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**End-of-life Care Experience for First-Generation Ethiopian Immigrant Patients and Families**

**A MASTER'S CAPSTONE PROJECT  
SUBMITTED TO THE GRADUATE FACULTY  
OF THE GRADUATE SCHOOL  
BETHEL UNIVERSITY**

**BY  
DEBREWOK DAMTE**

**IN PARTIAL FULFILMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF  
MASTER OF SCIENCE IN NURSING**

**December 2017**

**BETHEL UNIVERSITY**

**End-of-life Care Experience for First-Generation Ethiopian Immigrant Patients and Families**

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December 2017

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## Abstract of Critical Review of Literature

**Title:** End-of-life care experiences for first-generation Ethiopian immigrant patients and families

**Background:** The goals of end-of-life (EOL) or palliative care are as follows: provide comfort, promote death with dignity and provide support to patients' families. However, the observations and interactions with first-generation Ethiopian immigrant patients, the patients' families, and members of this community suggested an unsatisfactory EOL care experience among this community.

**Purpose:** To investigate EOL or palliative care experiences for first-generation Ethiopian immigrant patients and their families. It is hoped that the findings from this literature review will provide greater insight to nurses and other healthcare professionals. Also, the researcher wants nurses to purposefully and reasonably consider these findings and develop a plan of cares that enhances EOL care for this community.

**Theoretical framework:** Leininger's theory of Culture Care Diversity and Universality includes the following concepts: culture maintenance and/or preservation, culture accommodation and/or negotiating, and culture repatterning and/or restructuring.

**Methodology:** Critical review of literature. Articles related to EOL or palliative care experiences of first-generation Ethiopian immigrants as well as people from diverse religions, ethnicities, languages, and cultural backgrounds were included and synthesized.

**Findings:** The findings were as follows: a lack of awareness of EOL or palliative care, the existence of communication and language barriers that undermine access to palliative care and conflict between the health professionals and patients, and the extreme importance of family,

religion, and culture in the Ethiopian community. A substandard EOL care experience was evident among first-generation Ethiopian immigrant patients and their families.

**Conclusion:** Gaps exists between standard western EOL and palliative care practices and the experiences of first generation Ethiopian immigrant patients and their families. A plan of care that aims to close this gap will improve EOL palliative care outcomes.

**Implication for research, education, and practice and recommendation:** This project advocates for an enhanced EOL care through research and EOL or palliative care education.

**Keywords:** end-of-life care, OR palliative care OR terminal care AND Ethiopian OR, first-generation OR immigrant OR migrant OR multicultural



## **Chapter One: Introduction**

Chapter One provides some general background about Ethiopians and their ways of dealing with sickness, death and dying. This chapter also presents evidence for the need, the purpose, and the significance of this critical review project, namely to investigate end-of-life (EOL) care or palliative experience among the first-generation Ethiopian immigrant community members. Lewis, Heitkemper and Dirksen (2004) share their definition and goals for EOL as follows:

EOL care focuses on physical and psychosocial needs at the end of life for the patients and the patient's family. The goals for EOL care are to (1) provide comfort and supportive care during the dying process (2) improve the quality of the remaining life, and (3) help ensure a dignified death. (p. 160)

In addition, this chapter utilizes Leininger's theory of Cultural Care Diversity and Universality as the selected nursing theory in answering this project's question.

### **Background: The Ethiopian Community**

Ethiopia is home to many religious, ethnic, linguistic, and cultural groups. In Ethiopia, as well as other African countries and many places in the world, the handling of many aspects of life can be joyful or gloomy, depending upon cultural and religious practices. One of these life decisions is EOL care that takes its roots in the beliefs and views that are shaped by these diverse religious and cultural exercises.

In Ethiopia and other nations around the world, culture or tradition guides the care of terminally ill patients and their families. For example, Johnson and Kanitsaki (2009) reported that in Australia, Canada, the United States, and the United Kingdom, the healthcare system views autonomy as empowering. However, among some ethnic groups, such as Greek, Italian,

Chinese and Ethiopian, this concept of self-determination can be viewed as isolating and burdensome.

Macculloch (2009) identifies Ethiopians as one of the earliest Christian groups with historic documentation in the third century with Orthodox Tewahedo Christianity as their major religion. The word *Tewahedo* is an Amharic word that refers to the union of humanity and divinity. In addition, Islam and other Christian denominations, such as Lutheran and Seventh-day Baptist, have been the religions of people of Ethiopia. The most fascinating fact about the practice of the Jewish faith and Christianity are well documented in the Bible. “Ethiopia’s Semitic links are also apparent in the unique fascination with Judaism which has developed in its Christianity” (Macculloch, 2009, p. 243). Christianity, Judaism, Islam and other denominations make Ethiopia a land of a people of diverse religious groups. Since health practices and choices can depend on specific religious doctrine, it is important for nurses to note these differences and facilitate appropriate spiritual care that are congruent with one’s religious practices. A careful assessment of spiritual needs is useful for developing a plan for EOL care that meets the patient’s specific spiritual and religious needs and avoids categorizing all Ethiopians into one religious group.

In times of terminal illness, patients and their families experience various forms of physical, emotional and social distress. Some of the stressful issues include altered decision making, anxiety about unfinished business, fear of loneliness, fear of pain, lack of peacefulness, and restlessness (Lewis, Heitkemper & Dirksen, 2004). In many instances, in order to alleviate pain and suffering, particularly during grave illness and imminent death, patients and their families become more engaged in religious practices and rituals. In the case of Ethiopian Orthodox Tewahido Christianity, drinking holy water, receiving Holy Communion, praying, and

anointing are common practices used during serious illnesses. “In Ethiopia and other African cultures, religion and spirituality are integral components of life and health practices . . . Religion and spirituality play significant roles in the way Africans view end-of-life care” (Hiruy & Mwanri, 2014, p. 193).

In the Ethiopian tradition, it is expected that the family of the dying person provides EOL or palliative care. “EOL care in Ethiopia is marked by religious traditions, rituals, prayer and gatherings” (StratisHealth, 2009). In modern or developed countries, such as the United States, more emphasis is given to the scientific way of helping the dying, rather than traditional and individual family-based EOL care. For example, in Canada and in the United States, health information is openly discussed with patients; however, the Ethiopian way of disclosure supports withholding health information from the patient, especially diseases with a poor prognosis. “The North American culture of medicine advocates for explicit disclosure of cancer diagnosis to patients and frank planning for end-of-life issues” (Candib, 2002, p. 213).

Moreover, Ethiopia is a country that has numerous ethnic and religious groups. Therefore, the Ethiopian immigrants in the U.S. constitute various religions (Christian and Muslim), ethnicities (Amhara, Anuak, Gurage, and Oromo), languages and backgrounds. “In Minnesota, the Oromo, Amhara, Anuak, and other ethnic groups from Ethiopia live and work together, although each group speaks its own language and relationships are often strained because of a long history of political differences” (StratisHealth, 2009). Despite ethnic and language differences, the StratisHealth organization (2009) reported that there are cultural similarities among these groups. Patients are made aware of their illness through a family member. In Ethiopian culture, family has the primary role of caring for the sick and is responsible for receiving medical information and making healthcare decisions.

When Ethiopian doctors inform patients about their illness, especially those with a poor prognosis, certain culturally expected preparations are required. If possible, the knowledge of the extent and severity of the disease may be withheld from the patient, or they will be informed piece by piece. This information sharing with patients and their families is not done at once, but rather little by little. Beyene (1992) referred to this practice of sharing information as partial disclosure of information to patients.

When disclosing news about terminal illness, death and dying, planning when and how to inform the patient prepares immediate supports for all involved parties. However, it is interesting to note that “an Ethiopian doctor will never inform a patient of a terminal diagnosis. Instead, the doctor will tell a close relative” (Molakign, 1996, “Experience with western medicine,” para.3). It is clear that precautions should be taken when delivering poor health results to Ethiopian patients. For example, patients should not be alone when sharing bad news; rather, a family member (preferably not an immediate family member), friend, or relative who can provide emotional support is expected to be present. Generally, Ethiopians judge their doctors on their integrity and professionalism and by the way they disclose healthcare information, especially diagnoses with a poor outcome. In addition, timing of the news is crucial - evening and nighttime are not the preferred times to share bad news or the death of a loved one, especially with immediate family members such as a spouse, siblings, children or parents. In Ethiopia, “the situation is discussed among friends and relatives to decide the appropriate and the least frightening way of breaking the news” (Beyene, 1992, p. 330). In other places in the world, for example Vietnam, the sick family member withholds their poor prognosis as a way to protect family members from fear and anxiety (Candib, 2002). This way of protecting family is also very

common among Ethiopians. “In Ethiopia, and other African cultures, the dying person has the moral obligation to be concerned for the spiritual good of others” (Hiry & Mwanri, 2014, p.194).

In Ethiopia, during times of serious illness, people seek intervention, not only from modern medical doctors but also from culturally accepted sources that include the use of herbs and spiritual services (Stratishealth.org, 2009). Traditionally, the care of a dying person entails the family overtaking the provision of physical care, preparation of food (usually bland, non-spicy food), provision of hygiene, and participation in the decision-making roles. Family members’ opinions are well received and traditional interventions are often used to alleviate pain, any unpleasant physical and emotional symptoms, and even to cure diseases. Also, a greater need for religious or spiritual practices is anticipated, such as the use of holy water, talking to a spiritual father and going to confession. It is also common for the dying person to make peace and reconcile with everyone they feel they have offended. Moreover, those who have access to modern medical facilities hope to experience intervention and a cure from modern medicine. “When western-style medical care is available, antibiotics are used. Ethiopians who consult doctors usually receive medication for every illness” (Molakign, 1996, “Experience with western medicine,” para.3).

Ethiopians assume that when death is nearing, family members expect their doctors to inform them about the poor prognosis; after this news, the patient will be discharged from the hospital to spend the remainder of their time at home while surrounded by extended family members. “These last days are days where friends and relatives gather around the dying person talking to each other and with the dying person” (Hiruy & Mwanri, 2014, p.190). Even in times of imminent death, it is culturally expected for men to show courage, regardless of the situation, and not to show their real emotions. Moreover, it is common to see large numbers of people

travel from near and far to see the dying person to wish him or her a “good death.” Visitors also extend their wishes to the dying person to get well even if there is no sign of hope for survival. For example, people oftentimes say “egziabiher yemarwo,” which is roughly equivalent in English to “We wish that you receive a cure from God.” The Ethiopian culture highly values human relationships and believes that it is better to know a large number of people than to own material possessions. “In general, human relationship is valued over material possession, and a sense of pride is often driven not by what you have but who you have - your people” (Hiry & Mwanri, 2014, p.191). Therefore, in Ethiopian culture, it is highly appreciated when major life events, such as births, weddings, terminal illnesses and death, are attended by large numbers of people.

Due to economic, social and political reasons, many Ethiopians migrate to more developed countries. The United States, as well as other developed nations around the world, have become home to immigrants and refugees from Ethiopia. According to a report from the Migration Policy Institute (2014), which was prepared for the Rockefeller Foundation-Aspen Institute Diaspora Program, the number of Ethiopians who live in the United States grew from approximately 10,000 in 1980 to approximately 251,000 in 2013. This number makes Ethiopians the second largest group of African immigrants in the United States. Ethiopians represent a large, yet undefined population group.

The Ethiopian community is scattered throughout big metropolitan areas, including California, Virginia, Maryland, Minnesota, and Texas, with an especially large concentration in Washington, D.C. (Migration Policy Institute, 2014). The Ethiopian people have lived in the U.S. for several decades while their numbers have continued to grow. Also, many of the first-generation Ethiopian immigrants who settled here are now aging and living with chronic

diseases. “Demographic trends indicate that the number of Ethiopian immigrants will increase over time throughout the U.S. and Minnesota” (Ghobadzadeh, Demerath & Tura, 2014, p. 1). The research conducted by Ghobadzadeh et al. (2014) in an Ethiopian Orthodox church in Minneapolis, Minnesota also suggests that there is a higher incidence of cardiovascular disease (blood glucose, cholesterol and blood pressure abnormalities) among this community. Therefore, the growing size of the Ethiopian community and the prevalence of chronic health issues, coupled with the inevitability of death, warrant the need for nurses to identify EOL care needs for such immigrant groups. As Ethiopians develop a care plan to meet their health needs, it must include EOL or palliative care needs for the community.

Ethiopian immigrants generally demonstrate a high regard for developed countries; they usually welcome the country’s values (hard work and education) and appreciate the privileges that they have been offered, including access to healthcare. For example, “Ethiopian immigrants appreciate Israel as a developed country - a place of roads, elections, schools, and modern health care” (Schwarz, 2001, “The Golden Country: Israel,” para. 3). Also, Ethiopian immigrants generally take great pride in being contributing members to their communities in general. For example, Ethiopian immigrants, both first and second-generation, are active participants in the workforce. When compared to the general U.S. population, “members of the Ethiopian diaspora age 16 and older were more likely than individuals in the general population to be in the labor force” (Migration Policy Institute, 2014, p. 4).

Many Ethiopian immigrants are thankful for the healthcare services they receive: seeing doctors, the ability to receive treatment, getting medications, and the way nursing and healthcare teams care for them in general. “In-hospital treatment and physician interactions have generally been well received” (Molakign, 1996, “Reproduction,” para. 15). However, some

Ethiopian immigrants reported dissatisfaction over these services, particularly in EOL care service.

