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Kelley Obringer

Illinois State University, kobringer@cn.edu

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AFRICAN AMERICAN FAMILY MEMBERS' NEEDS AND EXPERIENCES DURING A
LOVED ONE'S END-OF-LIFE

KELLEY OBRINGER

65 Pages

This study aimed to explore African American family members' needs and experiences during their loved one's end-of-life. In Chapter 1, a literature review was conducted to review the current state of the literature regarding African American family members' needs and experiences during their loved one's end-of-life. Chapter 2 includes a qualitative exploratory study of African American family members' needs and experiences during their loved one's end-of-life. The study sample consisted of family members of African Americans being cared for through services provided by an outpatient palliative care facility in the Southeastern United States. Family members answered five open-ended interview questions via a telephone interview. Inclusion criteria were participants with a significant relationship with a patient at the end of life, including parents, grandson/granddaughter, siblings, children, spouse, or other family relationships, were African American, and were 18 years or older. Four themes emerged from participant responses: Reliance on God, poor communication regarding their loved one's health, wanting more time and having emotional reactions. Underlying subthemes were identified within each section. Chapter 3 includes a review of policy perspectives and initiatives.

KEYWORDS: African American; Qualitative research; The Palliative Care and Hospice Training Act; Family members; Caregiver; End-of-life.

AFRICAN AMERICAN FAMILY MEMBERS' NEEDS AND EXPERIENCES
DURING A LOVED ONE'S END-OF-LIFE

KELLEY OBRINGER

A Dissertation Submitted in Partial
Fulfillment of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

Mennonite College of Nursing

ILLINOIS STATE UNIVERSITY

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AFRICAN AMERICAN FAMILY MEMBERS' NEEDS AND EXPERIENCES
DURING A LOVED ONE'S END-OF-LIFE

KELLEY OBRINGER

COMMITTEE MEMBERS:

Kim S. Astroth, Chair

Wendy Woith

Sheryl Jenkins

Charlene Aaron

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CHAPTER I: AN INTEGRATIVE REVIEW OF THE LITERATURE: AFRICAN AMERICAN FAMILY MEMBERS' EXPERIENCES DURING THEIR LOVED ONE'S END-OF-LIFE

Abstract

Objective: To review the current literature regarding African American family members' experiences during their loved one's end-of-life.

Data Source: CINAHL Complete, PubMed, PsychInfo, and HealthSource were searched using the keyword combination of (a) African Americans or black Americans or blacks, and (b) family members or relative or carers or caregivers, and (c) end-of-life or palliative care or death or dying or terminally ill, and (d) experiences or perceptions or attitudes or views or feelings or qualitative or perspective.

Study Selection: The searches resulted in 164 articles identified. Upon further review, 149 were excluded, resulting in 15 articles retrieved meeting the inclusion criteria.

Data Extraction: The integrative method framework of Whittmore and Knafls was implemented. The articles chosen for inclusion were reviewed and organized using the Matrix Method. The Johns Hopkins Nursing Evidence-Based Practice Level and Quality Guide was used to assess the level and quality of evidence.

Results: Five major themes were identified: Lack of knowledge, spirituality, caregiver burden, enrollment in end-of-life services, and community involvement.

Conclusion: Methods to assess spiritual needs are essential in order to meet family members' needs during their loved one's end-of-life experience. Healthcare professionals need to be aware of how to address the lack of knowledge of African American family members caring for their loved ones, spirituality, and caregiver burden.

Introduction

The National Institutes of Aging (NIA, 2021) defines end-of-life care as the support and medical attention given during the time surrounding death. It is essential to consider cultural beliefs that may impact care during end-of-life. According to the Agency for Healthcare Research and Quality (2016), African Americans receive less preventive care and have worse access to care. Decreased access to healthcare services and less healthcare spending may also influence care decisions that may impact end-of-life care enrollment (Walkey et al., 2017).

Research has been conducted regarding improving end-of-life care for diverse cultures (Cain et al., 2018; Nunez et al., 2017; Song et al., 2016; Trong et al., 2014). Consideration of culture is crucial to competent care for African Americans during end-of-life since it can facilitate communication and allow healthcare professionals to better understand their family member's needs (Wicher & Meeker, 2012). African American cultural considerations include the importance of family decision-making, spiritual beliefs, and a decrease in advance directive completion because of mistrust of the health system (Collins et al., 2018). Song and colleagues (2016) reported providing interventions attempting to meet African American patients' goals of care resulted in a decrease in depressive symptoms during their end-of-life. However, few studies explored identified African American family members' needs during their loved one's end-of-life.

The aims of this integrative literature review are to explore African American families' experiences and identify their needs during their loved one's end-of-life, and to identify methods healthcare professionals may use to improve end-of-life care for the loved ones of African American families by considering family needs and how to meet them.

Methods

Whittemore and Knafl's (2005) approach was implemented for this integrative review. Whittemore and Knafl's five-stage method of problem identification, literature search, data evaluation, data analysis, and presentation was implemented to ensure a thorough approach to the review.

Data Sources

A review of the literature was conducted using Public Medline (PubMed), Cumulative Index of Nursing and Allied Health Literature (CINAHL) Complete, PsychInfo, and Healthsource databases utilizing the keyword combination of (a) African Americans or Black Americans or Blacks, and (b) family members or relative or carers or caregivers, and (c) end-of-life or palliative care or death or dying or terminally ill, and (d) experiences or perceptions or attitudes or views or feelings or qualitative or perspective. The inclusion criteria were peer-reviewed studies published from 2012 to 2022, reported in English, and performed in the United States. The included literature was relevant to adult African American family members' or family caregivers' experiences during their loved one's end-of-life care. Excluded criteria were studies that focused on pediatrics.

The combined searches resulted in 166 research articles. Two studies were removed by duplication before the articles were screened. Upon reviewing the titles and abstracts of the articles, 149 studies were removed as they did not meet the inclusion criteria. Fifteen studies were retained and part of the literature review. Figure 1 illustrates the literature search and review process. Fifteen studies were retained and part of the literature review. Figure 1 illustrates the literature search and review process.

Data Extraction and Quality Appraisal

Data were extracted and organized for the literature review using Garrard's (2017) Matrix Method (see Table 1). In the matrix, a collection of key themes from the literature around the concepts of African American family members' experiences during their loved one's end-of-life were condensed and organized in an inductive manner. This allowed for a clear and concise format for the data to be reported in a straightforward manner, and according to the relevance of the literature. The qualitative studies were analyzed using the content analysis approach developed by Miles and colleagues (2014).

The quality and level of evidence for each study were evaluated by using the Johns Hopkins Research Appraisal (JHNEBP) Model (Dang & Dearholt, 2018). This tool provided a guide to critically appraise the literature and label the evidence and quality of the research (Dang & Dearholt, 2018). The JHNEBP uses a quality scale employing an ABC scoring system, with A representing "high", B representing "good", and C representing "low" quality of evidence (Dang & Dearholt, 2018). The studies were ranked from levels 1 to 3. Level 1 studies included randomized controlled experimental studies, while Level 2 included quasi-experimental studies containing an independent variable with or without a control group and without any randomization of participants to treatment, and Level 3 included non-experimental descriptive, comparative, qualitative, and correlational quantitative designs (Dang & Dearholt, 2018).

Results

Of the 15 selected studies, five were quantitative and employed cross-sectional (Ezenwa et al., 2015; Pettigrew et al., 2020), correlational (Powe et al., 2013), and pre-posttest (Bonner et al., 2014) designs and one was a secondary analysis from a randomized controlled trial (Starr et al., 2022). The remaining 10 studies were qualitative and used a descriptive design (Bialong &

Coke; 2012; Delgado-Guay et al., 2013; Ejem et al., 2021; Hart et al.,2022; Iyer et al., 2019 Moss et al.,2018; Peterson et al., 2018; Reese et al.,2014; Rhodes et al., 2016; Siler et al., 2021). There was a total of 2,086 participants in the 15 studies; sample sizes ranged from six to 50 in the qualitative studies and from 68 to 722 in the quantitative studies. Of all the studies, samples in six of the studies were not exclusively comprised of African Americans (Bialong & Coke, 2012; Delgado-Guay et al., 2013; Iyer et al., 2019; Peterson et al., 2020; Pettigrew et al., 2020; Starr et al., 2022), Samples were mixed with patients and caregivers, with one studies sample including the health care team (Rhodes et al., 2016), and three studies samples were caregivers of loved ones with dementia (Bonner et al., 2014; Hart et al., 2022; Moss et al., 2018).

