concluded that it is. There may be some Garifuna people whose minds have been won over by such people who may look down on their own view of the world and likewise describe it as witchcraft. Those are people who don't know, but if they are happy with their view and they are at peace with themselves, then I guess one needs to accept that and let them be. There is no point in disturbing them, disturbing their equilibrium because we happen to believe that Garifuna spirituality and cosmology is based on love and oneness. But one is in a place where if he doesn't, and he is confused, it might be helpful to engage in a conversation that deals with more than the physical comforts. Your personal

needs being met because we are body and spirit. We are not just body. All your physical personal needs can be met and you are still not at peace and I think people at the last stages of their lives, as much as possible, can be helped through conversations and discussion by people who understand, are emphatic, can help engage them so that they can find that peace, whether it is something new that they have been introduced to that is non Garifuna, or a return to what they really are.

Participant 1 recommended the “full cultural understanding as a caregiver. In many cases you have whereby, we do understand taking care of the patient, but then if you don’t understand the cultural background and beliefs then it will be a more difficult task.”

Contextual Theme 7: Comfort and cleanliness. The Garifuna beliefs, worldview, and cosmology asserts that certain signs or messages are relayed from the dead to the family. Family members try to meet the needs of the ancestors and respond accordingly. For example, references and the importance of cleanliness exist even beyond this world in which we live. There are three principal rights in the Garifuna culture: (a) the Amuñadahani, also known as the burying of the dead or the bathing of the dead; (b) the Chugú, known as the feeding of the dead; and (c) the Dügü, known as the feasting of the dead. The Amuñadahani or bathing of the dead is known as the smallest and least important of the three rituals. However, it was noted that throughout the interview most participants referenced cleanliness as an integral part of what is considered dignified care

at the end of life in the Garifuna culture and an important to fulfilling the wishes of the ancestors.

Participant 5 spoke to this relationship between the two worlds, expressing that any program established should expose caregivers to the Garifuna culture by talking to people who know and understand the culture, the beliefs, and find some way to guide the individual to choose between their perceived reality and their actual reality, and thereby focus on that which exist. For example, all the different belief that exists, bath for the ancestors, Mass for the ancestors asking them pardon.

Additionally, participants spoke of the importance of keeping their living environment clean as well as keeping the patient clean in this life. Participant 10 said she would recommend “the patient’s food as usual, their cleanliness, and their surroundings should be okay.”

Themes Associated With Research Question 2

RQ2: What services and support systems would be most helpful to family caregivers of Garifuna patients for acceptance of the patient’s passing and throughout the grieving process?

General Theme: Garifuna worldview. The operational definition of grieving may be understood in the general context of grief. For example, an individual may begin the grieving process before the physical death of the patient. How we care and how we are able to care for the dying affects the grieving and recovery process. Themes such as cultural beliefs, which encompass the spirituality, cosmology, and the Garifuna worldview are important aspects of the grieving and recovery process.

I attempted to better understand grief and acceptance of the Garifuna patient's death and what services may be helpful during and after the patient's death. The relationship between the living and the deceased ancestors is one of deep understanding and respect. The requests of the deceased, which are communicated to living family members or through a *buyei*, or priest, are a responsibility addressed with reverence and diligence in order to fulfill the requests from the ancestors (Valentine, 2002). Some of these rituals include a bath for the deceased ancestors and, in collaboration with the Catholic church, there are masses for the ancestors as well. The activity is determined by the message relayed by the ancestors. The ancestors also use dreams as a way to communicate with their living relatives. They may request certain food items, a mass, or a bath. The families comply accordingly. It is also important to note that there are repercussions for the families who choose not to comply with the ancestral requests or demands. It is believed that the trouble will befall the individual or family. This is also referred to as *lamiselu* (Cayetano, 1974)

Contextual Theme 1: Cultural understanding. Participant 5 provided some specific details of the rituals that Garifuna people undertake to bring about peace and harmony, that can ultimately result in a peaceful transition for the patient and acceptance by the caregiver.

That program to me would be one [designed by people] who understand the culture and the beliefs. So all the different belief that exists, bath for the ancestors, mass for the ancestors asking them pardon, Let her go and once that is all done then you know the medical aspect of it is the focus, which primarily would be a

matter of comfort that that institution might be able to offer. So to cut a long story short is probably counseling.