Ethiopians, as well as many immigrants from various parts of the world, bring their unique life experiences to their new home countries such as the United States, Canada, Europe, and Australia. Some of the experiences Ethiopian immigrants bring to these technologically advanced Western countries may include a more traditional healthcare and EOL practice. In the United States, first-generation Ethiopian immigrants with terminal illness seek healthcare services primarily from the mainstream American healthcare system, which is different from their home-country experience. As a registered nurse, and in nonprofessional roles as a member of the Ethiopian community, the author of this project has observed and interacted with terminally ill first-generation Ethiopian immigrants and their families in healthcare environments, both in private and community settings. Some of the author's observations included: seeing first-generation immigrants upset by healthcare providers' discussion of the terminal diagnosis with patients and their families, declining palliative care services, going back and forth between hospice care and the acute care setting, and hoping for curative care rather than palliative care. Also, Ethiopian patients oftentimes wish to go back home if death is imminent in search of traditional treatments such as the use of herbals and holy water (*tsebel*) in addition to spending time with their families. A study conducted by Bray et al. (2014), on immigrants' experiences with dying in their adopted country, showed that immigrants' desire to return to their home countries to pass was overwhelming. These observations and interactions, both locally and out-of-state, have reasonably suggested to the author of this review project that a lack of satisfaction over EOL or palliative care experiences exists for this population. Limited research has been conducted on EOL or palliative care experiences of Ethiopian immigrants in



Minnesota and in the United States. All of these factors inspired the author to investigate the EOL care experience of first-generation Ethiopian immigrants in Minnesota.

### **Purpose**

The purpose of this literature review project is to investigate end-of-life (EOL) or palliative care experiences of first-generation Ethiopian immigrant patients and their families. The author of this study passionately investigated the issue with the intention that information generated from this review of literature will give greater insight to nurses as well as to all healthcare professionals and members of the Ethiopian community.

Moreover, when developing an EOL care plan for first-generation Ethiopian immigrants, it is hoped that nurses, palliative care practitioners, and other healthcare professionals will deliberately and reasonably consider relevant information from this critical review of the literature and assist in the delivery of care that meets U.S. healthcare standards and ultimately yield positive patient and family EOL care experiences for Ethiopian immigrants. The critical review project question that was posed to explore this issue was as follows: What is the end-of-life care experience for first-generation Ethiopian immigrant patients and their families?

### **Evidence of a Need for Critical Review of a Nursing Problem**

The World Health Organization's (WHO) definition of palliative care is to provide care to gravely ill individuals and their families in an attempt to alleviate pain and suffering and improve their quality of life (as cited in Koffman, 2014). Evidence suggested that there is a lack of uniformity in the way palliative care services are available among diverse groups of people. "Ethnic, racial, or cultural disparities exist at all levels of health care, including hospice and palliative care" (Kemp, 2005, p. 44). Among first-generation Ethiopian immigrants in Minnesota, and in different parts of the United States, some have expressed displeasure over

their end-of-life (EOL) care or palliative care. Feelings of disbelief, shock, and sadness are common experiences when Ethiopians are directly informed about their poor prognosis. Sometimes, patients and their families react to a poor prognosis by declining to use pain medication, delaying EOL care decisions, or hesitating to enter into palliative care. Bray, Goodyear-Smith, and Gott (2015) reported that minority ethnic groups felt significant dissatisfaction over the EOL care service they received and viewed some of the services they received as culturally unacceptable.

In Ethiopia, there are diverse religious, ethnic, language, and cultural groups. This diversity shapes the Ethiopian immigrants' views about healthy choices and decisions. In many traditional societies, this can include the Ethiopian tradition. Kemp (2005) indicated that when dealing with incurable, terminal illness, death, and dying, immediate and extended family members of the dying person assume the primary role and provide traditionally accepted EOL care. Like many other immigrants around the world, Ethiopians emigrate to the United States as well as to many other developed countries, seeking better opportunities and leave behind a fear of persecution. A sizeable number of Ethiopian immigrants live in the United States, most of them concentrated in big metropolitan cities, including those in Minnesota (StratisHealth, 2009).

In general, Ethiopian immigrants uphold American values including hard work, the importance of education, and paying their fair share. Predominantly, Ethiopian immigrants appreciate the healthcare services available to them. However, some immigrants displayed dissatisfaction over their care during terminal illness and EOL care. "Some black and Asian patients and their carers are very disadvantaged, as they do not know what they are entitled to and hence what to ask for by way of benefits and services" (Koffman, 2014, p. 10). Though progress has been made in EOL or palliative care, "the actual delivery of care at the end-of-life

may not meet main cultural concerns during terminal care” (Koffman, 2014, p. 6). Some members of the Ethiopian community view an open discussion about serious illness, death, and dying as odd, culturally unexpected, and even upsetting.

This unfamiliar way of openly discussing death and palliative care is different from what Ethiopian immigrants would or did experience in their home country; information about patients’ prognoses and EOL care are handled in a more traditional and private way. For example, Beyene (1992) and Molakign (1996) explain that a direct and business-like way of informing patients about their illness is in contrast to the more interpersonal approach of Ethiopian doctors. Instead of directly informing the patient, information needs to be shared first to a trusted community spokesperson (rather than with close family members), and then the patient can be made aware in the time and place that the spokesperson deems culturally appropriate.

The direct and indirect assessment of EOL care experiences among first-generation Ethiopian immigrants showed apparent deficiency and prompted the author to investigate their EOL care experiences in the United States. The goal of the critical review of literature is to research the EOL care experience of Ethiopian immigrants, to gain additional understanding, and, ultimately, to improve EOL care for Ethiopian immigrants.

The investigation of EOL care among Ethiopian immigrants is significant for the following reasons: 1) a large number of Ethiopian immigrants reside in the United States; 2) a strong link exists between culture and health practice among Ethiopians which requires an enhanced understanding of Ethiopian culture related to EOL care practice; 3) there is a lack of English language proficiency and potential barriers related to language and culture; and 4) there is a lack of adequate knowledge of palliative care in their home country. These combined factors call for the investigation of the EOL care experience of first-generation Ethiopian immigrants in

the United States. In this review of literature, Leininger's theory of Cultural Care Diversity and Universality (mainly cultural preservation/maintenance, cultural accommodation/negotiation, and cultural re-patterning/restructuring) was used.

The author of this critical review of the literature, a native Ethiopian and registered nurse, frequently observed these responses in some terminally ill Ethiopian patients and their families. First-generation Ethiopian immigrant patients and their families expressed their dissatisfaction to the author through various channels, including word of mouth, family gatherings, and traditional bereavement ceremonies.

These observations suggested that nurses and healthcare workers, as they plan to provide EOL care, should pay special attention to one's faith and spiritual practices to include care plans that accommodate patients' religious and cultural beliefs. This, in turn, will provide EOL care that meets the patients' needs and expectations.

Furthermore, it is reasonable to speculate that Ethiopians, when terminally ill, may expect practices to be similar to what they are accustomed to in their homeland. For example, family members caring for a dying person may expect to provide care in a home setting while surrounded by a large family. Moreover, a lack of knowledge about the American healthcare system and language barriers could exacerbate the problem as well. The patient's culture, spirituality, and previous healthcare experiences may all contribute to the dissatisfaction they have displayed regarding their EOL care experiences in the United States.

### **Significance of the Literature Review**

Koffman (2014) asserted that people leave their countries of origin in search of a better education as well as economic and/or social opportunities. This has resulted in a growing number of immigrants in the developed western countries, which in 2005 alone totaled 44 million people

settling in North America (Koffman, 2014). In addition, research conducted by Jeong, Ohr, Pich, Saul, and Ho (2015) indicated that there is a growing number of people from different cultures and linguistically diverse backgrounds settling in the United States and other developed countries. This signals to nursing and healthcare providers the need to provide EOL care to immigrant communities, including Ethiopians that best accommodate their specific needs. It should be noted that, regardless of the population of a particular community, every person deserves quality palliative care.

Koffman (2014) suggested that although there is a growing understanding of palliative care, the EOL care that is currently delivered is not addressing the fundamental cultural needs of minority groups. EOL care service, designed for the general United States population, may not address the cultural needs of minority groups such as Ethiopian immigrants. EOL care that does not address the culture of the patients and their families places both unnecessary suffering and imposes economic, social, and spiritual distress. “The WHO definition of palliative care specifies two main goals: (i) to improve quality of life of patients and families and (ii) to prevent and relieve suffering” (Koffman, 2014, p. 7). The examination of the EOL care experiences of Ethiopian immigrants will give nurses an amplified understanding that will help them develop a care plan that meets the needs of the community, avoids pain and suffering, and improves quality of life. This coincides with the goal of palliative care - death with dignity.

This review of literature project aims to better understand EOL experiences of first-generation Ethiopian immigrant patients and their families. Therefore, it is hoped that answering the question raised from nursing practice will provide more understanding about the EOL experiences of first-generation Ethiopian immigrant patients and families. An improved

knowledge from this review will help nurses develop a plan of care to ensure more accepted and culturally congruent EOL or palliative care and result in an improved EOL care experience.

**Conceptual Framework: Leininger's theory of Culture Care Diversity and Universality**

Leininger's theory of Cultural Care Diversity and Universality (McEwen & Wills, 2014) was selected to gain foundational guidance to examine the proposed practice question: What is the end-of-life care experience for first generation Ethiopian immigrant patients and their families? Leininger's theory of Culture Care Diversity and Universality includes the following three concepts: culture care preservation and/or maintenance of nurses to help cultures be preserved or maintained, culture care accommodation and/or negotiation to help provide culturally congruent care, and the culture care repatterning and/or restructuring to help modify or restructure one's life. These three concepts are utilized to synthesize this literature review.

Moreover, this theory is applicable in guiding nurses' actions in delivering end-of-life care for people from diverse cultural backgrounds, including Ethiopians. The purpose of applying Leininger's theory of Cultural Care Diversity and Universality is to investigate EOL care issues of first-generation Ethiopian immigrants from a cultural perspective. This approach may provide some understanding to nurses about the norms of EOL care practices in this community.

Leininger is a recognized nurse scholar worldwide (McEwen & Wills, 2014) and is prominent in articulating the impact of culture on health and the need to consider patients' beliefs, values, and cultures when providing nursing care. Leininger's theory of Culture Care Diversity and Universality, as the name indicates, is used to promote the delivery of culturally congruent nursing care that embraces people's culture. Moreover, many researchers and scholars use this theory as a conceptual framework to execute research, primarily in nursing. "Many

graduate students and nursing scholars have used Leininger's theory as a basis for research, and, as a result, hundreds of examples of articles can be located in the literature" (McEwen & Wills, 2014, p. 233).

In addition, Holt's (2001) research conducted on the EOL care issues of immigrants from Eritrea in Minnesota successfully applied Leininger's theory of Culture Care Diversity and Universality. In this study, Leininger's theory of Culture Care Diversity and Universality emphasized preservation/maintenance, accommodation/negotiation and re-patterning/restructuring cultural care. Cultural preservation, or maintenance, is applicable whenever a patient's cultural needs can be fully preserved in his or her care without compromising the safety and quality of patient care. An example of this application would be when a nurse fully accepts and implements a patient's request to drink holy water in the morning, provided the patient has no medical restriction to consume food and water. Honoring this request maintains the patient's cultural and religious practices without compromising safety. Cultural accommodation, or negotiation, involves discussion about the patient's care between nurses, patients and their families. For example, if a patient who has a medical restriction to not eat or drink before a pending procedure requests to drink holy water, then the nurse would negotiate by saying, "Yes, but at a later time - after you are done with the procedure." The cultural re-patterning, or restructuring, applies when nurses respond, "I am sorry, no." For example, if a patient who is medically deemed high risk of aspiration and choking asks to drink a glass of a holy water, the nurse, in order to prevent aspiration, can say "no." However, nurses can be creative and offer alternatives such as swabbing or applying the holy water on the patient's body. Leininger's three concepts, preservation/maintenance, accommodation/negotiation and re-patterning/restructuring, can be used to deliver culturally appropriate and safe nursing care.

Because of its wide applications for research and practice, as well as the global recognition of Madeleine Leininger, this theory was used as the basis for this project in investigating practices and providing nursing recommendations. It is clear that this theory is a good fit; it applies to global communities as well as to the unique Ethiopian culture.

During significant life events, such as death and dying, an individual's expectation of care depends on the individual's EOL care service experiences, beliefs, values, level of education and past exposure to the event. Therefore, the author of this critical review of the literature cautions against generalizations about all Ethiopian immigrants but rather advocates for culturally appropriate and individualized EOL care.

There is a growing understanding about the relationship between culture and health. "The goal of Leininger's theory is to generate knowledge related to the nursing care of people who value their cultural heritage and life ways" (McEwen & Wills, 2014, p. 233). Some of the concepts in Leininger's theory of Culture Care Diversity and Universality include culture, culture care, and culture care differences or diversity and similarities (universals) in regard to trans-cultural human care. This theory is useful when encountering patients from these diverse religious, ethnic, cultural, and linguistic backgrounds, including the Ethiopian immigrant community. This theory allows nurses to fully preserve, accommodate and restructure patients' choices in order to deliver sensitive and appropriate nursing care.

### **Summary of Chapter One**

In summary, Chapter One presented some common practices of Ethiopians during times of illness, death and dying. It also shared evidence of the need for this review and the main goals of the review project. This chapter presented the application of Leininger's theory of Culture Care Diversity and Universality as a framework for guiding this critical review project.



## **Chapter Two: Methodology**

This chapter describes the methodology that was used to obtain relevant information to answer the literature review project question: What is the end-of-life care experience for first-generation Ethiopian immigrant patients and their families? Answering this question will guide nurses to understand and provide culturally appropriate EOL care for Ethiopian patients. Nurses can play a large role in improving EOL care for first-generation Ethiopian immigrant patients and their families, especially in regard to making the care more relevant to their cultural and spiritual needs.

An electronic search was conducted to answer the research question. The search strategy, databases and search terms that were used to locate and retrieve literature are discussed. Also, this chapter presents criteria for the inclusion and exclusion of articles, the number and types of articles, and the criteria for evaluating articles that were used to answer the project question.

### **Search Strategy**

In order to answer the project question, information was explored from the following worldwide recognizable electronic databases: CINAHL, EBSCOhost Academic Search Premier, Google searches, and Scopus. The initial search terms that were used for finding evidence to answer the research question were: “end-of-life care” OR “palliative care” OR “terminal care” AND “immigrant” OR “first generation” OR “Ethiopians” OR “Minnesota.” However, the information that resulted from this search did not appear to answer the question.