Themes from the studies were identified. First, the lack of knowledge expressed by family members or family caregivers about their loved one's status during their end-of-life led to family dissatisfaction, anxiety, and depressive symptoms. Second, spirituality was a common theme throughout many of the studies and helped African American families cope with their loved one's illness. Studies reported the importance of spirituality and how it relates to end-of-life experiences with loved ones. Other themes identified from the literature included caregiver burden, end-of-life care services enrollment, and community involvement. Family members experienced caregiver burden when unsure of how to properly care for their loved one. End-of-life services enrollment is impacted by African American mistrust of the healthcare system and knowledge of end-of-life care services. The success of community involvement can be impacted by influential community members, such as pastors, who serve as gatekeepers.

Lack of Knowledge

Five studies identified lack of knowledge as an issue. Iyer and colleagues (2019) reported a lack of knowledge by a mixed racial sample of patients and caregivers concerning end-of-life

care options such as palliative care. One mixed-racial study (Bialong & Coke, 2012) and three others were related to African American family caregivers' lack of knowledge during their loved one's end-of-life experience. This knowledge deficit focused on their loved one's disease and the end-of-life care options available (Ezenwa et al., 2016; Hart et al., 2022) as well as end-of-life terminology specifically pertaining to advance directives (Moss et al., 2018). Lack of knowledge during end-of-life care may impact the ability to trust healthcare professionals. Participants reported feeling unprepared if their loved one's medical condition became worse, leading to mistrust in the system (Ezenwa et al., 2016; Hart et al., 2022).

Family caregivers often experienced a lack of knowledge needed to provide adequate care for their loved one. Iyer and colleagues (2019) indicated that knowledge to understand the illness and disease trajectory were important during end-of-life care. Bialong and Coke (2012) reported family caregivers need to receive more education on caregiver training and end-of-life care. Ezenwa and colleagues (2016) found that African American caregivers reported a lack of knowledge regarding their loved one's healthcare needs. Hart and colleagues (2022) also described gaps in knowledge of African American family members to adequately make important decisions regarding their loved one's care.

Spirituality

Five studies reported the significance of spirituality for family caregiver's during their loved one's end-of-life experience (Bialong & Coke, 2012; Delgado-Guay et al., 2013; Moss et al., 2018; Pettigrew et al., 2020; Siler et al., 2021), with one reporting the importance of spirituality for both African American family caregivers and their loved ones (Siler et al., 2021). In a study by Bialong and Coke (2012), caregiver burden was alleviated in family caregivers

because their strong spirituality, allowed the caregivers to better cope during their loved one's end-of life-experience.

Spirituality was a factor in overcoming fears for some family members. Family members rely on this spirituality during their loved one's end-of-life experience because it provided comfort, a sense of the meaning of life, and a coping mechanism (Delgado-Guay et al., 2013; Siler et al., 2021). During their loved one's end-of-life experience, African American family members may also rely on the church community for spiritual support (Siler et al., 2021). End-of-life decisions are often made by African American family members, and they often rely on spirituality during the decision-making process (Moss et al., 2018).

Caregiver Burden

Four studies discuss caregiver burden during the end-of-life experience (Bialong & Coke, 2012; Ejem et al., 2018; Powe et al., 2013; Starr et al., 2022). Caregiver burden is the psychosocial and physical reaction to the demands placed on the caregiver (Given & Given, 1991). Caregiver burden was found to be increased when caregivers needed more time providing care to their loved one, expressing time constraints (Bialong & Coke, 2012). Ejem and colleagues (2018) found that African American family caregivers experience caregiver burden while their loved ones experienced depressive symptoms. Starr and colleagues (2022) reported both Caucasian and African American family caregivers experience similarly high levels of caregiver burden during their loved one's end-of-life when unsure of how to care for their loved one. Furthermore, Powe and colleagues (2013) reported a strong relationship between caregiver strain or burden and decreased quality of life for the African American caregiver, including decreased mental, physical, and social health.

Enrollment in End-of-Life Services

Three studies report on the enrollment of African Americans in end-of-life care services and indicated a need for increased communication and education about these services (Bonner et al., 2014; Iyer et al., 2019; Reese et al., 2014). African American family caregivers reported they are less likely to hear about end-of-life care services such as palliative care and advanced directives (Bonner et al., 2014). A third study suggested there is a need for increased communication among healthcare professionals about end-of-life care services (Iyer et al., 2019).

In addition, in a mixed sample, patients and their family caregivers reported a need for more education about end-of-life services such as palliative care and prefer having the option for palliative care enrollment earlier in the disease trajectory (Iyer et al., 2019). Similarly, African American patients recommended more education about enrollment in end-of-life care services with the education geared to admission requirements and the referral process. (Reese et al., 2014). Reese and colleagues (2014) further reported that African Americans enrolled in end-of-life services compared to those not enrolled had more positive healthcare experiences; most of those not enrolled preferred the services after learning about them.

Community Involvement

Three studies discuss the importance for community involvement (Bonner et al., 2014; Reese et al., 2014; Siler et al., 2021). Reese and colleagues (2014) described how African American patients' and family members' lack of knowledge about end-of-life services can be improved through education provided through community outreach. Pastors may be well-equipped to serve as the liaison and build communication between end-of-life healthcare professionals and African American patients and family members. Bonner and colleagues (2014) advocated for community-based treatment plans for African American caregivers; treatment

plans were successful because family caregivers expressed comfort in their environment and had the trust they needed to make end-of-life decisions. Siler and colleagues (2021) reported the importance of the African American church community and the need for community partnership between faith-based organizations and end-of-life services.

Implications

This literature review focuses on specific themes of lack of knowledge, spirituality, caregiver burden, enrollment in end-of-life services, and community involvement. The literature has suggested African American family caregivers may be unaware of how to properly care for their loved ones during end-of-life (Ezenwa et al., 2016; Hart et al., 2022). Although the literature clearly reports caregivers lack the knowledge to care for their loved ones, it does not report what specific knowledge lacking. Nor does the literature report specific interventions healthcare professionals can do to educate caregivers. African American family members often rely on their spirituality during their loved one's end-of-life experience. However, it is uncertain how healthcare professionals can better meet family member's spiritual needs (Bialong & Coke, 2012; Delgado-Guay et al., 2013; Moss et al., 2018; Pettigrew et al., 2020; Siler et al., 2021).

Caregiver burden may occur when caregivers are trying to meet their own needs and the needs of their loved ones (Bialong & Coke, 2012; Ejem et al., 2018; Powe et al., 2013; Starr et al., 2022). Caregivers express a need for more assistance from healthcare professionals. However, there is a gap in the literature regarding interventions healthcare professionals can implement to better meet African American family needs in order to prevent caregiver burden.

Historically, African American family members and their loved ones are hesitant to enroll in end-of-life care services because of mistrust in the healthcare system (Iyer et al., 2019; Reese et al., 2014). The literature reports the importance of community involvement to build

trust between caregivers and healthcare professionals about end-of-life services but does not clearly describe an increase in end-of-life care enrollment once community involvement is implemented.

Conclusion

It becomes evident from the literature that African Americans rely on their family for help in making important decisions during end-of-life care. Since the family is an integral part of this care, a change in how healthcare is delivered is warranted and the priority is family-centered care. More research is needed to identify family members' specific lack of knowledge about caring for their loved ones and meeting their knowledge gaps in a culturally appropriate, individualized manner. Family members identify spirituality as an important component during their loved one's end of life; however, healthcare professionals may be uncertain about what spirituality is for them, and how to advocate for loved one's and meet their spiritual needs. Family members and health care professionals need to be aware of how to address such matters as caregiver burden and the relationship of caregiver burden to lack of knowledge and spirituality. Lastly, enhanced educational policies and guidelines can be explored and implemented across the healthcare spectrum to improve communication given to family members during their loved one's end-of-life. By examining measures taken to promote quality care during end-of-life, healthcare professionals can continue to examine family members' needs to promote holistic end-of-life care.