Contextual Theme 2: Familiarity with caregivers. Participants emphasized the importance of having a clean environment for the patient as well as keeping the patient clean.

Contextual Theme 3: Needs assessment and education and training. While participants were clear about their needs for supplies, equipment, and other support, they were also adamant in their plea for those providing the support to go into the home and assess the patients and see what is really needed by the patient. Thus, while supports are needed, it is important to show that those individuals and organizations care. Participants emphasized that these organizations cannot be success on their own, and collaborative partnerships between the two entities, home and organization, is essential for a comprehensive approach.

Participant 11 said:

I would recommend just like I mentioned before, the things that that the terminally ill patients need for example like wheelchairs, bedpans, urinals, mattresses. I would recommend that they give a helping hand to hospice because hospice cannot do it alone. But when other organizations are willing to give aid then, these are the things that I would ask them to even visit homes so that they can see for themselves the needs of these individuals.

Participant 4 said,

You need to investigate background. The real truth of the matter. Pay a visit to see if what you hear is true. In doing that, then you will determine what next step to take. See what Mr. X is needed then you can say, Mr. X, I can help you with this.

Participant 1 said,

I would first recommend for the individual to go into something not because of I want a job you love it and I understand the needs of the patient and as a caregiver and again it is rewarding not directly but indirectly. What you sow is whatever you reap. Again, I understand the environment understanding the environment plays a dynamic role. Again, it's based on cultural culture of that individual that would require certain physical movements both physical and the physical support and that mental support.

Participant 10 stated:

Again, education, training what we do the person need training because deep down you wonder, am I really doing the things that need to be done. Because sometimes you only feel your way. You know she needs to be changed you change her. You know she have to be fed you feed her. She wants a bath, then give her a bath if that is what you think she needs. But maybe there's more. Keep her company sitting down talking with her, singing with her, praying with her you know. And then, as I said, finances are very important. We need finance because our finances limited, and if you don't have it you can't give it to her and sometimes you look at her she wants this and you don't have it and I think, if I center, a training center would be very important whereby the caregiver can go

there and learn whatever they can learn so that they can treat the patient with love and care treat them the right way.

Summary

To better understand the lived experiences of caregivers of Garifuna patients, I conducted a qualitative, descriptive phenomenological study. The process included face-to-face interviews with 17 participants, 10 of whom were females and 7 were males. Each had provided his or her terminally ill family members with at least 2 weeks of direct care in Belize.

The findings were summarized in Chapter 4, along with the data collection process, the participant sample, the research questions, the data analysis procedure and tools I used, and the themes I identified. Excerpts from interviews were included to provide knowledge aimed at educating individuals, organizations, and agencies that may benefit from the firsthand information from individuals in this community, with the intent to better serve the community.

The interviews resulted in a board range of statements that were culturally and globally significant. Some of those statements were used as excerpts in answering each research questions and, therefore, were discussed under each research question. The first phase of my analysis started with a word query used to create a word cloud. NVivo served as a support tool to assist with the creation of 18 nodes, the source of each node, and the number of references of nodes. My criteria for theme decision was based on the frequency of the theme across the 17 participant responses. If references were made five

or more times across the sample, the theme as used in the study. As a result, 11 themes were developed in answer to the two research questions.

In addressing Research Questions 1 and 2, eight themes were identified. Those themes included cultural awareness, financial support, training and emotional support. Research Question 2 resulted in three themes: cultural understanding, familiarity with caregivers and needs assessment and education and training.

Transition Statement

In Chapter 5 I present my interpretation of the findings, and discuss the significance of the study, implications for social change in health care administration, implication for policy, conceptual framework implications, reliability and validity, and recommendations for future research and program implementation and practice and policy implementation.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative, phenomenological study was to examine the lived experiences of family caregivers of terminally ill Garifuna patients in the Stann Creek District in Southern Belize. I took a phenomenological approach to better understand family caregivers through their understanding and interpretation of their needs and ways to support them as well as the terminally ill patient (Van Manen, 2016). Chapter 5 includes an interpretation of the findings and conclusions based on the results presented in Chapter 4.