To increase the probability of obtaining evidence that would help answer the question, a few modifications were implemented. The search terms initially used (“Ethiopian,” “first generation,” and “Minnesota”) were modified and broader search terms were used. The updated search terms were “end-of-life” OR “palliative care” OR “terminal care” AND “multicultural

“OR “migrant” OR “immigrant “OR “first generation.” No related articles resulted when using these updated terms. The final search terms “end-of-life care” OR “palliative care” OR “terminal care” AND “multicultural” OR “migrant” OR “immigrant” OR “first-generation.” This search resulted in nineteen relevant articles from SCOPUS through CINAHL, one of the largest nursing databases.

### **Criteria for Data Inclusion, Exclusion, and Exceptions**

In order to ensure the validity and reliability of information and maximize users’ confidence in utilizing the findings of the evidence, criteria for data inclusion and exclusion were set. As cited in LoBiondo-Wood and Haber (2014), the purpose of the inclusion and exclusion criteria is to control extraneous variability or bias and to improve the strength and quality of the findings of literature review project.

The inclusion criteria encompassed research pertaining to human subjects and human EOL palliative care experiences (EOL palliative care as experienced by Ethiopians) with no limits to the year of publication for articles used. The main reason for these inclusion criteria is that the original search indicated a lack of published articles available that directly studied Ethiopians and their EOL care experience. Other criteria included literature published in the English language only. This was primarily to minimize the need for additional resources such as the use of interpreters which would incur additional cost.

The focus of this literature review project is to examine the EOL care experiences of first-generation Ethiopian immigrant patients and their families; however, due to inadequate literature on this specific population, evidence from other immigrant and minority groups was included. Finally, data selection criteria for this project included literature written by nurses and

other health professionals dealing with EOL care of Ethiopians, immigrants, and other similar minority groups.

### **Summary of Numbers and Types of Studies**

From the electronic database search, nineteen articles were used, including primary and secondary research, non-experimental research, qualitative case studies, cross-sectional surveys, and systematic reviews. The evidence obtained from the search and the corresponding strength and quality level was based on the Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) evidence scale (Dearholt & Dang, 2012). These selected articles consisted of thirteen level III-Grade B non-experimental qualitative research studies, three level III-Grade B systematic reviews of existing evidence and three level III-Grade B published articles and textbook chapters in addition to evidence from experts in the field of nursing, medicine and palliative care. According to Dearhold and Dang (2012), the quality of the research coincides with its level. For example, information retrieved from Level I grade A literature is research with the highest quality and the highest believability whereas level V articles are of inferior quality.

### **Criteria for Evaluating Research Studies**

There were nineteen level III-Grade B primary and secondary forms of research evidence which were compiled by healthcare professionals, including nurses and palliative care practitioners. The selected pieces of literature that were used in this project met the inclusion criteria and were selected to explore the EOL care experience among Ethiopian immigrants.

### **Summary of Chapter Two**

Chapter Two discusses the methods used to retrieve written evidence to answer the research question raised in this project. A variety of evidence that met the selection criteria were

chosen from well-recognized electronic databases. General terms such as “immigrant” rather than “Ethiopian” resulted in relevant information for answering the question.

### **Chapter Three: Literature Review and Synthesis, Strengths and Weaknesses**

Chapter Three presents the five major findings of this critical review: the low awareness of EOL or palliative care, the significant role of culture in EOL or palliative care, the importance of communication and language barriers in EOL or palliative care, the more visible role of family in caring for their terminally ill family member in certain cultures, and the auxiliary roles of religion and spirituality in times of terminal sickness. This chapter also discusses the synthesis of the findings and presents the strengths and weaknesses of the articles that were identified for the literature review (See Appendix A).

#### **Key Themes/Terms, Findings, and Synthesis**

To answer the research question used in this critical review of the literature, nineteen articles were read and reviewed. In three of these articles (Beyene, 1992; Hiruy & Mwanri, 2014; Grisaru, Witztum, & Malkinson, 2008), Ethiopian immigrants were the principal study population. One study, conducted by Holt (2001), was a case study on immigrants from Eritrea. The people of Eritrea and Ethiopia, despite the long civil war between these two groups that ended with Eritrean independence, lived for thousands of years together as one nation; they share common cultural values, particularly with the Amhara people of Ethiopia. “The literature review suggested that customs among Eritreans may resemble customs found among the Amhara of Ethiopia” (Holt, 2001, p. 151). The rest of the literature reflected EOL care and palliative care experiences of immigrants and people from diverse cultural, ethnic, linguistic and religious backgrounds in the United States, Canada, United Kingdom, New Zealand and many other developed nations. Generally, immigrants share similar experiences including life adversaries and challenges. Therefore, literature on a certain immigrant community can shed some light on other, similar communities.

The literature reviewed in this project provided sufficient evidence to believe there was sub-standard EOL care for Ethiopian immigrants and other people from diverse religious, ethnic, linguistic and cultural backgrounds. Also, the literature review suggested that this substandard EOL care experience was evident in the United States, Canada, and the United Kingdom as well as in many other developed countries.

The finding of this literature review project suggested a need for an increased awareness of palliative care, cultural sensitivity, improved communication and language services, formal ways of involving family, and allowing religious practice. These were the most prominent and recurrent themes that emerged from this literature review. In synthesizing the literature, an attempt was made to briefly illustrate the major findings as well as to use direct quotes to strengthen the findings.

#### **A Need for Awareness of EOL and Palliative Care**

Seven articles indicated a lack of knowledge of palliative care, including an advance care directive, assigning legal guardianship, and an overall end-of-life care service among immigrants from various cultural, ethnic, linguistic and religious minority groups. For example, Jeong et al. (2015) conducted a study exploring the preparedness of EOL care planning among community-dwelling older people from culturally and linguistically diverse backgrounds. This study found a low awareness of enduring guardianship (a person who is legally appointed to make decisions on behalf the appointee), an awareness of advance care directives (a legal form that is completed by an individual and dictates what doctors should do in case a person is unable to communicate), and the completion of an advance health directives form. A lack of knowledge about healthcare directives and/or enduring guardianship implies a potential for risk for inadequate EOL or

palliative care. This includes miscommunication among patients, family members and health care providers concerning how to proceed with the care for the dying person.

The African-Canadian population in the study conducted by Maddalena et al. (2013) expressed disappointment that information about EOL care was not presented to their community. Members of the African-Canadian community also indicated that community members could benefit from sharing EOL care information. Missing such valuable information about EOL or palliative care in communities, like the African-Canadian community, can hinder individuals from accessing EOL care services; this can be translated into uncontrolled pain and suffering for the dying persons and distress for their families. Western palliative care might not be well understood among first-generation Ethiopian immigrants. “The immigrant may not have had much exposure to or knowledge of palliative or hospice care services provided by hospice or other health care institutions in their countries” (Koffman, 2014, p. 8). Evans et al. (2012) indicated that insufficient information on palliative care caused a negative perception about this service.

Over the years, much has improved and continues to improve concerning the acceptance of interracial relationships. However, some people have been affected by slavery and medical malpractice in previous generations. As a result of these sad experiences, some groups, such as African-Americans, mistrust their providers. “Minorities’ mistrust of physicians in the healthcare system has been related to historical events, most notably the legacy of slavery and abuse in medical research” (Crawley, Marshall, Lo, & Koenig, 2002, p. 675). Mistrusting providers can create hesitancy and may prevent people from entering into EOL or palliative care, which also can mean physical, emotional, and psychological distress that could be avoided through service from trained palliative care workers (nurses, doctors, spiritual services).

Crawley et al. (2002) wrote that some ethnic minority groups preferred to have life-sustaining treatment over palliative or hospice care. They feared that completing an advance care plan might prevent them from receiving life-sustaining care which made them reluctant to complete the form. These kind of patient and family responses were surprising, and at times frustrating, to providers. “Providers are also often bewildered and frustrated by what they see as negative attitudes and at times hostile resistance towards advance care planning by patients and involved families of diverse cultural backgrounds” (Johnson & Kanitsaki, 2009, p. 408). It is interesting to note that providers have a gap of knowledge about their patients’ cultural backgrounds which may negatively impact patients’ care.

Evidence suggests that palliative care is relatively new to many immigrants, as the concept is not well known in developing nations, including Ethiopia. Therefore, immigrants come with limited knowledge and misconceptions about palliative care (Koffman, 2014). Nurses and all healthcare professionals who can provide proper EOL care need to learn the culture of palliative care. These individuals, in return, will assist in the delivery of an improved EOL care that meets the patients’ and families’ needs. This requires a great deal of resources to train healthcare workers. Besides formal training, seeking additional ways to learn about their patients is vital. For example, taking the time to interact with and get to know the patient and their family members would encourage cultural exchange and therefore increase the understanding of the patient’s needs.

Besides cultural and ethnic differences, individual differences, such as the education level of a family or individual, can also play a role in EOL care. Bray and Goodyear-Smith (2007) conducted a study on an Indian Muslim family who immigrated from North Africa. This research found that the family was able to understand and communicate well with providers,



which allowed their dying father to receive culturally acceptable and quality EOL care. The level of education and the ability to read and understand information about EOL care both have an impact on one's ability to access and receive appropriate and needed EOL or palliative care.

A study conducted by Jeong et al. (2015) found that there was a low rate of completion of advance care directives by community-dwelling older people from culturally and linguistically diverse backgrounds. The suboptimal use of advance care planning by this group was associated with a number of factors: the terms used in the form were too difficult to understand, completing the form was seen as time consuming, and patients lacked knowledge about how to complete the form. This suggests that a lack of English proficiency can limit immigrants from fully understanding Western palliative care, reduce access to EOL care, and contribute to a poor EOL care outcome. A lack of clear and effective communication can be a source of problems in consulting patients and can be the cause of misunderstanding among patients, family members and healthcare providers (Koffman, 2014). This misunderstanding and miscommunication undermines the care and the goal of the United States health and palliative medicine department - to manage symptoms of serious illness, to support patients and their families and to provide quality care, regardless of the patient's background including limited English. "The goal is to improve quality of life for both the patient and the family" (Meier, 2014, p. 2).

In addition, Hiruy and Mwanri (2014) reported that palliative and hospice care are not well known in African countries; it has only been a few years since the 2004 establishment of the African Palliative Care Association. A lack of prior exposure to western palliative care may negatively impact EOL care and cause substandard care experiences among Ethiopian immigrants here in the United States.

Generally, the studies (Hiruy & Mwanri, 2014; Johnson & Kanitsaki, 2009; Jeong et al., 2015) suggested the presence of low levels of palliative care knowledge among people of diverse religious, ethnic, linguistic, and cultural backgrounds. This contributed to their low use of palliative care, which can be translated into physical, emotional, and psychological distress, as well as poor EOL care. Therefore, this finding calls for ways to increase awareness of palliative care among Ethiopians and immigrants in general, which can ultimately improve the EOL care experience for these groups.

### **A Need for Cultural Sensitivity in Providing EOL or Palliative Care**

The role of culture is significant in how individuals and families view EOL care, make decisions for care at the final chapter of their lives, and make choices about the care after death for both the deceased and the family of the deceased. Hiruy and Mwanri (2014) reported a number of traditionally expected behaviors and practices among Ethiopians pertaining to terminal illness, death, and the time before and after dying. One behavior was using herbals and other spiritual care practices, which are generally facilitated by family members, friends and neighbors. Also, some people who have access, especially those who live near hospitals and clinics in big cities, hope to get help from modern healthcare.

Generally, death creates intense grieving for the family and the entire Ethiopian community. In some cases, intense grieving appears even with chronic illness and advanced aging. Sometimes, Ethiopians view death as a way to a better life with God. For example, a patient is described as “*arefe*” or “*tegelagele (male), or tegelagech (female)*” which means that he or she is at peace or was relieved from pain and suffering. This positive view towards death is shared with Eritreans. Holt (2001) reported that Eritreans and Ethiopians share many cultural similarities. Nazareth, one of the interviewees in Holt’s study (2001), said that death is not

feared. “The longer you stay, the more blessed you are, but it’s okay if you die” (Holt, 2001, p. 147). They do not think death is a bad thing. When death occurs, family, friends and community members participate in the funeral and bereavement practices. After death, many mourn loudly and adults and close friends or family members prepare the body of the deceased. At the funeral, large numbers of people attend, and the crying gets louder. Following the funeral, mourning continues for seven days at the deceased’s family home. People continue to show support by visiting the family of the deceased, sharing stories, and sharing meals.

A study conducted by Bray et al. (2015) found that towards the end of life, cultural and religious practices become more important for immigrants. For this reason, some immigrants wish to return to their home countries for a full-fledged ceremony in a familiar setting with people who truly honor these practices. However, due to financial, medical and personal reasons, returning to one’s country of origin is not always possible and EOL care, including burial and bereavement, occurs in the newly adopted country.

An Indian-Muslim family from Africa who settled in New Zealand received support from a palliative care team for their dying father at their preferred place of death - their home - which allowed the family to take turns and offer prayers for their father (Bray & Goodyear-Smith, 2007). In general, this family was satisfied with the EOL care their father received at home. According to the care providers, the family “received excellent palliative care, but their own social skills and educational levels no doubt assisted in this regard” (Bray & Goodyear-Smith, 2007, p. 98). These findings underscore that high education levels assist people to access EOL care and are a factor for a positive EOL care experience.

Holt (2001), in her study about EOL care of Eritrean immigrants in Minnesota, wrote that in the Eritrean culture, caring for and visiting the sick and the elderly are highly valued.

Moreover, placing a family member in a nursing home is considered abandonment. These cultural experiences are common in Ethiopian culture as well. Abeba, one of the informants in this study (Holt, 2001), called for respect for all cultures since no culture is inferior, just different. Therefore, issues and questions raised need to be looked at through a culturally sensitive lens.