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Table I.*Literature Review Matrix*

Reference	Purpose	Sample	Design	Instrument / Quality Rating	Results / Key Findings
Bialong & Coke (2012)	Evaluate CG stress.	(n=1) AA CG, (n=8) Caucasian CG	Qualitative Descriptive	Semi-structured interview Level 3	CGs had a need for more support. Faith alleviated caregiver burden. Findings support the need for more education and support for family members during their loved one's end-of-life. Limitations: Only one AA CG and small sample size.
Bonner et al., (2014)	Implemented advance care treatment plan and a group-based education to AA dementia CGs	(n=68) AA CG of adults with dementia	Pilot Study Pre-post test	ACT and CG Education Intervention Level 3	ACT Plan is feasible. ACT Plan improved knowledge about Advanced-care planning. Further studies that provide education in the community is recommended. Limitations: Single-center design. Recommend randomized selection.

“(Table Continues)”

Delgado-Guay et al., (2013)	Spirituality of CG of palliative care patients	White CGs (n = 43) AA CGs (n = 2)	Qualitative Descriptive	Semi-Structured Interview Level 3	Limitations: small AA sample size
Ejem et al., (2021)	AA patient’s preferences regarding religion/spirituality and AA family CGs’ preferences regarding religion/spirituality	AA Patients (n = 15) AA Family CGs(n = 14)	Semi-Structured Qualitative Descriptive	Level 3	Higher spiritual pain more distress, and less quality of life. Limitations: Small sample size.
Ezenwa et al., (2016)	CGs’ perspectives regarding their loved one’s oral comfort and any health changes	AA CG (n=8)	Cross-Sectional Quantitative	Oral Problems Scale Level 3	CGs asked about oral health infrequently of their loved one with cancer during end-of-life care indicating a knowledge gap.: 51% of CGs evaluated oral health weekly. Limitations: Single-center design.
Hart et al., (2022)	End-of-life decision making of AA caregivers of patients with advanced dementia	AA CG (n=8)	Semi-Structured Qualitative Descriptive	Level 3	AA caregivers lacked knowledge of disease prognosis and treatment options. Limitations: Probing question may lead participants to answer a certain way. Small sample size.

“(Table Continued)”

Iyer et al., (2019)	Identify patients and family CGs early palliative care needs across stages of COPD severity.	(n=10) Patients, 50% AA (n=10) Family Members. 40% AA	Qualitative Descriptive	Semi-Structured Interview Level 3	Patients reported poor quality of life, moderate-severe anxiety and social isolation. Family and patients reported need for more knowledge about prognosis. Limitations: Small sample and single-center design.
Moss et al., (2018)	Examine end-of-life decision making among CGs with dementia	AA CG (n=18)	Qualitative Descriptive	Semi-Structured Interview Level 3	End-of-life decision was a family decision based on past experiences and included reliance on resources such as spirituality. Limitations: Small sample.
Peterson et al., (2018)	Attitudes and experiences about end-of-life discussions and preferences including the role of the provider in the discussions	AA family members (n = 10); Caucasian family members (n = 20); Hispanic family members (n = 6)	Qualitative Descriptive	Semi-Structured Interview Level 3	To understand the experiences and attitudes of those who do not or do engage in end-of-life discussions. Limitations: Small AA sample.

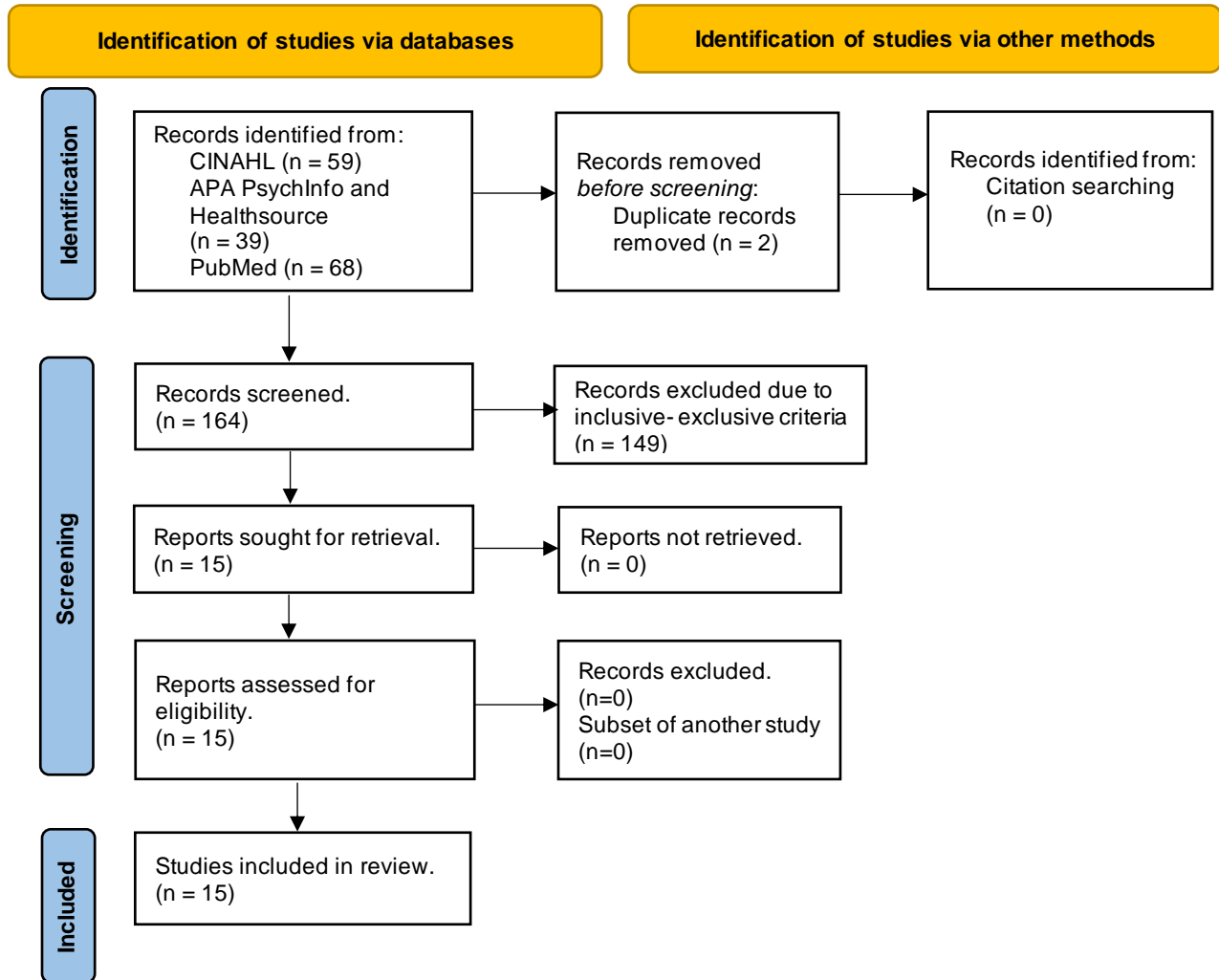
“(Table Continues)”

Pettigrew et al., (2020)	Factors that influence decision making, preferences, and their plans related to advance care planning	Racially diverse caregivers of dementia patients across the U.S.: Caucasian (n = 375), AA (n = 42)	Cross-Sectional Quantitative	Survey on Care Planning for Individuals with Dementia Level 3	AA CGs had a greater influence of spirituality on the disease and treatment plan. AA CGs had less knowledge of loved one’s disease process compared to Caucasians. Limitations: Small AA sample.
Powe et al., (2013)	Examine AA CG’s experience	AA caregivers (n = 136)	Correlational/Quantitative	CG Strain Index, Medical Outcome Survey Short Form 36, Symptom Distress Scale, and demographic questionnaire Level 3	Strong relationship between CG strain, symptom distress of patient, and patient quality of life
Reese et al., (2014)	Satisfaction with end-of-life care among AA caregivers in rural setting	AA CG (n=9) within hospice; (n=10) AA CG outside hospice	Descriptive Qualitative	Semi-Structured Interview Level 3	Better caregiver experience for those enrolled in hospice than non-hospice. Limitations: small sample.
Rhodes et al., (2016)	Perceptions of end-of-life care with a diverse sample	MD (n=1), M (n=1),	Descriptive Qualitative	Semi-Structured; Focus	Different perspectives and experiences about end-of-life care.