This study was important for several reasons. First, researchers such as Heyland et al. 2006 and Cook and Rucker (2014, have noted the challenge of understanding what quality EOL care means to a patient and the family caregivers. One of the primary findings in this study was the importance of trust in the patient's caregiver. As a result of the variations of the interpretation of "quality care," customizing care for dying patients was cited by family caregivers as extremely important (Cook, & Rucker, 2014).

Findings

I identified 11 themes that addressed the two research questions.

Research Question 1

RQ1: What are some barriers to quality end of life care, with an emphasis on caring for and meeting the basic needs of Garifuna patients in Belize?

Three general themes were followed by associated contextual themes. The general theme Cultural Understanding was expressed as two contextual themes: cultural beliefs,

and family and community support. Caregivers believed that cultural beliefs and family and community support are both essential components to quality EOL care. The second general theme, Financial Support, was expressed as two contextual themes: need for supplies and equipment, and proper nutrition. The burden expressed most frequently was the need for financial support to assist with purchasing the necessities such as supplies, equipment, and food. The third general theme, Training and Support, was expressed as three contextual themes: skills training, spirituality and emotional support, and comfort and cleanliness. The expressed needs focused on teaching caregivers the basic skills necessary to care for their patient. Many people are new to caregiving and lack the skills or are unaware of how to care for a terminally ill individual.

Research Question 2

RQ2: What services and support systems would be most helpful to family caregivers of Garifuna patients for acceptance of the patient's passing and throughout the grieving process?

The general theme I identified was the Garifuna Worldview, with three contextual themes: cultural understanding, familiarity with caregivers, and needs assessment and education and training. Knowing a person's own caregiver and being in a community receiving care from individuals who are known and trustworthy was important to patients and the families of the patients. Caregivers said that even though it may be difficult to care for their terminally ill family member, they would rather personally suffer than to leave their family with people they do not know or people who are not trained.

One of the most important aspects of the *dügü* is that it involves not only the immediate family of the person on whose behalf the offering is being made but all the relatives of both that person and the departed one to whom the *dügü* is being offered. Thus, most people in a village are involved; as noted earlier, the Garifuna of Central America constitute a community that cuts across national boundaries. Relatives usually travel from Honduras and Guatemala to participate in a *dügü* given in a Belizean village or town.

Conceptual Framework and Implications

Several theories underscore the barriers to quality EOL care and the most beneficial services and support systems for Garifuna family caregivers. The 17 family caregivers who participated in this study represent a cohort of caregivers within the Garifuna communities in the Stann Creek District in Belize. I discuss the conceptual framework and implications of this study as it relates to the major conceptual elements of Watson's theory of human caring including *caritas* processes, transpersonal caring, and the caring moment. Additionally, I discuss Kübler Ross's theory of hospice approach, which includes the five stages of grieving: denial, anger, bargaining, depression, and acceptance.

The Greek word *caritas* refers to an aspect of caring that represents therapeutic healing. (Ravi & Nair, 2018). *Caritas* invokes the manner in which a family caregiver chooses to approach a terminally ill family member and other relatives. When a person is cared for using a positive "caritas," interpersonal relationships and the environment form the foundation of a journey toward healing. The information gleaned from this study,

based on the lived experiences of family caregivers, reveals that a positive *caritas* is embedded within the Garinagu culture. The relationship between the caregiver and the patient is precious. Most participants cared for their relatives, it would appear, without regard for their own well-being. However, this selfless caring fits in line with Garifuna cosmology “*Au bün, Amurunu.*” literally, “I for you and you for me.” Broadly speaking, it reflects the Garifuna worldview that the well-being of a member of society is intricately linked to that of the other and is of the whole. When asked about how they cared for their personal needs when caring for their terminally ill family members, most participants paused before answering so they could think about their own needs before responding. Additionally, several participants asked me to repeat the question and asked for clarification about what is meant by their “own needs.” Further exploration revealed that the participants view their caring of their terminally ill relatives as caring for themselves. The importance of respect for the dying, a clean, safe, environment, access to necessities, and financial means suggested that the gifts of knowledge and wisdom imparted by the elders or their deceased relatives were expressions of caring. Garinagu culture views caring for dying relatives as a family obligation. The depth of the respect and gratitude for transitional and cultural knowledge imparted transcends any need or desires for worldly possessions. Additionally, relatives who are gainfully employed seek ways to schedule the patient care with other relatives in order to share the care time.