The systematic review of the primary research on minority ethnic groups by Evans et al. (2012) revealed that despite an emphasis on culturally appropriate EOL care, the caregiver's lack of cultural competence contributed to a low use of EOL care and substandard quality EOL care among minority groups. Johnston and Kanitsaki (2009) found that insufficient and difficult-to-understand palliative care information, such as advance care directives and fear and mistrust of providers, resulted in a low use of advance care directives and advance care planning. The findings led to a call to expand the caregiver's knowledge of how to approach patients in a more culturally acceptable way and to make the forms easier to understand. These strategies ultimately help in delivering culturally acceptable EOL care and in improving the EOL care outcome for people of diverse backgrounds.

Some ethnic minority groups, because of cultural, religious and historical experiences, demonstrated a preference for life-sustaining medical intervention over receiving help through palliative care even when faced with a severe illness with no hope of cure from medical intervention (Johnston & Kanitsaki, 2009). This choice was confusing and frustrating to many care providers.

Moreover, a number of authors on EOL or palliative care issues indicated that some healthcare providers were intrigued by patients' choices (Johnston & Kanitsaki, 2009; Crawley et al., 2002). Regardless of the terminal nature of the disease, patients and families of ethnic

minority groups wanted to avoid completing an advance care directive and preferred aggressive life sustaining measures for various reasons. For example, an African-American patient with advanced cancer preferred life-sustaining treatment due to a fear that stemmed from racism and abuse in research. “Minorities mistrust of physicians or of the health care system has been related to historical events, most notably the legacy of slavery and abuse in medical research” (Crawley et al., 2002, p. 675). Many African Americans fear that completing the form will prevent them from receiving appropriate care. In addition, a Spanish-speaking patient with severe congestive heart failure chose life-sustaining treatments over palliative care because of religious beliefs (Crawley et al., 2002). Enhancing providers’ attitudes, cultural sensitivity and cultural competence, as well as educating patients and their families about palliative care, are all important factors in promoting an EOL care that is more acceptable to these populations.

Evans et al. (2012) reported that although there was an increase in recognition for the need for culturally appropriate care, the lack of clarity in terminology related to EOL care poses a potential problem in providing appropriate EOL care. Inadequate cultural competence contributes to low EOL care service, and substandard care was evident among immigrants. “The recent focus on including a patient’s cultural needs is significant, and is supported by evidence of inequalities in care related to ethnicity” (Evans et al., 2012, p. 817). According to Koffman (2014), a low use of EOL care by immigrant and minority groups was related to providers’ lack of knowledge of palliative care, stereotyping, prejudice and bias; therefore, the researcher recommended clarifying the terminologies, as ambiguity can lead to service inequalities.

Generally, in western societies such as the United States, Canada, and the United Kingdom, the individual is the primary person to receive his or her own health information and has the ultimate decision-making authority (Kemp, 2005). In contrast, in many traditional

societies, such as Ethiopia, as well as some developed nations such as Japan and Italy, particularly in times of dealing with serious and terminal illness, the family and community are the decision makers and the first contact instead of the sick patient. Johnston and Kanitsaki (2009) support this idea with their research:

International research has shown, for instance, that some ethnic groups (e.g., Greek, Italian, Chinese, Ethiopian) do not regard autonomy as empowering at all but as isolating and burdensome to patients who are often too sick and too uninformed about their condition to be able to make meaningful choices. (p. 409)

Early discussion about EOL care and providing information about EOL or palliative care while a patient is well enough to understand and make decisions will better prepare the patient. These discussions and patient education sessions can be initiated formally or informally through a variety of venues such as primary clinics, churches and community settings.

Kemp (2005) suggested that by first identifying and designating a patient's preferred spokesperson or mediator, healthcare providers must uphold the principle of autonomy and the individual's right to know and make their own decisions. Moreover, both studies by Kemp (2005) and Johnston and Kanitsaki (2009) called for culturally sensitive care. Therefore, it becomes essential for nurses and providers to consider the impact of communicating information to the patient and to find an alternative and equivalent strategy to relay the message that respects patients' and families' cultural expectations while upholding the U.S. health guidelines. It is also essential to make sure patients and families receive information about the health issue.

According to Maddalena et al. (2013), African-Canadians preferred to care for the sick at home although they indicated that caring at home for the loved one was both financially and physically stressful. This population acknowledged that information about palliative care was

needed. They expressed their disappointment that EOL care information was not available in their community.

Upon arrival, immigrants possess little or no knowledge and experience of palliative care and also oftentimes hold misperceptions about palliative care (for example, they consider advance care directives as a legal means for withholding treatments). “Expectations for palliative care may thus be lowered amongst minority groups who bring from their country of origin misperceptions or lowered priorities for this type of care” (Koffman, 2014, p. 9). Therefore, nurses can play crucial roles in clarifying the misperception of palliative care and in educating immigrants that palliative care is intended to alleviate pain and suffering. Furthermore, preparing the EOL patient education seminars in the immigrant’s native language will make it accessible to the communities and will result in a greater understanding of palliative care among members of the Ethiopian community.

Bray and Goodyear-Smith (2007) suggested that some immigrant families received satisfactory EOL care based on the patient and family’s cultural preference to care for the dying family member at home. Home palliative care was then arranged which permitted the family to provide care. This study highlights the importance of facilitating home EOL care and providing support to the dying family members.

In the Ethiopian culture, news about terminal illness or the death of a family member is delivered by an adult (usually a male) friend or neighbor. Immediate family members do not typically share this bad news in order to avoid emotional distress. After death, many family and community members grieve as they prepare the body of the deceased for burial. Finding a culturally respected person, such as an elderly man in the village, to share news about death is important to ensure a culturally appropriate delivery of the message. Providers’ cultural

knowledge and skills are crucial in providing culturally appropriate EOL care. However, evidence suggests that providers lack this competence. “Research has found that nurses experience stress and frustration when caring for people from an ethnic minority group because of poor communication with patients and lack of knowledge of cultural differences, or lack of resources” (Bray & Goodyear-Smith, 2007, p. 98). This finding points to the need for cultural competency training for nurses and healthcare providers, in general.

### **A Need for Clear and Culturally Acceptable Communication in EOL or Palliative Care**

An individual's autonomy and informed consent are among the core values of the western healthcare system. An individual patient directly receives his or her own medical diagnosis, prognosis, life expectancy, and best available treatment choices. In Ethiopian culture, for example, it is culturally inappropriate to directly inform patients about their terminal illness, poor prognosis, or time left to live. It is believed doing so will take away a patient's hope and ability to fight the disease, and it hastens death. “The diagnosis of cancer changes all that and takes away enjoyment of the present. It condemns the person to a period of being among the dead while still alive” (Candib, 2002, p. 213).

Even informing patients and families in a culturally insensitive way can result in negative reactions and outcomes. Beyene (1992) reported that an Ethiopian patient's husband requested doctors not to inform his wife about her diagnosis of cancer because she did not want to know the details of her disease. Despite the request, the surgeon followed United States medical guidelines and told the woman she had cancer. The patient initially fainted, and after she recovered from her shock over the bad news, she declined to speak with the surgeon. The patient thought the surgeon was not respectful of their wishes and described him as “cruel and inconsiderate” (Beyene, 1992, p. 328). This finding further supports the idea that reporting a



poor prognosis directly to some patients can impact them negatively (Candib, 2002; Grisaru et al., 2008; de Graff et al., 2012).

On some occasions, western doctors' well-intended, ethical and standard palliative care discussions with a patient can cause misunderstanding and unnecessary traumatic experiences for both the dying person and the family members. For example, a doctor's discussion about palliative care prompted a family member to take the dying person home to complete certain rituals before dying (Johnston & Kanitsaki, 2009). "In keeping with their traditional practices, the family took the man home and painted him up and put him under a tree for three days because they thought he was going to die right there and then" (Johnston & Kanitsaki, 2009, p. 411). Had they better understood his situation, they would not have experienced sleepless nights. Also, they could have remained in the hospital to receive immediate care. Communicating effectively and confirming patients' and families' understanding of decisions is crucial in eliminating miscommunication.

In Ethiopian culture, whenever possible, it is believed to be beneficial for patients to avoid being informed of the extent and/or severity of their illness. Instead, the message should be relayed to the patient slowly and bit by bit. A study conducted on the EOL care experience among Ethiopian immigrants in Israel discussed a lack of sensitivity in how providers were sharing information about a patient's poor prognosis and discussing death (Grisaru et al., 2008). In Ethiopian culture, this way of information sharing is considered wrong and traumatic. In the study by Grisaru et al. (2008), one Ethiopian mother believed that the information about her son's death was communicated incorrectly. This mother expressed her deep disappointment in this way: "We were killed twice, once when our beloved son died, and then when we were informed in a wrong way" (Grisaru et al., 2008, p. 115).

Many studies (Beyene, 1992; Candib, 2002; Grisaru et al., 2008) indicated that a cultural insensitivity to patients when telling them about their incurable or terminal illness can have negative results including the following reactions: anger, emotional distress, physical symptoms such as fainting, shock conflicts with the healthcare team, withdrawal from palliative care, and potential risk of low use of EOL care. “With this tragic news, the patient fainted. After she recovered from initial shock, the patient refused to talk further to this physician” (Beyen, 1992, p. 328). These negative experiences may translate into pain and suffering, which defeats the purpose of palliative care - to die well. This calls for an improved, culturally acceptable method of information sharing that gives patients and their families better EOL experiences.

The perception and meaning of good care varies from culture to culture, which can result in miscommunication between patients and healthcare providers. In a study by de Graaff, Francke, Van den Muijsenberg, and Van der Geest (2012), a Dutch doctor presented palliative care as good care. On the other hand, among Moroccans and Turkish communities, curative care equates with good care; they desire medical intervention even if the patient is deemed terminal. A lack of clear and culturally appropriate ways of communication can negatively impact immigrants, including Ethiopian patients and their families.

### **Family Role in Caring for Terminally Ill Family Members: Pros and Cons**

Among diverse ethnic, cultural, and religious groups that include immigrants from Ethiopia, it was demonstrated that family involvement in EOL or palliative care decision-making and care of a dying family member are more emphasized in a number of studies (Jeong et al., 2014; Johnston & Kanitsaki, 2009; Crawley et al., 2002).

Family members of the sick and the dying are culturally expected to take the primary responsibility of caring for them, including making important healthcare decisions. Jeong et al.

(2014) found limited “planning ahead,” including having advance directives or assigning legal guardians and family members as the preferred healthcare decision maker. However, in developed countries such as the United States, the individual patient, rather than the family, makes the decisions, and the use of “planning ahead” is more common among the general population.

Beyene (1992), in her compilation on *Telling Bad News to Ethiopian Patients*, affirmed the importance of family in Ethiopian culture and stated that for Ethiopians, the extended family is the most important institute. In addition, Ethiopian children are deeply attached to their families and sensitive to the wishes of their parents. This implies that children can act on behalf of patients and can serve as the best decision-makers for their parents. This finding is consistent with the findings of de Graff et al. (2012), who found that in Moroccan and Turkish families, family members and relatives are highly valued in the care of sick family members. Therefore, these findings suggest that healthcare providers need to welcome family involvement and formally and legally involve family while respecting the United States’ health guidelines concerning an individual’s autonomy.

Generally, for Ethiopians and others from cultural and ethnic minority groups, family members of the sick are the preferred decision-makers. However, on some occasions, this practice can result in a communication problem. An information gap may exist between the decision made by the patient’s family and the patient's choice, which creates confusion and a lack of clarity about whether the patient’s choice is palliative care or not. As a result of this confusion, even though continuing treatment may or may not be in the best interest of the patient, out of caution, patients are placed for treatment. Also, despite the positive attitude towards family as a care provider, some studies indicated that family care may sometimes occur due to a

lack of choice or a lack of awareness of resources and may not be the best care (Holt, 2001; Candib, 2002; Kemp, 2005). This evidence suggests that there is a potential risk of lack of good EOL care when solely delivered by patients' family members.

Evans et al. (2012), in their study on minority ethnic groups and EOL care in the United Kingdom, explained that immigrants, since they live far away from their home countries, may not have as many family members nearby as they did back in their countries of origin. This calls into question which individuals a patient considers family members and truly trusts to act in their best interest. It also complicates how they might determine their degree of involvement in the care of a dying family member.

### **Religion and Spirituality Support for End-of-life**

Religion is ingrained in Ethiopian life. The orthodox Christian, Islam and Jewish faiths are the oldest and major religions of the Ethiopian people. The choices and decisions of life circumstances, including during times of sickness, death and dying, are made based on the patient and family's religion. "In Ethiopia and other African cultures, religion and spirituality are integral components of life and health practices" (Hiruy & Mwami, 2014, p. 193). During stressful times in life, such as dealing with an incurable and terminal illness, one pulls strength from their religious beliefs. When death becomes imminent, the family of the dying person performs rituals and prayers for a good death. A migrant family who resided in New Zealand affirmed that prayers were auxiliary in promoting a death that is an alignment with their faith (Bray & Goodyear-Smith, 2007). "We were four around him and every single one of us made that prayer around him . . . it was important for us and it's important for him and he went the correct way" (Bray & Goodyear-Smith, 2007, p. 97). Even though this was a report by a Muslim family, the practice of prayers, confession, communion, anointing and holy water are also

common among Ethiopian Orthodox Christians. It is assumed that these practices may bring one of two results: a cure or a peaceful death.

Overall, the literature that was reviewed in this paper depicts religion and spirituality as sources of hope and strength. Religion can also serve as a means for a peaceful death. It shapes EOL care choices. Patients and their families want to perform rituals and prayers at the time of dying that are in alignment with their religious beliefs. This implies the need for nurses and healthcare providers to consider the religious beliefs of the dying person and facilitate spiritual services. This also provides EOL care that meets the religious and spiritual needs of both the patient and their family.

### **Critiques, Strengths and Weaknesses**

This literature review project holds several strengths. The review reflects the EOL care experience, not only for first-generation Ethiopian immigrants, but also of people from diverse cultural, ethnic, language, and religious backgrounds. This review project also includes the EOL care experiences of Ethiopian immigrants in many parts of the world including the United States, Canada, and Israel. Moreover, the literature included for this review was conducted by highly qualified healthcare professionals, including nurses (PhD and masters level nursing) and medical doctors.