		CG (n=2), patient (n=1); all AA		Groups Level 3	Limitations: Small sample.
Siler et al., (2021)	Spirituality influences chronic illness experiences	AA adults with chronic health conditions (n=45); and their family caregivers during end-of-life (n=5)	Descriptive Qualitative	Semi-Structured; Focus Groups Level 3	Reliance on church community, spirituality. Mistrust toward healthcare system. Limitations: Limited caregivers and limited religiosity as only Christian
Starr et al., (2022)	Compare anxiety, depression, quality of life, caregiver burden, and perceptions of caregiver-centered end-of-life communication between AA and Caucasian family caregivers	AA and Caucasian an end-of-life care family members (n=722)	Quantitative Secondary analysis from two randomized control trials.	Generalized anxiety disorder, patient health questionnaire, caregiver quality of life index revised, Zarit-burden interview, and caregiver centered communication questionnaire. Level 3	AA family caregivers experience similarly high levels of anxiety, depression, burden, and perceptions of hospice communication

Note. AA=African American
MD=Medical Doctor
CG=Caregiver
M=Minister

Figure 1. *Flow Diagram of Literature Search Strategy*



Note. Adapted from "The PRISMA 2020 statement: An updated guideline for reporting systematic reviews," by M. J. Page, J. E. McKenzie, P. M. Bossuyt, I. Boutron, T. C., Hoffmann, C. D. Mulrow, I. Shamseer, J. M. Tetzlaff, E. A. Akl, S. E. Brennan, R. Chou, J. Glanville, J. M. Grimshaw, A. Hróbjartsson, M. M. Lalu, T. Li, E. W. Loder, E. Mayo-Wilson, S. McDonald, . . . D. Moher. 2021, *BMJ*, 372, n71. <https://doi.org/10.1136/bmj.n71>. Copyright 2021 by BMJ.

CHAPTER II: AFRICAN AMERICAN FAMILY MEMBERS' NEEDS AND EXPERIENCES DURING A LOVED ONE'S END-OF-LIFE

Abstract

African Americans prefer involving family members during end-of-life decision making, but family members' needs may be misunderstood or overlooked. The purpose of this qualitative study was to understand the needs and experiences of African American family members during their loved one's end of life care. The study sample consisted of 14 family members of African Americans being cared for through services provided by an outpatient palliative care facility in the Southeastern United States. Family members answered five open-ended interview questions via a telephone interview. Four themes emerged from participant responses: Reliance on God, poor communication regarding their loved one's health, wanting more time, and having emotional reactions. Underlying subthemes were identified within each section. Results of this study provide insight into African American family members' needs and experiences while caring for a loved one at end-of-life. Implications for future work include policy development and evidence-based guidelines to meet family members' needs.

Introduction

Culturally sensitive end-of-life care is one of the national priorities, according to the National Consensus Project for Quality Palliative Care Guidelines (Ferrell et al., 2018). Studies have shown end-of-life needs may differ by culture (O'Mara & Zborovskaya, 2016; Rizzuto & Aldridge, 2018). To provide the best care during the end-of-life transition, it is necessary to understand the needs and experiences of diverse populations. One such population is African American. The 2021 United States Census reported an increase in the number of African Americans, indicating a growth of 7% from 2010 to 2021 (United States Census Bureau, 2021). In addition, there were 49.6 million African Americans, which comprised 15% of the total population (United State Census Bureau, 2021). Furthermore, 17% of this population of African Americans are 65 years or older (United State Census Bureau, 2021).

According to the Agency for Healthcare Research and Quality (2016), African Americans receive less preventive care and have worse access to care. Decreased access to healthcare services and less healthcare spending may also influence end-of-life decisions (Walkey et al., 2017). Medicare expenses tend to be lower for Caucasians compared to African Americans during end-of-life because Caucasians traditionally discuss end-of-life planning in more detail (Byhoff et al., 2016). In addition, Caucasians have a higher rate of hospice enrollment compared to other cultures (Rizzuto & Aldridge, 2019). In contrast to Caucasians, African Americans are less likely to complete advance directives (Huang et al., 2016; Koss & Baker, 2016), and tend to believe in prolonging life (Sanders et al., 2019). Lack of trust in those providing end-of-life care influences African American end-of-life care decisions (Laury et al., 2019).

African Americans view spirituality as a method for coping with illness and death, and value spirituality as a significant component of end-of-life care (Hamilton et al., 2017). African

Americans support prolonging life because of their belief that God should determine when one's life ends (Johnson et al., 2016; Robinson, 2016). Family is an important consideration when caring for African Americans, as there is evidence they often rely on family during end-of-life (Orlovic et al., 2019). These cultural beliefs and practices may impact end-of-life care and end-of-life decisions.

African American culture values family and considers them an integral component when making decisions in contrast to relying only on documented individual patient's wishes (McDonnell & Idler, 2020). Therefore, African Americans prefer involving family members during end-of-life decision making. Despite African Americans' reported viewpoint about prolonging life, and their reliance on spirituality and family involvement, there is little research regarding the life experiences and needs of African American family members during a loved one's end-of-life experience and how spiritual beliefs impact family members' experiences.

Meeting families' spiritual needs may improve their quality of life during their loved one's end-of-life care (O'Brien et al., 2019), suggesting an opportunity for nurses to provide holistic end-of-life care, while incorporating spiritual care (Batstone et al., 2020). To provide the best care during the end-of-life transition, it is necessary to understand the needs and experiences of African American family members during their loved one's end of life.

Review of the Literature

This literature review will first describe palliative care as it is a component of end-of-life care. Then research related to African American culture and spirituality as related to end-of-life care will be addressed. The last component will be about caregiver burden. Caregiver burden is often reported in research during end-of-life situations (Janze et al., 2014). Caregiver burden is the level of multifaceted strain perceived by the caregiver from caring for a family member

and/or loved one over time (Zhu et al., 2020). It is defined as the psychosocial and physical reaction to the demands placed on the caregiver (Given & Given, 1991).

Palliative Care

Palliative care is delivered in all healthcare settings, including home health, with outcomes addressing care that is timely, patient-family centered, accessible, and evidence-based (Hughes & Smith, 2014). The goal of palliative care is to promote quality of life for patients with chronic or life-threatening illnesses by relieving or preventing pain and suffering (Hughes & Smith, 2014). Palliative care addresses physical, psychosocial, spiritual, cultural, and ethical aspects of care delivery (Hughes & Smith, 2014). Not only does palliative care address the needs of the patient, but it also includes equally important factors such as consideration of family preferences, values, beliefs, and spiritual needs (Hughes & Smith, 2014).

End-of-life care is a component of palliative care, which focuses on the last days and hours of life (Roth & Canedo, 2019). Hospice is one component of palliative care, but patients who qualify for hospice must have a prognosis of death within six months. Although the United States healthcare system strongly emphasizes medical intervention and many seriously ill patients pursue these options, others prefer palliative care and sometimes choose hospice services. Hospice provides care to patients and their families with an emphasis on comfort while providing psychological, spiritual, and social support (Roth & Conedo, 2019).