In responding to the family members involvement, all participants responded with *caritas*. The absence of hostility, frustration, and disappointment often seen in caring relationships with extended families when one family member feels overburdened were

not manifested in this population of caregivers. All 17 participants encouraged other family members facing similar situations to help in whatever way they could. They pointed out that every little bit of support helps and encourages those not involved to visit, provide manual help to move the patient when necessary, or to do what they could to reduce the stress of the patient and family system, such as refraining from doing drugs. The elements of *caritas* reflect Watson's (as cited in Ravi & Nair, 2018.) theory of human caring and validate the actions of these family caregivers.

All 17 interviewees noted the challenge of availing themselves of essentials such as food, supplies, equipment, and a safe environment. The theory of human caring suggests the presence of the essential needs prevents diffusion of attention on the patient. The caregiver is able to be authentically present, focusing on the care and comfort of the patient into the transition from life to death. The theory of human caring is applicable in the hospice or EOL care setting and provides the opportunity for caregivers to support the patient's spiritual and cultural needs. These needs are integral parts of the Garinagu culture and are essential components of dying well. Cultural needs expressed by the family caregivers as important in life and in death transitions in the Garinagu culture ranges from "cultural food," such as *hudut*, *tapou*, and *darasa*, and spiritual practices like *dügu*, *chugu*, and other forms of rituals for ancestral communication through relatives.

This study revealed a deep sense of ownership of the care for members of its community, particularly elders who are dying, regardless if the caregivers were caring for their mother, father, husband, wife, aunt, sibling, uncle, or cousin. The emphasis in ensuring that the individual was in a safe, clean place with caregivers who would love

and care for them was impetus for the decisions about caregiving. Caregivers said it was unlikely that family members in the Garifuna culture would allow their loved ones to be left in a facility for care by others they do not know. Some families do leave their patients in a facility or have them cared for by others outside of the Garifuna culture and community but only if the family feels confident the care will be compassionate and dignified. Throughout the interviews, a recurring theme was the fear of abuse of the patient as a central reason that family members did not want to leave their loved ones in the care of others outside the family unit. The authentic, trusting, and “healing” environment that forms a deliberate and important part of caregiving among Garinagu does not happen by chance. The family member assumes responsibility for the dying and care for the patient to the best of their ability. In one example, the participant sought financial support and support for food, medicine, and transportation so that the dying spouse could maintain a healthy diet and receive care from the best doctors that they could afford. The caregiver asked for whatever the spouse needed and sought the best care possible. The caregiver, along with the children and community members and organizations, relatives, and friends gathered what they could and provided the best care possible. Even though Garifuna music, such as song and drumming, is one of the core cultural practices, this practice as a part of the Garifuna transition from this life was not highlighted as an essential component during the dying process.

The second component of Watson’s theory of human caring is transpersonal caring-healing (Ravi & Nair, 2018). This aspect of Watson’s theory goes beyond the daily survival needs. This component encompasses a deeper appreciation for the spiritual

life and soul of the patient. The caregivers in the context of this study understood the cultural needs and spiritual needs of the patient in a way that would not be understood by a non-Garifunan caregiver. Being able to relate to and provide an accepting environment familiar to the patient is important in the final stages of life of the Garifuna patient.

According to several participants, even though there are traditional Catholic practices of prayer, the Garifuna believe in their own cultural rituals of healing and transition into *Seiri*, or heaven. For example, the *Dügu* is a weeklong ceremonial healing ritual that involves communal meals, dancing, and honoring the dead through the feeding of the dead, leaving food out to feed the dead. Through rituals such as this, family members are drawn together in a positive supportive atmosphere.