The literature reviewed in this project also carries some limitations. In the literature reviewed, the various terms used to describe immigrants could be a potential source for risk of overgeneralization of immigrants and Africans in one “bucket.” Caution is needed, for there are shared experiences as well as differences, even though people belong to the same geographical regions. In addition, the review of the EOL or palliative care experience for first-generation Ethiopian immigrants did not contain literature from Level I (one) and level II (two) studies.

### Summary

The literature review resulted in five main themes: limited awareness of palliative care; the importance of culture; experiences of communication and language barriers to EOL care; family involvement; and religion and spirituality as complimentary during terminal illness. Limited knowledge about available resources for palliative care and unfamiliarity with palliative and healthcare directives caused a low use of EOL care and a lack of satisfaction of EOL care by immigrants and religious, ethnic, language and cultural groups. Also, communication and language barriers contributed to low use of EOL care. Although interracial relationships continue to become more prevalent, historical abuse in medical practice and abuse of African-Americans still impacts patient healthcare decisions. A lack of trust in providers, a fear of not receiving treatment if they completed healthcare directives, and religious reasons (only God can take a life, and withdrawing from life support is against God's will) led some patients, including African-Americans, to make decisions favoring curative or life-sustaining treatments rather than palliative care. This literature review also shows that some immigrant families, due to their high levels of education and life experiences, were able to access palliative care and had a positive EOL care experience. Moreover, the literature evidence reviewed reported that healthcare professionals were not fully knowledgeable about the cultural needs of their patients during EOL care.

## **Chapter Four: Discussion, Implications for Nursing, Strengths, Limitations, and Recommendations**

Chapter four presents the discussion, implications for nursing, strengths and recommendations, as well as a conclusion of the literature review. In addition, the limitations of the review are acknowledged. This chapter also presents Leininger's theory of Culture Care Diversity and Universality and examples of its application for delivering EOL care or palliative care for Ethiopian immigrants.

### **Discussion/Synthesis**

The literature review confirms that limited awareness of EOL or palliative care, culture, family, language, communication and religion are significant findings that have strong relationships to EOL care experiences for Ethiopian immigrants. This critical review of the literature suggests suboptimal EOL care among Ethiopian immigrants that coincides with the original speculation of a substandard EOL care experience for this population. “Studies from the United Kingdom and the United States show that awareness of and access to palliative and hospice care service are low among people of African descent and other minority ethnic groups compared to the general population” (Hiruy & Mwanri, 2014, p. 189).

In totality, diverse groups of people, including African-Americans and Ethiopian immigrants, have experienced poor health care, most notably palliative care. “As a result, Black people often experience the physical and social ill effects of lifelong exposure to racism, and concomitant poor health and reduced access to health services” (Maddalena et al., 2013, p. 145).

Moreover, a systematic review of the primary research on minority groups and EOL care by Evans et al. (2012) concluded that minority ethnic groups had a low rate of EOL care service and also received a substandard quality of service. This brings one to question the EOL care experience of Ethiopian immigrants as well.

Individual autonomy (rather than group) and science-based practice (rather than traditional) dictate modern palliative care when there is no hope for a cure; these are examples of values held by healthcare systems in the U.S. and other developed countries. These values are embraced in all areas of healthcare specialties, including EOL or palliative care, and are meant to assist in providing quality EOL or palliative care. This ensures comfort, the alleviation of pain and suffering, and a positive EOL or palliative care experience for both the patients and their family members.

In western medicine, palliative care service, autonomy, informed consent and completing advance healthcare directives are viewed as valuable tools, especially during terminal illness in communicating the wishes of the patient and accessing services that helps alleviate pain and other symptoms. However, these valuable ideas from western society are not equally important among people from traditional or developing countries, such as first-generation Ethiopian immigrants; these options are unfamiliar and can create delay in receiving care, hesitation to receive care, and miscommunication among patients, family members and providers. These factors place Ethiopians and other immigrant groups at a higher risk of poor access and poor EOL care.

### **Improving Awareness of Palliative Care**

Advance care planning (advance care directive and assigning a legal representative) plays an important role in delivering EOL or palliative care. “Advance care planning (ACP) is one means of improving end-of-life care as it enables a person’s prior wishes to be known should they lose decision-making capacity” (Jeong et al., 2014, p. 245). Patients’ and families’ lack of knowledge about palliative care, being new to the idea of palliative care, and the inability to complete the advance healthcare directives are common facts among first-generation Ethiopian



immigrants and diverse minority groups; these factors correlate with poor communication of patients' health care wishes and substandard care (pain and suffering) for Ethiopian immigrants. This calls for nurses and other healthcare professionals to find ways to increase an awareness of EOL or palliative care services. Increasing the awareness of palliative care can be achieved through providing education about palliative care, such as preparing a form that is easier to understand. For example, having a copy of the advance healthcare directive form in Amharic (the official Ethiopian language) would enhance patients' and families' understanding of EOL or palliative care and their ability to access and receive these services.

A lack of knowledge and experience with palliative care greatly impacts one's ability to access EOL or palliative care. Because of this knowledge deficit, some immigrants demonstrated difficulty completing the advanced health directives form. An advance healthcare directive clearly communicates a patient's wishes and explains to providers how to fulfill these wishes. An incomplete advanced healthcare directive can result in miscommunication, unnecessary treatment, and the omission of treatment or inadequate EOL care to patients and their families.

Other paradoxes and inconvenient circumstances were discovered in the literature review. Offering patients an opportunity to complete an advance healthcare directive and communicating poor prognoses directly to patients are standard practices in the American healthcare system. However, these services were found to be offensive and inappropriate to some members of the Ethiopian community (Beyene, 1992).

Furthermore, healthcare providers held misperceptions about people of color. According to Crawley et al. (2002), "Healthcare workers' misperception of their patients would impact the quality of EOL care they would provide" (p. 675). Regardless of religion, ethnicity, color, or culture, every human being deserves care that meets their needs. Therefore, increasing healthcare

workers' knowledge about their patients and their families' health practices would reduce stereotyping and promote the delivery of a satisfying EOL care.

Additionally, racism has a negative impact on African-Americans decisions about palliative care. For example, due to past experiences involving mistrust of providers, some patients prefer life-prolonging measures such as ventilation, even when dealing with terminal illnesses where it is medically deemed there is no hope of recovery. Nurses and healthcare workers need to understand the reasons behind their patients' choices. Establishing a trusting relationship is vital for providing appropriate EOL care, in particular for those patients who have had negative healthcare experiences in the past.

Nurses have the primary duty of assessing the level of awareness of palliative care, including the cultural, religious and spiritual needs of the patient that relate to EOL care. Also, involving family members in the care plan will close the gap and improve EOL care for Ethiopians. Since immigrant communities continue to grow, "diversity is therefore a reality with an increased proportion of people who do not live in her own native country or culture" (Koffman, 2014, p. 8). For this reason, there is an increasing need for nurses and other healthcare workers to understand other cultures and how to care for people from diverse backgrounds. Learning about immigrant communities can be accomplished through formal training, informal interactions and by reading articles on various cultures. Interacting with community members from Ethiopia in public or in community settings is another way to learn about Ethiopia and Ethiopian culture. For instance, nurses can learn a lot about Ethiopians' EOL care practice by attending bereavement and funeral ceremonies. Observing bereavement and funeral ceremonies and interacting with friends and family members of the deceased can provide some insight into EOL care practice in this community. Kemp (2005) indicted that making contact with

community members in community settings such as restaurants and laundromats are better ways to get information about communities.

### **The Important Role of Culture**

The literature review in this project indicates that culture plays an important role in the EOL care experience of Ethiopians. There is a strong link between cultural health practices and care of the dying during terminal illness. Therefore, it is essential that nurses pay attention to the traditional ways to deal with terminal illnesses. These include the use of home remedies (garlic, honey, and other herbs) and large numbers of visitors.

The United States' practices for caring for the terminally ill may create cultural misunderstanding and dissatisfaction in EOL care among Ethiopians. Services offered to alleviate the pain and distress of the dying person and their family members resulted in some degree of paradoxical effects among these diverse groups. For example, an admission to a palliative care program means access to care for managing pain and other distressing symptoms that are related to death and dying as well as meeting EOL standards and ensuring a positive EOL care outcome for the dying person and their family members. However, the EOL care practice of Ethiopian immigrants was more traditional and grounded in religious and cultural beliefs and practices than in western medicine. Hiruy and Mwanri (2014) identified common Ethiopian cultural values such as a sense of community life, good human relations and the sacredness of life and religion. These values influence their end-of-life care choices.

The literature review reported that Ethiopian immigrants expressed disappointment over their EOL care. For example, Kemp (2005) reported that minorities, especially immigrants who have limited English proficiencies, experience unnecessary and poorer EOL care outcomes. The provider's disclosure of an Ethiopian patient's poor prognosis lacked adequate cultural

accommodations. For example, communicating information about death or dying in the evening time or when the patient is alone by themselves is unacceptable among Ethiopians. Instead, it is culturally appropriate to inform patient during daytime with family and friends who are available to provide reassurance and support for the immediate family of the deceased. (Beyene, 1992; Grisaru et al., 2008).

However, as reported by Hiruy and Mwanri (2014), sometimes a recommendation for admission to a palliative care service creates a deep sense of guilt for Ethiopian family members. The family thinks that once the patient is admitted, they will no longer be able to care for their loved one at home, which can lead to feelings of exclusion. A difference in culture surrounding EOL care practice, as well as an incomplete or absent understanding of palliative care, could be the main reasons for these negative palliative care experiences.

Nurses need to carefully assess the level of pain and other distressing symptoms in Ethiopian patients. For instance, men are expected to act boldly and may smile or deny pain, even though they are experiencing immense pain and suffering. “The Ethiopian tradition demands that a man shows great resilience no matter what the situation” (Hiruy & Mwanri, 2014, p. 190). This implies that nurses need to make an ongoing assessment and offer interventions, such as pain and nausea medications. Nurses can promote the involvement of friends and family members who can influence and convince the patient to receive treatment.

### **Involving Family**

This literature review reports that, among people from diverse groups, family involvement during terminal illness and dying is significant. “In other cultures, decision making may be seen primarily as a duty of the family, whose responsibility is to protect the dying patient from the burden of making difficult choices about medical care” (Kagawa-Singer & Blackhall,

2001, p.14). Providing physical care, giving emotional support and making decisions for the sick and the dying are some of the roles played by the family members of the dying person. These family roles require proper acknowledgement by nurses, nurse leaders and healthcare professionals so that families will feel welcomed to care for their dying family member. Also, being cared for by families and relatives can be comforting for patients. As immigrants left their extended families behind, they built a new support system, including family and friends from church and other connections in their community. For legal and ethical purposes, as well as to respect the patient's private information, identifying and documenting individuals who the patient considers family becomes crucial.

In Ethiopian culture and other traditional societies, family members are expected to take primary responsibility for the care of the dying person. Because of this, an admission of an Ethiopian patient in Israel to a palliative care service did not settle well for family members of the dying person (Hiruy & Mwanri, 2014). "Traditionally such an arrangement would be less acceptable (at least in rural Ethiopia). His wife, his children, and even his relatives would be considered as people who let their loved one down" (Hiruy & Mwanri, 2014, p. 190). In this case, the family assumed that they were excluded from caring of their loved one. An EOL care that intentionally integrates patients' and families' values while acknowledging and encouraging family to provide care for the dying would be more effective in producing an enhanced EOL care.

Regardless of backgrounds, western or traditional, family is typically involved in the care of their loved ones. For example, Jeong et al. (2014) reported that appointing a family member to be a healthcare decision maker is evident among white people. Because of this fact, the author of this review acknowledges that in every culture, family is important; however, their roles in

providing direct EOL care may be more emphasized in non-traditional and developing nations. Kemp (2005) pointed out that family care might not be consistently outstanding or perfect. It can be stressful among these diverse populations to care for a dying family member, especially during EOL care. It adds emotional and physical stress to family members' lives. Sometimes taking time off from work to care for an ill family member can strain resources and finances. Therefore, when providing EOL care for Ethiopians as well as other immigrant groups, considering the availability and capability of certain family members to care for the dying person helps nurses deliver care without causing additional stress.

### **Language and Communications**

The literature review reports that language barriers and communication barriers correlate with poor access and low use of EOL care and negative EOL care experiences. "A lack of joint decision-making caused by communication problems among the many care providers involved in the case, resulting in both family and care providers being dissatisfied with the care" (de Gfraaff et al., 2012, p. 376). In some instances, there is a discrepancy between what the provider told the patient and his family and what the patient and the family understood. For example, in Johnston and Kanitsaki's (2009) study, the misunderstanding that the patient was actively dying provoked family members to take the patient from the healthcare facility to perform common cultural EOL care rituals. As a result of this miscommunication, one patient, who was in need of palliative care, was left in the backyard to spend several sleepless nights. "Based on what the family understood they had been told, and in keeping their traditional practices, the family took the man home 'and painted him up and put him under a tree for 3 days because they thought he was going to die right then and there" (Johnston & Kantisaki, 2009, p.411). Providing trained medical interpreters and checking patients' and families' understanding reduces the negative impact of

language and communication barriers, prevents unnecessary distress and improves the EOL care experience for patients, families and nurses.

## **Religion**

Much evidence indicates that for many people, Ethiopians' religion plays a significant role during times of life-threatening illness and impending death (Hiruy & Mwarni, 2014; Kemp, 2005). As reported in Grisaru, Malkinson and Witztum (2008), after the death of an Ethiopian immigrant in Israel, the spiritual father sprays holy water on the family of the deceased's house as this purifies and protects the family of the deceased. This implies that nurses, and healthcare workers in general, need to honor and make their best effort to facilitate these common and important religious practices towards the patient's end-of-life. Welcoming spiritual fathers, priests, and pastors are crucial for the spiritual well being of the patient and their family members. Nurses can play a vital role in incorporating prayer time in the care plan and facilitating prayers and visitation from a spiritual director or priest.