Culture and Family

Previous studies regarding end-of-life care for African Americans considered the responsibility of the family (De Souza et al., 2020). Family is defined as African American patients often rely on trusted family caregivers and clergy to make decisions for them (Gott et al., 2019; Siler et al., 2021; Wiles et al., 2018). These family members or family caregivers often

play a role in end-of-life discussions and decisions (Hovland & Fuller, 2022; Smith-Howell et al., 2016). In the qualitative study by Hoyland and Fuller (2022), family members expressed the importance of being prepared for a loved one's death. Although family is an important component during end-of-life care, it is reported African Americans can be unaware about these types of services (Wicher & Meeker, 2012). Wicher and Meeker (2012) reported differences in preferences for end-of-life care services between White Americans and African Americans, with African Americans reported to be less likely enrolled in end-of-life care services and have advance directives. This may be attributed to lack of knowledge, mistrust toward the health care system, and the importance of spirituality (Rhodes et al., 2015).

Similar to the African American culture, other cultures such as White Americans, favor family-centered care during end-of-life (Starr et al., 2022). Both African American and White American families may suffer from the impact of being closely involved during end-of-life. Starr and colleagues (2022) reported both Caucasian and African American family caregivers experience high levels of anxiety and depression with no racial differences. However, White Americans reported lower quality of life compared to African Americans (Starr et al., 2022). This may be attributed to African American family members' spirituality but may require further research.

Spirituality

Spirituality is defined as the process of finding purpose and meaning by connecting with God or others (Burkhart & Hogan, 2008). African American family caregivers identify spirituality as being helpful in dealing with the stressful aspects of providing care (Wiles, 2021). Spirituality is often a component for caregiver decision making during end-of-life (Moss et al.,

2018), and a coping mechanism during their loved-one's end-of-life (Hamilton et al., 2018; Siler et al., 2022).

African American beliefs often view God as the determining factor for when life should end (Johnson et al., 2016; Johnson et al., 2021). African Americans often have a mistrust in medical intervention during end-of-life; instead, they rely on God's intervention (Catlet & Campbell, 2021). In a study addressing African American's spirituality views during their loved one's end-of-life care, Hamilton and colleagues (2017) reported African American family caregivers attributed their faith in God as a method for getting them through the difficult time of their loved one's illness. Faith in God and mistrust in the health care system affect advance directive completion rates, suggesting that African Americans believe advance planning interferes with God's decisions regarding end-of-life. Moreover, spirituality, is a key component for African American family caregivers when making decisions regarding end-of-life care (Moss et al., 2016).

Caregiver Burden

Caregiver burden is defined as the psychosocial and physical reaction to the demands placed on the caregiver (Given & Given, 1991). Family members may experience caregiver burden, particularly because of the responsibilities they have during their loved one's end-of-life. Anticipatory grief is a component of caregiver burden. Anticipatory grief entails mostly sadness and anger but can include anxiety and difficulty concentrating (Coehlo & Barbosa, 2017). Bialong and Coke (2012) found a relationship between caregiver burden and lack of support caregivers experienced. Lack of support included lack of knowledge about caregiving, and lack of education to adequately care for their loved one. Caregiver burden was noted to increase when family caregivers were employed. In contrast to an increase in caregiver burden, spirituality

provided a method for coping during their loved one's end of life experience (Bialong & Coke, 2012).

Despite reported reliance on spirituality, family involvement, and viewpoints about prolonging life, there is a lack of research regarding the understanding of the life experiences of African American family members during a loved one's end-of-life care experience and how spiritual beliefs impact their experience. The purpose of this study was to understand the experience of the African American family members' during their loved one's end-of-life. The research aims for this study included an exploration of the:

- Experiences of a family member during a loved one's end-of-life, and
- Impact of spirituality on a family member's experience during their loved one's end-of-life.

Methods

Design/Sample/Setting

We conducted a qualitative exploratory study to meet the research specific aims. We received approval from the University's Institutional Review Board and the outpatient facility provided written approval to access potential participants. The Director of Nursing from the outpatient palliative care facility provided the primary investigator with a list of possible participants and their contact information.

The study participants were drawn from a convenience sample of family members of African Americans being cared for through services provided by an outpatient palliative care facility in the Southeastern United States. The outpatient facility uses a multidisciplinary approach to providing end-of-life care, and employs physicians, physician's assistants, nurses, nurse practitioners, a director of nursing, a medical assistant, a social worker, and an

administrative assistant. According to the director of nursing from the outpatient palliative care facility, end-of-life care is provided to an average of 200 people annually, and approximately 11% of these people are African American. People being treated at this outpatient clinic are seen at least monthly.

Inclusion criteria were participants that (1) had a significant relationship to a patient at the end-of-life, including parents, grandson/granddaughter, siblings, adult children, spouse, or other relationship considered as family, (2) were African American, and (3) were 18 years or older. Exclusion criteria were any cognitive inabilities that may affect the ability to effectively communicate and/or understand the interview process. One family member per patient was included in the study. Sixteen individuals were invited to participate; two declined stating they were not interested in being interviewed. The remaining 14 completed the interview process.

Procedure

The primary investigator (PI) interviewed participants via telephone. Prior to the interview, the primary investigator described the study and obtained verbal consent assuring the participants met all inclusion criteria. The demographics and interview tool was designed by the researchers and included demographic questions (See Appendix). The interview was comprised of five broad questions with open ended prompts to elicit participants' descriptions of their experience. To facilitate consistency, the PI conducted all the interviews. The interviews took between 30 and 45 minutes. No names were attached to the data, and pseudonyms were used as identifiers. Participants received a \$25.00 Walmart gift card mailed to their residence after completion of the interview. Member checking was done to enhance credibility (Lincoln & Guba, 1989). Member checking involved asking a few participants to confirm that their interview results adequately represented their experiences. Two participants agreed to be

contacted for a follow-up phone call to ensure their interview responses correctly matched their transcript.

Data Analysis

At the completion of the interviews, tapes and field notes were transcribed by the interviewer. Field notes were used to note ideas, impressions, and thoughts about the interview. Data transcription was compared to the corresponding audiotape. The data were coded through categorization and then evaluated by looking at trends. The trends were then categorized under themes and patterns. Themes were developed by the process of rereading content, comparing content to the literature for similarities, and grouping into themes and subthemes. Data saturation was achieved with 14 participants. Content analysis of themes (Krippendorf, 1980) was employed to allow researchers to analyze data in terms of the meanings and symbolic qualities.

We attempted to limit researcher bias through triangulation (Krippendorf, 1980). Strengthening of the study was assured by member checking and allowing only one family member per patient to be enrolled. Pseudonyms were used in reporting data to protect the identity of the participants. Another method used to strengthen the study was confirmability (Lincoln and Guba, 1985). This was done by keeping notes that were clear from data collection through analysis. Transferability was accomplished to strengthen the study by using thick description (Lincoln and Guba, 1985). This was done by providing adequate details of the collection of data.

Results

Of the 14 participants, 71.43% (n = 10) were spouses, 21.43% (n = 3) were children, and 7.14% (n = 1) was a parent. Of the spouses, most (90%; n = 9) were female. Of the children, 100% were female. The one parent was a female. Most (79%; n = 11) were over 60, with 21% (n

= 3) between 40-60 years of age. Most (92.9%; n = 13) participants indicated being Protestant, while 7.1% (n = 1) reported no religious affiliation.

Four themes emerged from participant responses: Reliance on God, poor communication regarding their loved one's health, wanting more time, and having emotional reactions.

Underlying subthemes were identified within each section.

Reliance on God

Thirteen family members described a theme of Reliance on God. This included underlying subthemes of having prayer and a sense of peace, and God as providing a sense of assurance,

Having Prayer and Sense of Peace

Marcella, a wife, voiced, "I pray every day to God. He gives me peace and somehow, I manage to start new each day." daughter, Ella, expressed, "I pray every day to my God, my savior. He alone gives me peace and comfort through this journey." Mary Anne, a wife voiced, "every single day I am stressed, and I can at times do nothing but pray, rely on God. When I do, I have peace."