The third component of Watson's theory is the caring moment. Unlike a caring environment in which the patient and caregiver may not know each other or meeting the caregiver for the first time, this relationship differs. In this study, the caregiver and the terminally ill patient know each other or have known each other in some capacity for most of the caregiver's life. Therefore, the caring moment component of Watson's theory is expanded with regard to the "moment." In this study, the caring moment is what leads to the determination of a caregiver of the dying patient and the decision by the caregiver to support that dying patient. The caring moment is therefore expanded in this study. The caregiver and the patient can bear witness to a deeper knowledge, understanding, and appreciation of each other. In the Garinagu culture, this caring moment predates the caregiver and patient relationship. It is a cultural norm that, according to the findings in

this study, is challenged only by the caregiver's physical ability to provide care and access the essentials and physical strength to provide optimal care.

The second theory used to frame this study was Kübler-Ross's hospice approach. Kübler-Ross identified five stages of grieving: denial, anger, bargaining, depression and acceptance (Kübler-Ross et al., 2010). Denial is characterized by patients' refusal to believe that the fate of death is upon them. This is coupled with the distancing of oneself from the caregivers, other family members, and the outside world in general. Anger is often experienced in varying degrees by the patient and ranges from resentment, feelings of rage, anger toward God, and everyone in their path. When patients experience anger, it is important that there is a healthy, controlled outlet to allow the patients to vent their emotions. The bargaining phase can be experienced when patients try to seek more time in this world in exchange for something they feel they still have control over, such as good behavior, or making sacrifices, such as donating their organs. The depression phase is often a direct result of the current condition of the patient's illness or depression resulting from the imminent approaching death of the patient. The final phase is acceptance. This can be characterized as resting after continuous or intermittent struggle with one's emotion. It is a place of peace and rest and devoid of the struggle to live. Approaching death can often be identified, but the duration of time can be misleading and varies from patient to patient.

Kübler-Ross's hospice approach addresses the patient's stages of grief. Its application to caregivers mirrors the stages of grief of the patients. In this study, of the 17 two of the 17 caregivers were actively caring for a terminally ill family member. One

expressed feelings of disappointment in the doctors and thought that if he had the proper support such as nutrition and financial support to access better medical care, the patient would not be in the current situation of dying. The remaining 15 caregivers had passed the stages of denial, anger, and bargaining. They expressed through their narrative that they thought they had done all they could and were physically calm. Several caregivers referred to their deceased relatives in the present tense, which can traditionally be interpreted as a sign of denial and an attempt to “hold on” to the patient; however, in Garifuna cosmology, this is viewed as a “spiritual presence” of the deceased. Five caregivers expressed their frustration with the medical system and the challenges faced in the absence of a comprehensive system of care for terminally ill patients that is both accessible and of high quality. While Kübler Ross’s hospice approach is often used to identify stages of grief, in this study, the stages of grief as expressed by caregivers can be used to provide support to family caregivers and enhance support systems for caregivers of terminally ill patients and their family unit.

Limitations of the Study

I functioned as the sole researcher in this study, including interviewing all participants, and gathering, organizing, and analyzing the data. To increase credibility, I audio recorded each interview and asked clarifying questions immediately and made written notes as necessary. Data were transcribed, and I manually checked and edited the transcription. Following the second edit, I reread each interview transcript and verified the transcript against the audio recording using a headphone and the original recording to ensure verbatim transcription.

Eight of the participants who participated knew me or knew of me through my association with community programs. This is a noteworthy limitation, as it had the potential for researcher influence during the interview process.

Recommendations

The findings highlight the importance of patient and family knowledge of hospice services. This information can be used for future planning to enable hospice to both provide high quality evidence based palliative care services for patients and families and provide consultative services to primary health care providers in the community.

Additionally, the lack of knowledge regarding Garifuna cosmology, spirituality and worldview can be used to educate the Garifuna population about their unique culture and assist in understanding the transition from life to death. Understanding stress and how stress impacts quality of life, and the importance of recognizing and acknowledging stress is also important for family caregivers. Establishing programs that would be proactive and in locating caregivers and their patients and sharing information on available resources such as trainings, supplies, finances and psychological support are areas that can be improved based on the caregiver feedback.

Social Change Implications

Results from this study revealed a glimpse into the Garifuna worldview as it relates to family values and how caregivers of terminally ill Garifuna family members prioritize the importance of the various aspects of care. In this study, 3 family caregivers revealed that they would not leave their relative with anyone outside the home under any circumstances, while 14 said they would leave the patient with other nonfamily

caregivers if they know the care would be similar to that received in the home and without abuse of the patient.