## **Implications for Nursing**

This literature review reported a preference for a more traditional EOL care practice for immigrants and minority groups such as African Canadians. "For many African Canadians living in Nova Scotia, palliative care services have historically been underutilized. Family-centered care in the home setting at the end of life is indeed preferred" (Maddalena et al., 2013, p. 144). This traditional way of caring for the dying at home is common for Ethiopians as well. Their choices and decisions for EOL care are oftentimes dictated by their religious, ethnic and cultural practices. Unfortunately, the review indicated that many immigrants, including Ethiopians, feel disappointed in how they are informed of a poor prognosis and frustrated by the perception that an admission of a dying family member to a palliative care service would restrict them from

providing care to their loved ones (Hiruy & Mwanri, 2014). Another example of this disappointment is found in Beyen's (1992) research when a patient who was diagnosed with terminal cancer was upset with her provider for telling her of her illness. The review brings opportunities for nurses to improve practice, provide education, as well as conduct research on EOL care issues among Ethiopian immigrants.

### **Application of Theory**

Much evidence indicated that culture plays a significant role in EOL or palliative care for first-generation Ethiopian immigrants (Hiruy & Mwanri, 2014; Holt, 2001; Crawly et al., 2002). It is clear that Ethiopian community members want to be cared for by family members and have a strong desire for religious and spiritual practices (Evans et al., 2012; Jeong et al., 2014; Ko & Bonillia, 2012). In addition, a limited awareness of palliative care as well as language and communication barriers are evident and contribute to low use of EOL and palliative care as well. "A scarcity of information in appropriate language and formats was frequently identified as a cause of low awareness and negative perception of palliative care" (Evans et al., 2012, p. 278).

Nurses, by taking on these challenges and opportunities, can deliver an enhanced EOL care delivery to Ethiopians as well as to other people from diverse cultural, ethnic, language religious backgrounds. This care can be implemented by applying the three facets of Leininger's theory of Culture Care Diversity and Universality: culture preservation and/or maintenance, culture accommodation and/or negotiation and culture repatterning and/or restructuring.

#### **Leininger's theory: culture preservation and/or maintenance.**

Nurses can apply culture preservation and/or maintenance whenever patients' requests can be fully integrated in their care. The nurse's answerer for these requests is "yes," we can do this. "This option can be followed when the client says, in effect, 'this is what I want,' and the



nurse thinks, ‘that is good. Let’s do it’” (Holt, 2001, p. 152). For example, when a patient or family member requests to be visited by their spiritual father, then the nurse can preserve the patient’s religious practice by allowing the visit.

Nurses strive to assist in preserving the culture of their patients and their families, as culture plays a significant role in care, especially towards the end of one’s life. This can be done in a number of ways. Cultural preservation is a “yes” answer to the patient’s requests. The request should be something that can be done without violating the health practice guidelines and the safety of all involved parties. Some examples of nurses’ actions that promote the patient’s cultural preservation include allowing visits from families or religious fathers and promoting involvement while welcoming the family. It is important to relate to patients and families and create rapport by offering simple gestures such as smiling, offering a place to sit or water to drink, or even sharing their culture.

**Leininger’s theory: accommodation and/or negotiation.**

Nurses can also apply culture accommodation and/or make negotiations. This allows nurses to negotiate with the patient and take action to reasonably meet the EOL or palliative care needs of the patient. In this literature review, much evidence points to the ill-effects of directly disclosing a terminal illness to a patient (Beyene, 1992; Grisaru, Witzum & Malkinson, 2008; Hiry & Mwanri, 2014). Nurses’ knowledge of this cultural issue can assist to make a better plan that accommodates the patient’s culture. Nurses can advocate for a reasonable accommodation by talking to the patient’s doctors about slowly sharing the poor prognosis and making sure the patient’s family is present during this time. A plan to share difficult information slowly will accommodate the patient’s culture and be less traumatic to patients and their families.

“According to Dr. Willems, the message should be tailored to the recipient, and bad should news

be delivered in small doses and in phases” (de Graff et al., 2012, p. 377). Another example of cultural accommodation or negotiation is when a nurse says, “let's make a plan.” For instance, it is important to work with the patient when they receive a large number of visitors rather than limit the number of guests.

**Leininger’s theory: culture repatterning and/or restructuring.**

By applying Leininger’s culture repatterning and/or restructuring, nurses can promote safe care. In times when nurses believe that requests from patients and/or their families interfere with the delivery of safe care, nurses may decline these requests while acknowledging patients’ beliefs and values. A nurse might say, “We may not be able to organize care in the way that was most familiar to you, but let’s try at least to find something more satisfactory than what you are experiencing now” (Holt, 2001, p. 152). A nurse may politely offer other options as well. They could say, “For safety reasons, this is not how things are done here,” if a patient takes herbs from home which are difficult for nurses and healthcare professionals to identify. Providing adequate explanations to patients and their family members and offering alternative ways of care may provide privacy and help the family to feel that everything was done to maximize their experience. Nurses may take action by declining patients’ requests and offering other safe alternatives when a patient’s request does not align with the legal, ethical standard of care. When a dying family asks to take the body of the deceased home for religious and cultural reasons, nurses should explain that it is not a standard practice, but that the body can be kept longer in the hospital room. This will give families time to have prayer. Nurses may offer other alternatives such as suggesting family members to go to the funeral home to make sure the body is prepared in a way that is accepted according to their cultural and religious practices.

These three frameworks of Lieninger's theory of Culture Care Diversity and Universality give nurses a more culturally appropriate and systematic way of responding to patients' EOL care needs. Nurses need to become familiar with the culture of their patients. Knowledge of a patient's culture prevents nurses from being confused by the patients' requests. In addition, nurses should conduct a patient's cultural needs assessment. Nurses can learn from interactions with diverse groups about the EOL care experience and palliative care (advance care planning, use of healthcare directives, assigning representatives). Nurses can take the lead in promoting an early discussion of palliative care so that this information will be made available. These resources will help patients access EOL or palliative care and enhance their experience.

In Ethiopian culture, greetings are highly valued as a welcoming sign for Ethiopians. Nurses should consider a simple greeting such as smiling, head bowing, or saying hello with the Amharic word *Selam*, which means "peace with you" or "I wish you peace." Other examples include patients requesting an interpreter or a community leader to be present during the discussion who knows the language and the culture (Holt, 2001; Evans et al., 2012). Prior to allowing mediators, nurses needed to receive permission from the patient.

Generally, nurses, by applying Leininger's theory of Culture Care Diversity and Universality, have the ability to improve EOL or palliative care for first-generation Ethiopian immigrants as well as for people from diverse religious, ethnic, linguistic, and cultural backgrounds; this is achieved through patient education about EOL care, initiating early discussion of palliative care, and providing culturally appropriate care.

### **Recommendations for Practice**

The literature review of EOL care for immigrants, including Ethiopians, indicated unmet EOL care needs among this community. This calls for an improved EOL care practice for these

patients and their families that can be achieved from multiple directions. For example, making reasonable considerations about patients' cultures and religions, assessing patients' and families' level of knowledge about EOL care in practice and making an effort to incorporate their choices will address the EOL care needs of patients. Involving family members, facilitating religious practices and accommodating and negotiating cultural preferences may assist in delivering an enhanced EOL care and achieving the goal of palliative care - to provide comfort, alleviate pain and suffering and allow patients to die with dignity.

### **Recommendations for Research**

It is unknown to the author of this review whether it is due to a lack of research conducted or a lack of publication, but searches from electronic databases suggest that there are limited studies available on the EOL care experience of Ethiopian immigrants. This suggests that Ethiopian immigrants and their EOL care experiences are not sufficiently represented in research. This brings valuable opportunities for nurses to conduct research related to this topic, particularly in the form of case studies, interviews, ethnographies and advocating for the publication of research materials pertaining to this issue.

Furthermore, conducting research may not always be feasible due to limited time and resources in addition to other constraints. Nurses, as well as nurse leaders, can increase their cultural awareness by reaching out to community members in different community settings such as restaurants, the marketplace, corner stores, and talking to coworkers from various cultural backgrounds. Churches and communities can also be helpful resources to observe group activities. "Because if you do not know a person, you got to go find out his identity, go where he lives, where he goes, where he was born, who's in his family" (Kagawa-Singer & Blackhall, 2001, p. 3).

Immigrant-led institutions, such as the Ethiopian Orthodox Christian Church and the Ethiopian Community Center, are good informational resources that provide a variety of high quality services to their members. For example, in Minneapolis, Minnesota, data that was used in the Ghobadzadeh, Demerath, and Tura (2014) study was collected by the church's parishes nursing program volunteer health professionals. This contributed to an enhanced understanding about some health challenges of this community, including the risk for cardiovascular disease. When collecting subjective information from an organized institution, one should take caution, because one's personal circumstances related to Ethiopian economic, political, and social responses from some members of the community might be a reflection for or against certain political or social issues that stem from their home countries. "Making community contacts is extraordinarily easy in most cases. This author prefers contacts in restaurants, laundries, and the like over community centers and churches and so on" (Kemp, 2005, p. 45).

The author of this project recommends an enhanced integration of patients' cultures and religious preferences into EOL care. This project revealed that few articles are available on Ethiopian immigrants' EOL care experience. For this reason, the author of this project recommends future research to be conducted, preferably original study rather than a review of literature. The author also recommends that nurses advocate for the publication of research that is conducted on the EOL care issue on this community.

### **Recommendation for Education**

This review of literature calls for an integration of EOL care education and information about immigrants and diverse groups of people. This education can be provided in the nursing program's palliative care section. Also, this teaching needs to be included in staff development and during nurse orientations and trainings. Acquiring a greater knowledge base about EOL

practices for minorities will assist in EOL care; this will bring comfort and a greater positive EOL care experience for these demographics. Moreover, it is crucial to formally integrate EOL or palliative care needs of first-generation Ethiopian immigrants into nursing education and staff development.

### **Strengths**

This review of literature holds a number of strengths. First, highly qualified healthcare professionals, including authors who are nurses and medical practitioners, wrote the articles used for this review. Second, this literature review represents diverse research conducted not only on Ethiopians, but also on those from other diverse backgrounds (Eretria, an Indian Muslim family from North Africa, Moroccan and Turkish families, African-American and Spanish, community-dwelling older people) which all generally share similarities in their EOL care experience - low EOL or palliative care experiences.

Third, the literature was from several developed nations including the United States, Canada, the United Kingdom, New Zealand, and Australia. Despite differences that exist in each immigrant group, these religious, ethnic, linguistically and culturally diverse groups share a low EOL care experience in their adopted countries. The immigrant family in the Bray, Goodyear-Smith, and Gott (2015) case study had a positive EOL life care experience. This may be due to their own education level and ability to access care. However, this may not be true for other immigrants. Generally, low quality of EOL care, low awareness of palliative care, cultural and religious influence and family involvement are evident across the diverse groups and in a variety of developed countries, which make the case stronger and not an isolated incident.

### **Limitations**

There were limited publications available (electronic or non-electronic) regarding EOL care experiences for first-generation Ethiopian immigrants. It appears this population has not received enough attention, particularly in publications and nursing research in general.

There was also limited literature available specifically pertaining to the experience of EOL care of Ethiopian immigrants. Immigrants from Africa, for example, share similar adverse life experiences such as famine, war, and leaving families behind. Also, pain, death and dying are common human experiences. For these shared experiences, literature about EOL care of diverse backgrounds and immigrants from traditional societies were used to answer the practice question: what is end of life experience for first-generation Ethiopian immigrant patients and their families? Attention needs to be given not to place all immigrants and minority groups in one basket. There is uniqueness within each culture concerning EOL care preferences. Also, due to the scarce publication of articles, older studies were included in this project. Although old studies hold truth, recent research may better reflect the changing and current trends in EOL care practices of patients and their families.

### **Conclusions**

This literature review has demonstrated clear evidence for a substandard or unsatisfactory EOL care experience for Ethiopian immigrants as well as for many people from diverse religions, ethnicities, languages and cultural backgrounds. Much of the evidence (Jeong et al., 2014; Hiruy & Mwanri, 2014) used in this review directly and inferentially supported poor EOL care experiences among these diverse peoples.

This poor EOL care experience directly correlates with limited knowledge, lack of information and resources about EOL or palliative care, as well as cultural, language and communication barriers. Moreover, unpleasant and historic experiences, such as racism, fear and misperceptions of providers among people from diverse culture, ethnicity, language, religion backgrounds such as African-Americans, contribute to the low use of palliative care.

Nurses and nurse leaders can gain some understanding about the various factors that contribute to a poor EOL care experience for Ethiopians such as patients' knowledge about palliative care, language and communication barriers, and the significance of culture, family, and religion during the end of one's life. Nurses may use the knowledge and understanding that is obtained from this review to provide better EOL care experiences in the future, especially for these diverse populations. It is vital for healthcare professionals to seriously consider the patient's level of knowledge about EOL or palliative care as well as their specific familial, cultural, language and religious influences. Doing so can result in an improved EOL or palliative care outcome for these communities.