Adam voiced, "my wife is much more spiritual than I am, but I do pray. I am still praying that God will heal her and he is the only one that can." A wife Frances, described, "having him so sick is overwhelming, I think ahead as I know he will not be here long. I already feel a loss. I pray, and it is my beliefs in the higher power of God that is getting me and him through this." Violet explained "The only thing that has helped me during this time is my spiritual beliefs. I truly know God is the decision maker. Even with knowing this, each day is difficult. The one thing that I need the most is prayer.... I cannot believe he is so sick at times, and I just pray."

Virginia asserted, “God is the only one getting me through my mother’s illness and the only one giving me strength to function every day. God is my strength and provides peace.” Darin described “when I stumble, God picks me up and through that I have peace.” Adam described, “I have complete and utter peace God’s decision will be what’s best. But this time is difficult to say the least. Again... she is much more spiritual than I am.”

Assurance

Darin, a husband, stated his spirituality as a coping mechanism. “I have more control when I pray, believe in God as the decision maker, and who I can rely on at all times.” The peace was described as assurance. Annetta, a daughter explained, “during daily stressors I try to rely on God. When I do that, I have a deep feeling of peace and assurance.”

Poor Communication

One of the most frequent complaints and a theme described by 10 participants was poor communication about their loved one. Poor communication included the subthemes of not knowing what to expect and barrier to providing best care.

Not Knowing What to Expect

Poor communication in the form of lack of instructions on caregiving from health care professionals resulted in family members believing they were not providing the best care to their loved ones, resulting in the subtheme of not knowing what to expect. Violet noted, “We would just like to know more about what to expect. As his caregiver, often I am not informed about how he is doing is normal or not with his illness. More information during routine visits would be beyond helpful.” Frances voiced, “I often feel uninformed and clueless. Communication is an issue with the nurses and staff.” Lillian said, “Somedays feel like a nightmare. I wish I knew how to care for her more. I wish I knew what to expect regarding her health. It would help, if I

was told what I am doing right or wrong at least when she has her visits at the clinic. It would help if I knew how she truly is doing.”

Barrier to Providing Best Care

Mary Anne noted, “I feel that I do not understand how to take care of my husband correctly. Because of this, I have guilt that I am not doing a good job taking care of him.” Adam asserted his experience during his loved one’s end of life was “... lacking in many areas. I cannot take care of my wife correctly because I do not know how to. At the clinic, I have not received much information.” Another family member, Vestel, described the entire experience as a “roller coaster” of emotions. “I often feel misinformed or really uninformed. I know our days would be a lot easier if we were told at each appointment what to expect. I do not know if he is declining rapidly, as they do not tell me.”

Marcella described lack of information as a barrier to providing best care. “My husband attends the clinic monthly, and sometimes the scheduling for his next appointment is a problem. That’s just one example. I am uninformed with so many things, I think. I worry about taking care of him as I really don’t know if I am doing things right. It would be nice to be told what more I can do for him and what I need to know. I am just trying to get through the day. At times, I cannot sleep well. It can be overwhelming.” One wife, Frances, reported during the interview, “I need more information about how he is doing. He has lost weight and I just want to help. During his visits at the clinic, it seems like the same things are done. Which at times, feels like very little.

Violet voiced, “Any communication I have had lately about my husband from the nurses at the clinic is not enough, I think. I really don’t receive a lot of communication detailing information about taking care of him. Because of this, I am not sure if I am helping him enough.

When I discuss this with family, it makes me anxious. It just doesn't seem right sometimes, and I can be uptight and angry then with family because I don't not have enough information. I need to pray about calming down and talk to the clinic about my concerns."

Time

Time was a theme described by seven participants. Participants reported frustration regarding time constraints either in their lives or pertaining to how time was addressed in healthcare appointment visits for their loved one. Time resulted in the subtheme of limited self-care.

Limited Self-Care

Virginia voiced, "having time for myself just does not happen. I also have little time for other members of the family. My mom requires all of my time and energy. "Sal described "since my wife has been so sick, I rarely have time to finish needed chores around the house and have minimum time for myself. It is exhausting taking care of him. I would not do it any other way, but it is exhausting." Another spouse, Sam, reported, "I rarely have time anymore to attend church services, nor spend time with friends, or even go on a walk alone." Marcella described having no time to take care of grandchildren. "I have absolutely no extra time. I would like to spend time with the grandkids, but my husband requires all my time and energy." Ella noted time constraints regarding her mother's activity of daily living. "My mother is weak, and it takes her a long time to dress and walk in the house. I need to be by her side. I do not have much time to myself."

Mary Anne said "I rarely have time for my own life such as playing cards that I used to enjoy. But it is not just that, I would love to go get a haircut. I cannot, as I do not have much help with my husband." Darin voiced time constraints, but these time concerns focused instead on

attending medical outpatient visits. “The nurses seem to be in such a rush. We drive over an hour for appointments, and I think we spend more time in the car driving than the appointment itself.”

Emotional Reactions

Three participants described having anger and anxiety, although the causes varied and included fear of the unknown and family dynamics.

Fear of the Unknown

One family member, Vestel, explained “I seem to anger more easily. I think it is because of the stress and how I am reacting to my husband’s health”. This same family member also stated “Before my husband’s clinic appointment, I get sometimes so anxious. I am not sure why but think it’s because of the unknown. I fear he is declining rapidly, and it worries me as I cannot do a lot about it.”

Family Dynamics

Doug described getting angry and anxious when handling different family dynamics. He described, “About every time I speak to other family members as well, it seems like a lost cause as we may argue, I become angry, and overall, my heart beats quickly and I sometimes feel like I am not handling anything well. I probably need medication myself.” Annetta explained “My family can be difficult. I do not have much help with my mother. When I speak to my sister about how my mom is doing, it makes me angry at times. I feel like all of the responsibility is on me. I wish I had people to help, but I absolutely hate to ask. No one volunteers, and it is all me.”

Discussion

The main themes for this study were reliance on God, poor communication, time, and emotional reactions. Similar to this study's theme of reliance on God, Hamilton and colleagues (2018) reported African American family member's value and rely on God during end-of-life care. Ejem and colleagues (2021) also reported the importance of spirituality during end-of-life care and suggested healthcare professionals increase communication about African American family member's spiritual needs as it is poorly addressed.

This study reported the need for improved communication, particularly information regarding their loved one. Similarly, Hart and colleagues (2022), reported African American family members may lack knowledge of disease prognosis and options regarding treatment decisions during end-of-life. In addition, Iyer and colleagues (2019) reported family members communicate a need for knowledge about their loved one's illness and prefer implementation of palliative care earlier in the disease trajectory.

In order for there to be caregiver burden, strain needs to be perceived by caregivers. Caregiver burden is reported in this study through participants' description of having time constraints. Time is just one need associated with caregiving. Similar to Lam (2017), our participants reported having a decreased ability to be able to spend time on oneself, or with other family members such as grandchildren. Lam (2017) noted caregivers such as family members may have increased frustration because of such reasons as needing to be off work due to the time commitment of taking care of their loved one. Power et al. (2017) also reported about caregiver burden and found that high burden impacts quality of life.

Emotional reactions such as anger and anxiety were reported in this study. Silva and colleagues (2021) report such emotional reactions such as anger and anxiety are common during

end-of-life care but can be improved with forgiveness. The authors recommend healthcare professionals assess emotional reactions and continue to provide open communication to address needs and the concept of forgiveness.

Limitations

This qualitative study is based on a small convenience sample; therefore, generalizability is limited. The interview format may have made interview participants uncomfortable, limiting verbally expressive responses. The study examines African American family members during their loved one's end-of-life experience and only included African American adults.

Implications/Conclusion

Healthcare professionals have a responsibility to advocate for family needs as they are vulnerable during this time, but there has been limited research to date on effective methods of assessing those needs. One assessment tool that may be implemented to assess family caregiver's needs is the Caregiver Reaction Scale to measure caregiver burden. However, this tool does not address cultural considerations (O'Malley et al., 2019). Healthcare professionals can address caregiver's spiritual needs by initially providing a thorough spiritual assessment, but that is only one component of the assessment. Healthcare professionals have a responsibility to advocate for holistic family needs. In order to fully advocate for African American family members needs during their loved one's end-of-life, it is imperative to be aware of any possible healthcare professional bias about African American enrollment and participation in end-of-life care services. Healthcare providers bias can be communicated in a nonverbal manner, but impact trust between African American patients and family members (Elliott et al., 2016).