In addition, this study adds to the paucity of knowledge as it relates specifically to the needs of family caregivers of terminally ill Garifuna patients, first, by addressing how grief is manifested in the Garifuna culture, and second, the importance of human caring within the Garifuna culture. The potential impact on social change can be significant because of the findings in this study, which include the cultural components and an in-depth exploration of the Garifuna understanding of death and the Garifuna worldview. Grief, in Garifuna culture, is often manifested through music and dance (Cayetano, 1974). While the appearance of celebration may be superficial, the lyrics, tone, and essence of the music, such as the Mali performed during the Dügu, carries a somber note that echoes the general feeling of loss and grief (Cayetano, 1974). In this study, many caregivers who had lost their relatives had a deep sense of empathy and obligation to improve current conditions and envision a more caring community. Most participants indicated that they were willing to help in their community to help to improve current situations where patients die with the financial burden on a few family members who lack support from the extended family. These caregivers or potential change agents can be a catalyst for positive social change and a way forward in implementing and establishing hospice care in Belize. Interested persons may determine that the outcome of this research study may be generalizable to other situations, thus impacting social change outcomes (Creswell, 2017).

Finally, literature for the purposes of education and awareness, may require diversified methods of dissemination in order to reach this population. Participants indicated that a lack of resources was a significant barrier to accessing the basic needs, but they lacked knowledge about what resources were needed within the community with regard to access to care.

There is a gap in hospice services in Belize, as documented by the WHO's global map (Lynch et al., 2013). The conceptual frameworks of human caring and the five stages of grief reflected caregivers' responses to grief from a culturally sensitive perspective and how caregivers relate to their patients relative to health, culture, ethnicity, and health care. In determining a comprehensive understanding of a qualitative, phenomenological design outlining the data collection methods, limitations, delimitations, scope, and assumptions were important indicators of a thorough understanding of how those components impacted the outcome of this study.

There are many models of hospice. Several studies focused on the design of hospice and service offerings; however, the absence of a caregiver-informed hospice model with an emphasis on the specific needs of the culture under consideration for design and implementation remains a problem. Although there are residential programs, day care programs, respite hospice programs, and hybrid models, those models are based on global perspectives to meet the needs of the masses rather than a boutique style to meet the needs of a homogenous community. In light of the results of this study, caregivers would utilize hospice services if they were being served in a culturally sensitive facility. Trusted caregivers of a similar culture and care by family members

would increase hospice service utilization. This finding, along with other indicators of the global hospice movement and implementation, can be used to impact positive social change as it relates to services offered within the Garifuna community that would effectively meet the needs of the people.

Analysis of the research findings revealed that finances, knowledge of resources, lack of family support, training and support, spirituality, comfort, caregivers of the same culture providing patient care and cleanliness were primary factors influencing the utilization of services outside of the family caregiver structure.

The findings revealed that caregivers were willing to sacrifice their own comfort and needs in order to ensure the needs and quality care of the patient. These caregivers had a deep sense of obligation and respect for the elders and their ancestors. The findings suggest that community education regarding available resources can serve to improve quality of care through access to resources for the patients, thus reducing the burden on the caregiver and the family system.

Discussion

EOL care in developing countries is a complex health care issue that involves culturally sensitive matters of death and dying (Valentine & Cayetano, 2002). Although the United States has well-established hospice health care services, little is known about sustainable hospice models in developing countries. Emerging research suggests there are significant gaps in assessing the needs of establishing hospices in multicultural societies and developing countries (Cagle & Lamantia et al., 2015).

Without the reference point of successful sustainable hospices in developing countries, best practices and recommendations are limited. Information on such culturally sensitive models from hospice experts' professional experiences can provide valuable information to help to fill the gap in the establishment of hospices in multicultural societies. Therefore, identifying best practices and models may eliminate some barriers and encourage the establishment of more hospices in developing countries.

Hospice models aim at meeting the physical, social, psychological, cultural, and spiritual needs of populations facing the EOL (Fraser et al., 2017).