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## Appendix

## Evidence Synthesis Matrices

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Results & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Jeong, S., Ohr, S., Pich, J., Saul, P., &amp; Ho, A. (2014). 'Planning ahead' among community-dwelling older people from culturally and linguistically diverse background: A cross-sectional survey. <i>Journal of Clinical Nursing</i>, 24(1-2), 244-255. doi:10.1111/jocn.12649.</p> <p>Level: III</p> <p>Quality: Grade B (Good)</p>	<p>To explore preparedness of end-of-life care planning among community dwelling older persons of culturally and linguistically diverse background.</p> <p>To explore cultural beliefs, values on death, dying, truth telling, advanced care planning, and preference for EOL care.</p>	<p>Culturally and linguistically diverse background 453 community older adults (65 +) who attended 17-day care centers were invited</p> <p>229 community-dwelling older participants completed the survey.</p> <p>Conducted in Australia.</p>	<p>Descriptive quantitative cross-sectional study.</p>		<p>Enduring guardian 37.5% of Anglo Celtic 15.5, Mediterranean, 24.1 Eastern European, and 13.3 % Lower knowledge of advanced care planning.</p> <p>Lower number of completed advanced care plan.</p> <p>Lower practice of "planning a head" lack of time and knowledge of the healthcare directive forms. Family (daughter, son, and spouse) preferred decision makers.</p>	<p>Further research needs to be conducted for developing EOL care for ethnic groups, to inform practice. Also, research should be conducted to investigate the effectiveness of education proved to promote "planning ahead". Research from around the world is critical element to inform best practice. The challenges surrounding end of life care with a growing number is faced not only by Australia.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Results & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Hiruy, K., &amp; Mwanri, L. (2014). End-of-life experiences and expectations of Africans in Australia: Cultural implications for palliative and hospice care. <i>Nursing Ethics</i>, 21(2), 187-197. doi: 10.1177/0969733012475252</p> <p>Level: III</p> <p>Quality: Grade B (Good)</p> <p>Conducted in Australia</p>	<p>1) To provide some insight into the sociocultural end of life experience (EOL) of Africans.</p> <p>2) To provide points of discussion to consider an ethical framework.</p> <p>3) To highlight the importance of considering many factors such as migration history.</p>	<p>It was a single participant case study involving an Ethiopian patient in Australia who was admitted to a palliative care program.</p>	<p>Phenomenological study of some Africans and the researcher's lived experience</p> <p>The evidence supported by A case study, involving observation and interaction with a 40-year-old male participant from Ethiopia, East Africa.</p>	<p>The study participant, "Dagne" was known by one of the authors of the study for 4 years. The authors' observation and interaction with the participant during and after the participant's admission to the palliative care was documented.</p>	<p>Results: Culture plays a critical role in how the involved parties (patients' families' members and health providers) see end of life care. When planning end of life care, it is important to consider cultural, spirituality experiences as these shape patients and families' end of life care choices.</p>	<p>The authors recommended further study to be conducted on end of life care issue on African immigrants in Australia.</p> <p>The author cautions generalization of all Africans as one.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Results & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Bray, Y., Goodyear-Smith, F., &amp; Gott, M. (2014). Transnationals' experience of dying in their adopted country: A systematic review. <i>Journal of Palliative Medicine, 18</i>(1), 76-81. doi: 10.1089/jpm.2014.0044</p> <p>Level: III Quality: Grade B (Good)</p>	<p>To identify the lived experience of migrants dying in a country different from their country of birth.</p>	<p>Seven qualitative studies met the criteria. Electronic database search (EBSCO, CINAHL, MEDLINE, Geobase, PsychINFO, and Scopus).</p> <p>The research focused on migrants or transnational in New Zealand.</p>	<p>A systematic review of published evidence of researches, restricted to human subjects and English language</p> <p>Thematic analysis.</p>	<p>The preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used in the search process.</p>	<p>The three themes emerged: Dual identity (country of origin and country of adoption), the importance of traditions, and dying preference for end of life (place of dying final resting place, rituals and religious practice). Some prefer to return to their country of origin to spend time with family and for a complete ritual and some not.</p>	<p>The authors pointed out the need for more research on the issue. This systematic review of published articles informed future research to be conducted with phenomenology study design.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Bray, Y. M., &amp; Goodyear-Smith, F. A. (2007). A migrant family's experience of palliative care. <i>Journal of Hospice &amp; Palliative Nursing</i>, 9(2), 92-99.</p> <p>Level: III</p> <p>Quality: Grade B(Good)</p>	<p>To explore the lived experiences of Palliative nursing for different generation of migrant family in the New Zealand context.</p> <p>The study explored the underpinnings of culturally safe palliative care of an Indian Muslim from Africa.</p>	<p>An Indian Muslim family from Africa who resided in New Zealand for 3 years.</p>	<p>Qualitative Research: Intrinsic case study (interview) of immigrant family from Africa who had their family member died, passed 6 months bereavement.</p>	<p>The strategy of “bracketing” was implanted to avoid the researcher’s personal values and outlooks, NVIVO (QSR International, decanter, Interview was taped. Australia) a commuter assisted coding program was used to code the taped interview.</p>	<p>Six main themes emerged from the data analysis were family, community, culture, religion, furthering knowledge. Conclusion: The study revealed involvement of extended family and to die at home with family presence, prayer is critical The family had positive EOL care experience. The family education level, communication skill helps for quality EOL care and positive experience.</p>	<p>Involvement of extended family and often wishes to desire to die at home are significant. By respecting the different culture needs and empowering the family to direct the plan of care a cultural and Muslim-based model of care instead of the general model was created. Nurse’s knowledge about palliative care is critical. All patients deserve the most appropriate EOL care.</p> <p>The needs of each individual and families are different, he case study may not apply to all others</p>



Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (include reliability & validity)		
<p>Holt, L. L. (2001). End of life customs among immigrants from Eritrea. <i>Journal of Trans cultural Nursing</i>, 12(2), 146-154.</p> <p>Level: III</p> <p>Quality: Grade B (Good).</p>	<p>To avoid cultural imposition on the part of U.S health care providers.</p> <p>To explore source of strength within the Eritrean community.</p>	<p>Two participants from Eritrean Community who live in Minnesota, U.S.</p>	<p>Ethnonursing study.</p> <p>Interviews.</p> <p>The interview was audiotaped and transcribed.</p>	<p>Six open ended interview questions administered to the participants.</p> <p>The researcher collaborated with Cross Cultural Health Care Program (CCHCP) of Seattle. CCHCP serve as a link between communities and health care institutions and enhance full access to culturally and linguistically appropriate care.</p>	<p>Eritrean immigrants considered aging is a blessing, Death is not feared among elders. It is believed that whatever happens is accepted to be God's will. Culture and religion are interlinked closely. Cautious to be made when doing anything that might take away a person's hope, such as telling a person he or she has a terminal illness, or estimate time of imminent death. Conclusion: suggests to allow for family involvement, prayers and allow visiting</p>	<p>Throughout life and at the time of death, Eritreans depend on values of respect, faith, close family ties, and visiting.</p> <p>The authors feared for imposing American cultural values upon immigrants, suggested to shape our American environment to support Eritrean values that will benefit both the U.S and Eritreans.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (include reliability & validity)		
<p>Evans, N., Meñaca, A., Andrew, E. V. W., Koffman, J., Harding, R., Higginson, I. J., . . . Gysels, M. (2012). Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom. <i>Journal of Pain and Symptom Management</i>, 43(2), 261-286. doi: 10.1016/j.jpainsymman.2011.04.012</p> <p>Level: III</p> <p>Quality: Grade B (Good)</p>	<p>To systematically review original studies of minority ethnic groups and EOL –care in the U.K and appraise their quality.</p> <p>In the contexts of patients from minority ethnic groups in the United Kingdom experience lower rate of referrals to EOL care service, higher level of dissatisfaction, some perceived culturally inappropriate EOL care.</p>	<p>45 research studies met the inclusion criteria and used for review.</p> <p>The review involved Literatures in English language on ethnic minority group and EOL care in the U.K.</p>	<p>A systematic Review of the primary research on minority groups and End of life care. .12-database search, 8 journals, reference lists and lay literature were used.</p>	<p>The review was conducted as part of “PRsMA”, a program that aim to coordinate research and practice about EOL care in Europe and Africa.</p>	<p>Key themes age structure, inequality by disease group palliative care focuses on cancer, low referrals, caregivers (family may not be always available to support the dying), preference for place of care and death varies (ex. hospital, return to home country), low awareness of services and less likely to understand the information, communication problem, language barrier and cultural competency.</p>	<p>Recommendations for healthcare providers and policy makers: EOL care to non-cancer patients, improve awareness of service, improve communication and holistic approaches. This systematic review of literatures indicated that lack of agreement on the definition of “cultural competence”. It was recommended the need to clarify what entailed in “culturally component” EOL - care</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Kemp, C. (2005). Cultural issues in palliative care. <i>Seminars in Oncology Nursing</i>, 21(1), 44-52. doi: 10.1053/j.soncn.2004.10.007</p> <p>Level: III Quality: Grade B (Good)</p>	<p>Ethnic, racial, or cultural disparities are evident in health care, including hospice, and palliative care which result in underuse and under treatment which bring unnecessary suffering and poor outcome especially to foreign born and non-english speaking. To review the common issues at issues at the end of life across cultures and the measures that can be taken to address the issues.</p>	<p>31 published articles and texts were used to discuss the issue of end of life care across culture.</p> <p>Common cultural issues at the end of life, Texas, U.S.A.</p>	<p>Review of published articles and textbook chapter.</p>	<p>The article prepared based on information extracted from thirty years of experience in working with immigrants and refugees in the Unites States and overseas” (Kemp, 2005)</p>	<p>Culture plays a critical role in how patients, families, and health care providers view the end of life care. culture guides one’s preference for place of death, care after dying</p> <p>Faith and religion are part of EOL care but some may not support clergy involvement.</p> <p>Family involvement</p>	<p>Increasing cultural knowledge among nurses will serve foundation for initiating the investigation of individuals or family beliefs.</p> <p>Identifying and learning about a culture is the first step to providing quality care by reading literature, contacting to communities, restaurants, shopping laundries and from patients and families.</p> <p>The beliefs of individual and family are fundamental when discussing EOL care</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Johnston, M., &amp; Kanitsaki, O. (2009). Ethics and advance care planning in a culturally diverse society. <i>Journal of Trans cultural Nursing</i>, 20(4), 405-416. doi: 10.1177/1043659609340803</p> <p>Level: III Quality: Grade B(Good)</p>	<p>To provide critical cross-cultural examination of the mainstream bioethical foundations of advance care planning and advance directives and their possible implications when applied without modifications in a culturally diverse society.</p>	<p>Critical crosses examination of existing evidences. Over 50 references were used.</p> <p>Review of existing evidences in multicultural societies: Australia, Canada, United Kingdom and United States of America.</p>	<p>Examination of Critical crosses examination of existing evidences. Over 50 references were examined.</p>	<p>The Authors of the articles were registered nurses' independent scholars and possessed PhD.</p>	<p>patients of minority cultural and language backgrounds do not possess advance directives or advance care plan; many consider the idea as being strange, think completing the form will prevent them from getting care, mistrust health care providers, providers not aware of the mistrust, preferred family as decision maker, prefers life prolonging treatment, Conclusion: Mainstream health care, autonomy and patient choice and policies need to be culturally sensitive (ex. partial truth telling).</p>	<p>Efforts needs to be made by policy makers, health service providers and cultural care theorists to ensure the policies and programs are properly informed by cross cultural care What is beneficial for one group may not hold the same benefit of or the other group (e.g. Greek, Italian, Chinese, Ethiopian) do not regard autonomy as empowering. Families should be regarded as important part of the care team.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Ko, E., Cho, S., &amp; Bonilla, M. (2012). Attitudes toward life-sustaining treatment: The role of race/ethnicity. <i>Geriatric Nursing</i>, 33(5), 341-349. doi: 10.1016/j.gerinurse.2012.01.009</p> <p>Level: III Quality: Grade B (Good)</p>	<p>To explore attitudes regarding life sustaining treatment (LST) between Koreans American and Mexican American individuals.</p> <p>LST includes ventilator, artificial nutrition and hydration, medications that prolong life or delay death.</p>	<p>A convenience sampling was used to elect the participants. IRB approval obtained. Informed consent obtained.</p> <p>Sample was 122 older adults residing in urban areas of west coast (64 Korean Americans and 58 Mexican American is)</p>	<p>A cross sectional design. Measures: Life sustaining treatment (LST) general attitude score consists of 13 items. 15 strongly disagree to use LST. 45 strongly agree with the use of LST. Interview method was used for data collection.</p>	<p>The Short Portable Mental Status Questionnaire (SPMSQ) was used to assess the participants' cognitive ability. 30-40 minutes length allocated for each interview. Bilingual professionals translated were used. Hierarchical multiple regression was used to (LST)</p>	<p>Both groups are ethnic minority. However, Mexican-Americans are more likely to use LST than Korean Americans.</p> <p>Conclusion: There was a difference in attitudes towards LST. Mexican Americans were more likely to show a positive choice and attitudes towards LST than Korean American.</p> <p>Spirituality and religion play role and withdrawing LST is seen as against God's will.</p>	<p>End of life (EOL) care planning is complex yet imperative for all racial ethnic groups. Including an understanding of attitudes towards end of life care decision with persons of different ethnicities. Is essential in promoting culturally appropriate EOL care.</p> <p>Cross cultural experience may give health care professional with different ways to ease the dying.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Koffman, J. (2014). Servicing multi-cultural needs at the end of life. <i>Journal of Renal Care</i>, 40 (Suppl. 1), 6-15. doi: 10.1111/jorc.12087</p> <p>Level: III Quality: Grade B (Good)</p>	<p>There is a growing concern that end-of-life cares is not offering Black Asian and Minority Ethnic (BAME) groups the most appropriate service. The purpose of the study is to give greater understanding, of diversity, explore the experience of BAME patients with advanced disease and its responses and the role of religion and spirituality.</p>	<p>Garfield, a 68-year-old African Caribbean gentleman with advanced disease. Mrs. Garfield insisted to continue treatment, her trust to the team and their motives. However, the medical team believed Mr. Garfield was no longer a candidate and dialyzing him will cause home unnecessary burdens. The case presented is an African Caribbean patient admitted in a teaching hospital London, U.K.</p>	<p>Review of current evidence primarily from United Kingdom and United States of America.</p>	<p>Bio-data of the author: Dr. Jonathan Koffman, a senior lecturer in Palliative Care.</p>	<p>When providing of care, dying and bereavements, it is important to understand the needs of specific communities requires us to apply framework of equity of provision. Black and minority ethnic groups underutilized palliative care. Immigrants may not know about the palliative care. The service is unavailable or limited in many developing countries. Culture, religion, spirituality impacted EOL care significantly.</p>	<p>An individualized approach to care with a focus on quality is paramount for any patient regardless of the ethnic or cultural background. Cross cultural experience may add to the knowledge, skills and expertise of healthcare professionals that ease the dying process for all the involved parties: patients, their families and healthcare professionals...</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Evans, N., Menaca, A., Koffman, J., Harding, R., Higginson, I., Pool, R., &amp; Gysels, M., (2012). Cultural competence in end-of-life care: Terms, definition, &amp; conceptual models from the British literature. <i>Journal of Palliative Medicine, 15</i>(7), 812-820. doi:10.1089? JPM.2011.0526</p> <p>Level: III Quality: Grade B (Good)</p>	<p>To survey cultural competence approaches described in the British literature on EOL care and minority ethnic group. The framework” cultural competency approached originated from the U.S.A. by Dr. Madeleine Leininger, who is the pioneer in cultural care in nursing.</p>	<p>38882 articles screened.</p> <p>One hundred thirteen articles on minority groups and EOL care in the United kingdom were identified.</p>	<p>Critical review of articles on cultural competency from systematic review of literature on minority ethnic groups and EOL care in the United Kingdom.</p>	<p>Content analysis of definition (words or phrases) and models. Models predominantly of American Origin. Two models: cultural competency teaching and assessment of patients’ cultural backgrounds. Models predominantly of American Origin.</p>	<p>Most frequently used term: cultural sensitivity, More often defined term: cultural competency. Seventeen different terms used to describe cultural care sensitivity</p>	<p>Further research is needed for conceptual clarity of cultural competency or cultural sensitivity for providing a framework and to measure outcomes of EOL care.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Maddalena, V., Bernard, W. T., Davis-Murdoch, S., &amp; Smith, D; (2013). Awareness of palliative care and end-of-life options among African Canadians in Nova Scotia. <i>Journal of Transcultural Nursing</i>, Apr2013; 24(2), 144-152.</p> <p>Level:III</p> <p>Quality: Grade B(Good)</p>	<p>To answer question: -understanding of African Canadians regarding their option for accessing palliative and EOL care service -what are lacking to support the family and community, -influence of knowledge of palliative and EOL care service 4: policy changes are needed to improve EOL care service.</p>	<p>-purposive sampling and Snowballing Sampling.</p> <p>-the focus group formed of six participants (4 women and 2 men) The research was conducted in North America, Canada</p>	<p>Qualitative Naturalistic Enquiry: interviewing the focus group.</p>	<p>Thematic Analysis and Discourse Analysis.</p>	<p>-Lack of knowledge of palliative care service and lack of understanding of service were barriers to entering into palliative care service. Culture plays a significant role in EOL care issues.</p>	<p>Recommended research in exploration of how health care professionals in palliative care understand and attended to EOL care of vulnerable and marginalized segments of populations. Recommended in exploration of more effective ways to increase population participation to identify the palliative care needs of the population.</p>



Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>de Graaff, F., Francke, A. L, van den Muijsenberg, M. e., &amp; van der Geest, S. (2012). Understanding and improving communication and decision-making in palliative care for Turkish and Moroccan immigrants: a multiperspective study. <i>Ethnicity &amp; Health, 17</i>(4), 363-384.</p> <p>Level III</p> <p>Quality B (Good) Conducted in Dutch Netherlands</p>	<p>-To investigate how communication and decision making in palliative care is influenced by different forms of care management between the involved parties (Moroccan and Turkish patients and their relatives and Dutch care providers).</p> <p>-To suggest solutions to the problems.</p>	<p>-Eighty-three participants (6 patients, 30 relatives and 47 professional providers)</p> <p>-The study involved 33 patients with incurable cancer. Due to their health states only 6 patients directly participated in the study.</p> <p>-The study involved Turkish and Moroccan immigrants in Dutch/Netherlands.</p>	<p>Data gathered through a qualitative semi structured interviewing method.</p>	<p>Thematic and Contextual analysis.</p>	<p>Communication barriers (Language) disagreement on the meaning of “good care” undermined joint decision making. Conflicts within the family resulted in lack of joint decision. Absence of communication among providers led to absence of joint decision making and dissatisfaction and dissatisfaction. Sufficient communication and care strategies resulted in an increase in trust and confidence of all the involved parties.</p>	<p>Factors that challenge communication and decision making in palliative care include: the dominant culture that gives emphasis on quality care rather than cure, not fully recognizing the role of family care group, and involvement of the care providers and lack of good communication among providers. Providers should keep these factors in mind when engaging in palliative care.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Beyene, Y. (1992). Cross-cultural medicine, a decade later: Medical disclosure and refugees--Telling bad news to Ethiopian patients. <i>Western Journal of Medicine</i>, 157(3), 328-332.</p> <p>Level: V (Non-research evidence)</p>	<p>-To discuss cultural reasons for choosing non-disclosure of terminal illness by some Ethiopians.</p> <p>-To provide suggestions to decrease conflicts between American providers and their refugee patients</p>	<p>Three case studies that involved Ethiopians patients who reside in the United States of America.</p>	<p>Case studies of Ethiopian patients in the United States of America.</p>	<p>The author Beyen,. Y. holds PhD, and a member of the Ethiopian community. Twenty six literature evidences resources were for the discussion. Discussion conducted with Ethiopian patients, their families, community members and providers from Ethiopia and U.S.A.</p>	<p>Disclosure may cause conflicts between patients and providers. Disclosure is staged; family and friends will inform patient at appropriate time and place. Family decisions supersede the individual decision. Extended family are important. Ethiopians rely on doctors for cure, they will get well Ethiopians believe that telling bad news takes hope Healers (doctors, priests) are from God.</p>	<p>Ask patient for a designated spokesperson, family involvement in discussion and decision making, Consider partial instead of full disclosure and staged disclosure. A designated person can sign consent. Provide a welcoming approach. Talk about Ethiopian culture, trivial will help serve as an icebreaker. Reassure confidentiality of information.</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Kagawa-Singer, M., &amp; Blackhall, L. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives". <i>JAMA</i>, 286(23), 2993-3002.</p> <p>Level V (Non-research evidence).</p>	<p>To describe major issues involved in cross-cultural care. To recommend how patients, families, and healthcare providers can navigate among diverse cultural beliefs, values, and practices.</p>	<p>Two case studies involving an African American family and a Chinese American family in the United States of America.</p>	<p>Case Studies Involving African American family and Chinese American family.</p>	<p>Interview. Eighty-one evidences were utilized for reference.</p>	<p>Six issues were identified. Inequalities in care, communication and language barriers, religions and spirituality, truth telling, family involvement, hospice care. Possible consequences of not addressing the issues indicated were: increase desire of aggressive treatment, lack of family collaboration, misunderstanding, emotional/physical suffering, anger, hopelessness, removal of patient from care, conflicts of family with medical team, decreased use of hospice care use and decrease quality of EOL care.</p>	<p>Recommendations: make it clear you work together to achieve the best care, avoid medical jargons, avoid using family, especially a minor as an interpreter, ask about the importance of faith/spirituality, informed refusal, use examples, recognize non-verbal indirect communication, ascertain key family members and their involvement in decisions and decision making, and emphasizes hospice as an additional options to assist the patient and the family not to replace the family when caring for a patient at home.</p>

Citation, Level & Quality	Purpose of Study	Sample/ Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Grisaru, N., Witztum, E., &amp; Malkinson, R. (2008). Bereavement customs, grief and rituals among Ethiopian immigrants to Israel. <i>Illness, Crisis &amp; Loss</i>, 16(2), 111-123. doi:10.2190/IL.16.2. b</p> <p>Level V expert discussion completed by case examples.</p>	<p>Discuss displacement related to death, breaking bad news, mourning customs rituals as experienced by Ethiopian Jewish immigrants. Describe characteristics of mourning and burial rituals. Propose culturally sensitive ways of breaking bad news to Ethiopian Immigrants.</p>	<p>Discussion and three case presentations of Ethiopian immigrants in Israel.</p>	<p>Expert discussion of bereavement, customs, grief and rituals among Ethiopian immigrants to Israel.</p>	<p>Author's reflection, and concluding remarks presented. (Examples of other author's credential publications on "Zar-phenomenon" by Grisaru, which is traumatic reaction of Ethiopian immigrants, Loss and bereavement, in Jewish Israel society by Malkinson, R., and "Soul and bereavement, and loss" by Witztum, E.E.</p>	<p>Lack of cultural sensitivity way when informing bad prognosis. (Families were informed directly about the death of their son, which is customary to Israel but contrary to the culture). Lamentation and wailing preserved. Handling of body of the deceased and purification ritual not preserved. In Israel, mourning happens in the decisions home or in a temporary construction but in Ethiopia, mourning happens in a tent. Suicide is severely stigmatized.</p>	<p>Cultural broker (male) to deliver bad news. (this avoids additional distress). Assesses and consider the disappearance of bereavement customary unpreserved culture such as handling deceased body purification as a source of distress). Consider suicide is stigmatized among Jewish Ethiopians. And Christian Ethiopians. All the same except Burial for suicide is at the corner or the edge of the cemetery. No religious learner participates in the bereavement. Crucial for family and extended family to participate in the bereavement ceremonies/funeral. Clinical sensitivity approach is important. Plan for cultural needs when planning interventions when a difference between practice and tradition exists (The case of Workesh)</p>

Citation, Level & Quality	Purpose of Study	Sample/Setting	Design		Result & Conclusion	Authors' Recommendations
			Methodology	Instruments (reliability & validity)		
<p>Candib, L. (2002). Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. <i>Families, Systems and Health</i>, 20(3), 213-228.</p> <p>Level V (non-research evidence).</p>	<p>-Presents how the dominant biomedical culture approach to end of life becomes difficult for patients who place a higher value on family connectedness than individual autonomy. Suggests stopping privileging individual autonomy. Offer collaborative conversation with those who value family. To discuss culturally sensitive approaches to non-disclosure.</p>	<p>-Four case presentation (It involved two Vietnamese, a Russian, and a black woman In the United States of America)-</p> <p>Presentation of an empirical study that involved 800 elderlies (200 European, 200 African Americans, 200 Korean-Americans and 200 Mexican-Americans).</p>	<p>Expert opinion that involved four case examples and an empirical study.</p>	<p>The author's credibility includes being a medical doctor and a professor of family medicine and community health.</p>	<p>Disclosure of a medical diagnosis directly to a patient is not appropriate. Many did not possess advance health care directives. Family involvement is high. African Americans prefer aggressive life sustaining treatment to biomedical quality care. Diverse response of disclosure and health care directives were evident. Age acculturation social class, experience influences one's attitude towards disclosure and health care directives. Generalization of ethnic group by health care workers may not be useful.</p>	<p>Initiate conversation with patient and family early while patient is well about end of life care, advance care directives, choice for the intensity of treatments, and preference of disclosure. (Use structured questions). Review the conversation periodically with the patient and their family. This review allows the family as well as the individual autonomy.</p>

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<p>Crawley, L. M., Marshall, P. A., Lo, B., &amp; Koenig, B. A. (2002). Strategies for culturally effective end-of-life care. <i>Annals of Internal Medicine</i>, 136(9), 673-679.</p> <p>Level: V</p>	<p>Describe cross-cultural end of life practice issues. Propose ways to compromise common end-of-life care problems.</p>	<p>Two case examples: a Spanish speaking woman from El Salvador and an African American man that demonstrated the impact of culture in end of life care.</p>	<p>Describing cross-cultural end-of-life issues using two cases and 65 references/evidences used to support the description of the issues and proposal.</p>	<p>High level of education attained by the four authors (two medical doctors and both hold PhDs. Large number of articles and evidenced used.</p>	<p>Initially, patient declined discussion about hospice, hostile to the provider and indicated life sustaining treatment. Patients preferred family as their decision maker. Providers were unaware of patient's background, surprised by patient's responses and requests for life sustaining care. After consulting with a cultural insider, patient became engaged in hospice discussion. Use of a trained medical interpreter was helpful. Knowledge of cultural background is helpful to understand the reason behind patient's choices.</p>	<p>Use a trained interpreter. Calling an African American man by first name is inappropriate. Physicians should avoid being defensive when dealing with African Americans. Keep in mind that African Americans are historically mistreated and neglected. Avoid stereotyping African American as non-complaints of medical treatment, as substance abusers, and as people of low intelligent. Be non-judgmental and ask open-ended questions. Recognize individual differences while considering cultural backgrounds. Develop advance care planning that is congruent with patient's values, culture and individual preferences.</p>

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			Methodology	Instruments (reliability & validity)		
<p>Lopez-Sierra, H. E., &amp; Rodriquez-Sanchez, J. (2015). The supportive roles of religion and spirituality in end-of-life and palliative care of patients with cancer in culturally diverse contexts: A literature review. <i>Current Opinion in Supportive and Palliative Care</i>, 9(1), 87-95.</p> <p>Level: III Quality: Grade</p>	<p>Review the supportive roles of religion and spirituality (R/S) in end-of-life (EOL) and palliative care of patients with cancer in a culturally diverse context.</p>	<p>Twenty-six noteworthy articles from the worldwide-recognized databases (Medline, EBSCO, Psych-info (OVID) and Google scholar). The review included research conducted on peoples from diverse backgrounds including: African Americans, Africans Brazilians, Chinese, Koreans, Canadians, middle eastern, aboriginal, Jewish people.</p>	<p>A systematic search of peer reviewed literature which were published between 2013 and 2014.</p>	<p>Articles were peer reviewed. Retrieved from worldwide reputable databases : Medline, EBSCO, Psych-info (OVID) and Google scholar.</p>	<p>Connection was evident between cultural diversity, religion, spirituality and end of life and palliative care. Spirituality, faith, and social support served as sources of hope, courage and coping. Religious practice was linked with lower rates of depression. In some cases, for example, Jewish people did not take God as a</p>	<p>Correlation present between cultural diversity, religion, spirituality and health. Take account of the role of culture religion and spirituality in the care of patients with terminal illness. By being sensitive and in support of cultural diversity, healthcare providers can improve EOL care. Avoid making generalizations of all individuals in a particular group. They may not hold the same values.</p> <p>Pay attention to individuals' differences.</p>

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