In order to appropriately address family caregiver needs in a holistic manner, the physical, social, psychological, spiritual, and cultural are to be considered (Glachen, 2019).

Caregivers lack adequate knowledge about their loved one's disease progression and how to adequately care for their loved one. Healthcare professionals' competency in this area is shown by assessing caregiver's needs and guiding caregivers to the resources they need.

The findings of this research can be used as a basis for the implementation of interventions to further meet the needs of African American family members during end-of-life care for their loved ones. Needed strategies entail raising the priority for family assessment and exploring the complex challenges families experience during their loved one's end-of-life. Further policy development and guidelines to improve end-of-life care is recommended. More research is needed to explore educational strategies and implement education to families and healthcare professionals to improve end-of-life care and expand research.

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Table II.

Interview Questions

1. Tell me about your experience during your loved one's end-of-life.
 2. Tell me about your wants and needs during your loved one's care
 3. Tell me about your stressors during your loved one's end-of-life.
 4. Tell me about what has helped you during your loved one's illness.
 5. Tell me if and how spirituality has impacted your experience during your loved one's end-of-life.
 6. Gender
 7. Age
 8. Relationship to patient:
 - a. Child
 - b. Spouse
 - c. Grandchild
 - d. Sibling
 - e. Parent
 - f. Other: Please specify_____
 9. Religion
-

CHAPTER III: POLICY PERSPECTIVES AND INITIATIVES FOR AFRICAN AMERICAN FAMILY MEMBERS DURING A LOVED ONE'S END OF LIFE

Abstract

End-of-life care is an important topic for healthcare initiatives, including support for programs such as palliative care services. African Americans may benefit from programs such as this and specifically from the implementation of The Palliative Care and Hospice Education and Training Act because African Americans have a lower enrollment in end-of-life care services compared to other racial and ethnic groups (Rhodes et al., 2017). This Act will provide support for end-of-life care services such as palliative care and hospice. With the implementation of this Act, education will be available to patients and family members, and health care providers to facilitate provision of well-trained multidisciplinary teams available to provide end-of-life care to those in need.

Introduction

As the U.S population is aging, older diverse groups are increasing in number. For example, the black or African American population aged 65 and over is projected to increase to 12.1 million by 2060. In 2016, these African Americans aged 65 or older made up 9% of the population. By 2060, the percentage is projected to be 12.8% (Administration for Community Living, 2017). When the number of older adults in a population increases, so does the need for family involvement and caregiving (CDC, 2022). While the need for family support and caregiving is growing, families are having fewer children, and those who serve as caregivers are often employed and have other responsibilities (Caregiving in the US, 2015). Although many family members become involved during end-of-life care, few studies reports on the needs and experiences of family members' during their loved one's end-of-life (Schultz, 2013) and more research is needed to evaluate how assessment of family needs can inform clinical practice, supported by policy (Bloomer et al., 2022).

While some family caregivers do not have a legally defined kinship, it is important to note that to be considered “family” within the context of end-of-life care, one may be a friend or partner who has a significant relationship with and provides assistance to a person with an end stage illness (Keeley, 2017). Family caregivers often have very limited prior exposure to death and dying and do not know what to expect or how to manage and provide necessary care (Hansen, 2017). This lack of experience leaves them unprepared for the loss of their loved one and their role in end-of-life care (De Korte-Verhoef et al., 2014). Caregiving can be emotionally and physically stressful; a decline in the health of caregivers compromises their ability to give adequate care to their loved one (CDC, 2019). Additionally, there is a lack of support in the U.S healthcare system for these family caregivers (Eldercare Workforce Alliance, 2017).

Furthermore, these family members often interact with a wide array of healthcare professionals and may receive different input from many, which may also contribute to the lack of preparedness (Wittenberg et al., 2021).

Despite the integral role of family caregivers, their needs are often ignored in public policy (Scribner et al., 2017). Family caregivers are at greater risk for economic problems because of the hours of care given to family members and the possibility of being unable to work outside the home. These caregivers have limited or no access to paid workplace leave (Saad-Lessler & Bahn, 2017). By meeting their responsibilities toward caring for a loved one, they lose income, consequently reducing their social security and retirement benefits (Family Caregiving, 2016). In addition, there are factors that are perceived to be a strain on caregivers taking care of a family member. Some of these factors include sleep deprivation, disruption of routine schedules, having to change personal plans, demands on time, emotional adjustments, the loved one's upsetting behaviors, changes in activities and lifestyle, and social isolation (Powe et al., 2013).

End-of-life care is progressing to a family-centered care approach. With family-centered care, it is essential for health care professionals to respect the family's values, beliefs, and preferences (National Quality Forum, 2016). Finding methods to support families is a public healthcare need, and interventions to meet a family's needs can be targeted at the individual, organizational, and societal levels (American Public Health Association, 2013).

At the individual level, interventions are directed to the specific family and are targeted to meet their physical and emotional health. Thus, interventions may include holding family meetings that help increase the cohesiveness or support of other family members, having support groups, and providing education specific to the needs of individual families (American Public

Health Association, 2013). At the organizational level, methods to meet a family's needs are tailored to the family group, such as hospice, and include such things as respite programs and employee education (American Public Health Association, 2013). At the societal level, interventions such as The National Family Caregiver Support Program can be implemented. Implementation of such a program is just one example to attempt to meet families' needs. However, healthcare professionals need to be aware of how to address the needs of families during their loved one's end-of-life within a growing, culturally diverse population.

The Institute of Medicine (IOM) provides recommendations for creating change in the models of end-of-life care delivery that focus on improving communication, care planning, professional education, reforming policies and payment systems, and engaging and educating the public about delivery of family-oriented care (Dobbins, 2016). Patients receiving end-of-life care and family members involved with their loved one undergoing this care may experience a fragmented health care system because of the lack of organized care delivery, high rates of preventable hospitalizations, and poorly managed transitions between care settings (Dobbins, 2016). Because medical interventions are stressed within this fragmented healthcare system, there is less social support for family members of those at end-of-life. However, the IOM reiterates that the hospice care approach benefits not only patients, but family members as well because it also provides social, emotional, and spiritual support to patients and family. Sometimes referral to hospice is too late; however, the experiences of patients and family members improve once they collaborate and agree to enroll in hospice (Dobbins, 2016).

The IOM report also elaborates on important end-of-life issues. One such topic within the American health care system is the lack of incentive or reimbursement to health providers to communicate to patients and families regarding end-of-life care decisions (Dobbins, 2016).

Furthermore, the topic of advance directives is not explored, especially with minorities such as African Americans. Another important topic from the IOM report is regarding expertise. There are now two well-established educational programs, the End-of-Life Nursing Education Consortium and the Education in Palliative and End-of-Life Care Program, yet there remains a shortage of hospice and palliative care specialists (Dobbins, 2016).

According to Rees and colleagues (2020), a problem with end-of-life care in the United States is lack of knowledge. Many patients and families do not understand enrollment costs, terms, and eligibility (Trevino et al., 2019). Reluctance to accept a referral for end-of-life care such as palliative care and hospice can vary from one culture to another. However, lack of knowledge regarding the enrollment process leads to decreased end-of-life care admissions even among families without cultural inhibitions (Aldridge et al., 2016). Barriers to end-of-life care involving enrollment continues to be a problem in the United States particularly for African Americans (Hart et al., 2022). To attempt to meet families' needs during end of life, a focus on education and culture is key (Boblanski et al., 2016). As healthcare providers, it is essential to investigate hospice admission enrollment and its barriers. Family support during end-of-life care is essential, and family members are often the caregivers. In the changing U.S. healthcare system, much has been done to improve end-of-life care. However, there is a need for further investigation of methods to improve this care through policy or program development.