My research focused on seeking the knowledge and expertise of family caregivers to determine how to best meet the needs of the caregiver and their patient. This knowledge may be used to inform health care professionals and strategic partners of ways in which barriers can be eliminated and establishment and sustainability of hospices in developing countries may be achieved. Given the complexity of this problem, I used a phenomenological approach to interview/explore the professional knowledge of hospice experts in designing a culturally sensitive hospice model tailored to the diverse needs of citizens of Belize.

Terminally ill patients have unique needs when faced with EOL decisions. What matters most to the patients is trusting the doctors who are caring for them (Cook & Rocker, 2014). They must know that they would not be kept alive on life support when they have little or no chance of recovery. Most importantly, the doctors must provide honest communication with the patients regarding their disease (Cook & Rocker, 2014).

To this end, uniformity is needed in determining and understanding the stage of life referred to as end of life. This is important in order for policies and systems of care to be understood and implemented globally. Having a common language and approach to EOL care supports and facilitates the understanding of hospice care globally (Higginson et al., 2013). With diverse attitudes toward death and dying, understanding the context in which a hospice is being established is critical in order to effectively meet the needs of this population (Fraser et al., 2017). Some of the major challenges of establishing hospice care in developing countries include the availability of opioid medication, capacity building, and human resources reflecting a critical mass (Fraser et al., 2017).

Summary and Conclusion

The major findings in this research include a better understanding of caregiver needs as well as ways to support their terminally ill family member. Lack of resources, such as supplies; the financial support needed to provide these needs to the patients; the lack of training in how to effectively care for terminally ill patients with confidence; and the importance of cultural understanding within the family system in a manner that it positively affects the extended family to unite and support each other during the EOL process were important knowledge gained. The establishment of hospice policies is in its infancy in Belize. Thus, this study may be used to better understand how to develop a culturally sensitive hospice movement in the Garifuna community. Such policies can serve as a model for exploring comprehensive and inclusive EOL care policies among other ethnic groups in Belize. The findings in this study emphasized the caregivers' commitment to caring for the patient, even if it means doing so alone. This sacrificial

approach is dictated by the caregivers' cultural understanding of the functionality of the family system within the Garifuna community. Therefore, health policies within the Garifuna community and the strong emphasis on caring for each other as a part of the Garifuna worldview can be used to improve care both locally and nationally. Harmony between the individual and the community and the environment is the cornerstone of Garifuna spirituality. The belief that achieving good in this world, whether collectively or individually, can only be accomplished if one maintains harmony. Should a disruption of the environment occur whereby the physical, social and spiritual are disrupted, the potential for evil in many forms can impact all involved. Conversely, if harmony is maintained, all will be rewarded with undisturbed peace or harmony.

The guiding principle of the Garifuna existence is *au bun, amürü nu* (I for you and you for me). The worldview is the central concept in Garifuna cosmology and spirituality. Not surprisingly, it is also the guiding principle of Garifunaduáü (being Garifuna) and the means by which harmony is maintained so all can be well. *Au bun, amürü nu* represents both the individual and collective worldview working in tandem. When individuals behave in a manner that is acceptable with the collective, such actions are rewarded with good fortune. It is believed that the environment reciprocates with in kind.

Looking at the family unit for example, if the relatives take care of their elders in their transition to *seiri*, they will maintain harmony in the family unit. The findings revealed a threat to Garifunaduáü. The fact that 14 of the 17 participants expressed the need for family members to support and get involved rather than leaving the burden on

one individual poses a threat to harmony in the community. Additionally, the Garifuna believe that they hold in trust the responsibility to harmony for future generations as was done for them. It is believed that failure to maintain harmony brings about misfortune in many forms. It is the responsibility of the individual, the community, and the nation to do what is right and just to maintain harmony.

Based on the findings in my study, another threat to Garifunaduáü is the lack of education and training pertaining to Garifuna spirituality. Of the 17 participants, 14 stated that no cultural beliefs would prevent them from leaving their ill family members with others. While it is generally acceptable to leave their family members in the care of non family members, the fact that these participants did not express awareness of the central concept of Garifuna spirituality, *au bun, amürü nu*, demonstrates a departure from the central belief system of the Garifuna worldview. They no longer see or were educated about the individual and communal responsibility or obligation to care for one's own, and leaving the patient with others is a threat to the central concept of Garifuna spirituality. Conversely, this lack of knowledge explains Participant 5's explanation of the importance of maintaining harmony and ruling out any causes that could be attributed to the individual's responsibility to maintain harmony before turning to medical explanation for one's ailment.