Literature Review

Family

Care for African American families at the end-of-life poses challenges for healthcare providers. It is essential for providers to understand the culture of African Americans to understand the family dynamics. The influence of culture is an important role in defining family

(Epps et al., 2019), and African American families have strong familial structures. The African American family is a multi-generational one due to economic and social factors (Song 2016). To provide competent care to the African American family, it is recommended that healthcare professionals identify the family's needs in a non-judgmental manner with questions geared to specific family needs (Mountford & Dening, 2019). Priority to delivery of culturally sensitive care is essential (Mountford & Dening, 2019).

The African American culture views caregiving as an expression of commitment toward immediate relatives and those they consider family (Vaughan & Kofmehl, 2020). Because of the medical community that is distrusted, African Americans may turn to family before using formal healthcare services (Vaughan & Kofmehl, 2020). Caregiver support and the use of formal healthcare services depends on prior knowledge and the service's reputation. African American families also turn to community groups such as churches for additional assistance in meeting caregiving needs (Revell and McGhee, 2012). During end-of-life care and treatment, African American family members are significantly involved in decision making regarding their loved one's care (Collins et al., 2021). With involvement of family as caregivers during end-of-life, there are challenges. The American Association of Retired Persons (2015) and the National Alliance for Caregiving (2021) have helped describe the challenges involved with family caregiving. Two of these challenges include financial strain of caregiving and the emotional stress. However, research on family caregiver roles, needs, behavior, health risks, and interaction with professional healthcare members is not well developed (Dying in America, 2015).

Barriers

Palliative care and hospice are services from which African American family caregivers may benefit. Although palliative care and hospice services have grown, with more than 1.6 million Americans receiving these services (Hughes & Smith, 2014), African Americans continue to underuse these services. Only 8% of Medicare decedents who used hospice and palliative care in 2018 were African American (National Hospice and Palliative Care Organization [NHPCO], 2020). There is a need for improving access to palliative care and hospice, as there are barriers to enrolling in these end-of-life services among African Americans (Frey et al., 2013). Because these communities often rely on God as the determining decision maker, end-of-life services can be perceived as giving up, making enrollment a significant barrier (Johnson et al., 2016; Rhodes et al., 2017).

Other barriers are lack of knowledge about the services and overall mistrust of the healthcare system (Rhodes et al., 2017). The underuse of palliative care and hospice can also be explained by costs such as a lapse in insurance coverage, and out-of-pocket costs may cause African Americans to avoid or delay pursuing medical care (Dillon & Basu, 2016). In addition, Melhado and Bush (2011) asserted that African Americans assume that hospice is a location and are unwilling to move loved ones out of their homes. This assumption is an example of lack of knowledge regarding the health care system. Individuals with lower health literacy may favor more aggressive care during end of life (Pullis, 2011). Unfortunately, because of some of these barriers, African Americans do not often enroll in palliative care and hospice, even though enrolling in end-of-life services early can benefit the patient and family members. It is reported that those patients enrolling end of life services such as palliative care early have a reduction in depression among family caregivers (Dionne-Odom et al., 2015).

Policy

The NHPCO and Hospice Action Network (HAN, n.d.) work closely to make an impact on end-of-life policy. The NHPCO mission is to lead for improved end-of-life care, and the HAN's mission is to advocate for policies that ensure quality care for patients and families facing end-of-life, protect the structure of the Medicare hospice benefit, advocate for quality care, and represent any palliative care, hospice care, and end-of-life advocacy issues (NHPCO, n.d.). The HAN (n.d.) is affiliated with all of the services and issue areas impacting end of life, with a current goal to advocate for legislation that incorporates family-centered care. The HAN is dedicated to expanding access to hospice care in the United States.

NHPCO (2018) announces a campaign called My Hospice. to support and reinforce the Medicare hospice benefit among policy and healthcare decision makers and to encourage an environment that fosters end of life policy. In 2000, less than 25% of U.S. hospitals had a palliative care program, compared to 75% in 2015 (NHPCO, 2018). In addition to the increased usage of palliative care in hospitals, palliative care has increased services to communities, as well as affiliations with hospice programs. Although palliative care programs have grown since 2000, not all palliative care programs have the interdisciplinary teams necessary to provide care (NHPCO, 2018).

A particular goal of the My Hospice campaign is related to the Palliative Care and Hospice Education and Training Act, a bipartisan bill that helps facilitate healthcare professionals 'training for end of life care, promotes career development for those pursuing hospice and palliative care medicine, establishes workforce development by providing fellowship programs in which healthcare professionals such as nurses are intensively trained to care for end of life care patients and families (Palliative Care Education, 2019). This bill

provides for the establishment of a national campaign to inform patients, families and health care professionals about the benefits of end of life care such as palliative care (Congress.Gov, n.d.). In addition, this bill supports further research for end-of-life care by encouraging the IOM to expand research and to develop methods for improved end-of-life care such as advancing education and training programs specific to this expertise for health care professionals (Congress.Gov, n.d.) . This bill passed the United States House of Representatives in October 2019, but stopped in the Senate December 2019. Recently it has been reintroduced at the Senate in October 2022. The Senate status for the bill is currently called “introduced “. The Senate has referred the bill to the committee on health, education, labor, and pensions.

Although there is much support for the Palliative Care and Hospice Education and Training Act, there are those who oppose it. The Association of American Physicians and Surgeons (AAPS, 2018) reported that the bill only considers education on palliative and hospice care. In addition, having a government education program centered around the practice of medicine and giving patient care responsibilities to a committee instead of the family may result in negative outcomes. Additionally, the AAPS opposes the bill on the grounds that it supports increased intervention in the patient-physician relationship and consequently may not align with the goal of prioritizing patient care. The organization proposes that palliative care should not be a separate specialty; instead, all healthcare professionals should be trained at relieving symptoms in all patients, not just those that are dying (AAPS, 2018). The AAPS believes the bill exaggerates the meaning of the term palliative and as a result, harms patient care.

Implications for Nursing and Conclusion

Although some have opposed the bill, The Palliative Care and Hospice Education and Training Act may promote interdisciplinary education and research for hospice and palliative care. This bill facilitates an increase in trained palliative care professionals and public awareness. Campaigns can be established that continue to educate the public to benefit those in need of such services (Center to Advance Palliative Care, 2022). Johnson and colleagues (2016) described African American underuse of end-of-life services because of their spiritual beliefs can serve as an advantage. The authors further describe the influence of the church can be a connection to improve communication between healthcare providers and the African American community about end-of-life care. Healthcare providers can communicate through a church community liaison about end-of-life care and the importance for policy development and implementation.

The government has an interest in end-of-life care, particularly because the Medicare hospice benefit covers palliative care for beneficiaries with terminal illness (Kaiser Family Foundation, 2016). Patients who receive palliative care have outcomes consistent with their healthcare goals, and they and their families benefit from receiving early communication regarding the benefits for palliative care (Mehta, 2017). It is essential for healthcare professionals such as nurses to be adequately educated regarding end-of-life care such as hospice and palliative care.

The African American culture is one that benefits from education regarding end-of-life services as this culture requests more information regarding end-of-life care (Bazargan et al., 2021) indicating a possible knowledge gap. Johnson and colleagues (2016) described African American underuse of end-of-life services because of their spiritual beliefs can serve as an advantage. The authors further describe the influence of the church can be a connection to

improve communication between healthcare providers and the African American community about end-of-life care. Healthcare providers can communicate through a church community liaison about end-of-life care and the importance for policy development and implementation.

The Palliative Care and Hospice Education and Training Act may benefit the nursing profession as it provides for palliative care and hospice education training centers to educate nurses in effectively communicating with and educating patients and family members regarding end-of-life care services. In addition, with these opportunities as career incentive awards, nurses may receive professional advancement. Nurses can lead the reform for improved end of life care; the Palliative Care and Hospice Education and Training Act supports this vision. Further training for healthcare providers about African American spiritual needs with respect to end-of-life is warranted.

Nurses can advocate for this bill to pass through the Senate for implementation. Nurses can notify local and state legislators regarding its importance. Leadership in the African American community such as the church community can work closely with nurses and voice their support together for the bill. Nurses can further encourage support for the bill by reaching out to ANA and AARP.

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