The findings and my understanding of the Garifuna culture suggested significant components of the Garifuna culture are intact, but there are threats to the Garifunaduáü. These identified threats can be attributed to the disconnect within the family unit and negligence in supporting the family unit in caring for the terminally ill family member.

The disruption of harmony due to the overwhelming burden on one individual providing care rather than communities uniting to support each other. Additionally, according to the Garifuna culture, music plays a vital role in the Garifuna understanding of death, life, and life transitions (Cayetano,1994). Of the 17 participants, only three participant referenced music or dance as a vital component to comfort, healing, or transition from this life.

Family caregivers did not express an aversion to utilizing medical care; instead, they expressed that convenient medical care would be of great support to the patient and the caregivers. This, then, provides some insight into the comfort level of the caregivers in seeking assistance and utilizing external medical support. Given this history of medical service use, one option for leveraging resources could include integrating hospice into the service delivery system with the health care system in Belize or through partnerships with independent organizations or NGOs committed to providing hospice services (Lynch et al, 2013). The Garifuna family caregiver needs and concerns regarding using hospice services support the WHO's advocacy for the inclusion of hospice services within the health care delivery system (Lynch et al, 2013). The three primary needs outlined by the participants included finances, training, and education and nutrition. Of the three, two were listed by the WHO as requirements for the implementation of hospice care and for integrating hospice services into a health care service delivery system. This would serve to move Belize from Level 2 and 3 on the Global Hospice map into a category offering advanced services within a service delivery system (Lynch et al, 2013).

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Appendix A: Interview Questions

Interview Introduction

The purpose of this interview is to gain knowledge about the needs of individuals who care for their terminally ill Garifuna family members. To learn from you about how and when support is needed most, as well as what needs (are) or (would have been) most important in supporting you and the patient. I will ask you some questions that will help me to better understand family caregivers' needs.

To guide the research and elicit the most detailed responses, I will ask each participant the following questions:

Interview Questions

1. What is your name?
2. What is your gender?
3. How old are you?
4. Where do you live?
5. What is/was the ethnicity of the patient you cared for?
6. What is your ethnicity?
7. How long did you care for your relative?
8. How are you related to the relative that you cared for?
9. What did you do for your *relative* as a daily routine?
10. Did you receive any training by anyone to know what to expect?
11. When caring for your *_insert relationship of relative here-* What would have been most helpful to you in supporting him/her?

12. What did you need the most during the time you took care of *insert name of relative here*-?
13. What recommendations or advice would you offer to other relatives who are not involved during the EOL care process?
14. What would have been most helpful to you during the time you cared for *insert name of relative here*?
15. How do you address your own needs when caring for others facing end-of-life decisions?
16. If you could have left your (*Insert relationship to patient here*) in a place for a few hours with people who would care for *him/her* while you take/took a few hours rest, would you have done it? Are there cultural beliefs that would support this or prevent you from doing this?
17. If you had a place where you could go and be a part of a caregiving team that would be able to assist you with your relative and support you through this process would you have done it? Why or why not?
18. What are some unique needs that should be considered when caring for a terminally ill Garifuna patient?
19. If you were asked to describe a program to support people at the end of life, what services would you recommend based on the needs of caring for a Garifuna patient, as well as your own needs as a caregiver?

20. What recommendations would you make to anyone seeking to support individuals and families caring for terminally ill family members in Belize?
Why?

Appendix B: Demographic Information Table

Table D1

Demographic Characteristics of the Sample

Participant number	Gender	Age group
1	Male	45-50
2	Female	65-70
3	Female	60-65
4	Male	65-70
5	Male	55-60
6	Female	75-80
7	Female	45-50
8	Male	35-40
9	Female	50-55
10	Female	40-45
11	Female	55-60
12	Male	50-55
13	Female	50-55
15	Female	55-60
16	Female	65-70
17	Male	70-75
18	Male	55-60

Note. The ethnicity of all participants and patients was Garifuna.