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Social Work Practitioners Working in End of Life Care: Learning to Provide Culturally Appropriate Care to Clients of Middle Eastern Descent

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SOCIAL WORK PRACTITIONERS WORKING IN END OF LIFE CARE:
LEARNING TO PROVIDE CULTURALLY APPROPRIATE CARE TO
CLIENTS OF MIDDLE EASTERN DESCENT

A Dissertation
Submitted to the Graduate Faculty of the
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in
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by
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For my family.
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ABSTRACT

This study utilized an interpretive qualitative methodological approach to learn about the experiences of individuals with a Master of Social Work degree (MSWs) working in end-of-life (EOL) care with patients of Middle Eastern descent and their families. Specifically, it examined (1) how a sample of social workers obtained the skills necessary to provide culturally appropriate EOL care to clients and families of Middle Eastern descent; (2) the common intervention strategies social workers employ while providing this care; and (3) the recommendations they offer to others who anticipate encountering this population in their own practice. Data collection consisted of in-depth, semi-structured interviews with 12 social workers in the greater Houston area. A directed approach to qualitative content analysis was used to analyze the data, with the assistance of Atlas.ti software. Participants cited formal educational preparation, on-the-job training, and their own life experience as the means by which they attained the skill set needed to provide culturally appropriate EOL care to patients of Middle Eastern descent and their families. Rapport-building strategies, educational interventions, interdisciplinary teamwork, and conducting EOL discussions were identified as common intervention strategies used by the participants when providing EOL care to patients of Middle Eastern descent and their families. Assessing the patient and family’s level of acculturation to U.S. society, the use of appropriate body language, and demonstrating sensitivity regarding the family’s values were common recommendations the participants made for other social workers encountering this particular population. Implications for social work practice and education include recommendations to increase opportunities for experiential learning, infusing palliative care principles into the curriculum of generalist
social work practice, and the development of continuing education workshops to teach practitioners how to best provide EOL care to specific populations.
CHAPTER 1: INTRODUCTION

According to the U.S. Census Bureau, persons age 65 and older made up 14.9% of the U.S. population in 2015. By 2030, the Federal Interagency Forum on Aging-Related Statistics (FIFARS, 2012) projects that 20% of the United States population will be over the age of 65. This dramatic growth of the older population, due to the maturing Baby Boomer Generation (the generation born between 1946 and 1964), began in 2011, when the first of the “Baby Boomers” reached age 65, and will continue until the last of the generation reaches 65 in 2030. As the U.S. population ages, it is also becoming more racially and ethnically diverse. Statisticians have estimated that by 2050, 42% of persons over age 65 will be non-White (FIFARS, 2012).

Increased Need for End-of-Life Services

The aging of America is an issue that most people are aware of, and the fact that the number of older people has and will continue to grow faster than the rest of the United States’ population for many years to come is undeniable (Palmore, 1999). Along with the rising number of older adults, caring for such a large and vulnerable group, especially at the end of life, is also a growing concern. The social work profession has a unique role in the provision of care to older adults. It is therefore of vital concern that social workers be provided with state-of-the-art training in services to the elderly, particularly in end-of-life (EOL) care. As many researchers in the area have noted, there is a pressing need for the expansion of EOL training at all levels of social work education (Raybould & Adler, 2006; Roff, 2001). The Social Work End-of-Life Care Education Project conducted a study that found that 54% of social workers working in health and hospice care reported that their Master of Social Work (MSW) coursework contained no EOL content (Raybould & Adler, 2006). Academic content related to EOL, such as loss and grief, are frequently covered only when discussing late adulthood in human behavior courses, but issues of
loss and grief are pertinent and should be covered throughout the lifespan in both human behavior courses and practice (Kovacs & Bronstein, 1999). On-the-job training continues to be the means most commonly cited by social workers for obtaining the skills necessary to perform psychosocial work with the dying (Berzoff, 2008; Snow et al., 2008).

For social workers and other professionals in healthcare settings, working with aging populations often means working with death and dying. In 2014, approximately 1.2 million individuals died while in hospice care, 84% of whom were adults over age 65 (National Hospice and Palliative Care Organization [NHPCO], 2015). The number of non-White hospice recipients is steadily increasing. Hospice utilization of non-White individuals of all age groups rose from 18.1% in 2008 to 24% in 2014 (NHPCO, 2013; NHPCO, 2015).

As America’s aging population rapidly becomes more ethnically diverse, challenges to social work education are occurring (Lu, Dane, & Gellman, 2005). Social workers must possess an understanding of a patient and family’s background, and if they are recent immigrants, their level of acculturation to American society, to adequately provide services to the growing number of minority patients they will encounter in their practice. Disparities regarding health care among cultures are known to be a far-reaching problem and have been linked to a lack of cultural competence among healthcare providers (Stein, Sherman, & Bullock, 2009). Service utilization, health care access, and quality of care received for chronic illnesses are a few areas where disparities related to culture, race, and ethnicity are found.

**Cultural Competency in End-of-Life Care**

Cultural competency in healthcare has become a topic of interest in recent years among scholars and policy makers (Khanna et al., 2009; Reese et al., 2010). Interactions between patients and their families with healthcare providers have been shown to be influenced by
multiple cultural factors such as the patient’s use of folk medicine, health beliefs, religious affiliation, and other cultural-based values, norms, and gender-specific roles. Experiences with discrimination in prior utilization of health care have been cited as a factor in many minority patients’ reluctance to make their needs known to providers (Stein et al., 2009). Culturally competent practice involves “the need to understand ourselves as practitioners, build a strong interpersonal and collective relationship with the patient and family, recognize cultural uniqueness, and utilize effective outreach strategies to reach diverse group members and professionals” (Thomas, 2001, p. 44).

The very philosophy of hospice care may conflict with patient and family values—it is a philosophy that promotes open communication of death and the dying process, death at home or in a home-like setting, relief of pain through the use of pain medication, quality of life over quantity of life, and provision of services via a multi-disciplinary team (Reese, 2011). The culturally-grounded value base upon which hospice care policies and practice lie is important to recognize because these values are not shared equally across all cultures. Some hospice patients may find the expression of these values by well-meaning hospice workers offensive and their responses to them may be negative. Western values regarding EOL care emphasize the importance of personal autonomy and open communication between patients and healthcare providers; however, it is important to be aware that many non-Western cultures place more value on the opinions of the collective family unit and greater community when met with EOL decision-making (Weissman, 2000).

It is crucial that social workers learn about both the similarities and differences regarding EOL care preferences among cultures in order to facilitate successful interactions with their clients (Braun & Nichols, 1997; Reese et al., 2010). Knowledge about medical systems and how
access to healthcare services may be impeded by barriers, and an understanding of social systems, such as the socioeconomic, cultural, and spiritual aspects of family life (Raybould & Adler, 2006), are essential skills for a social worker practicing with clients at the end of life. Social workers working with EOL issues need an awareness of patients’ potential mistrust of their healthcare providers, how language and cultural differences may complicate the treatment process, and the challenges of providing appropriate care to patients whose values and beliefs may vary from that of the mainstream (Bosma et al., 2010; Raybould & Adler, 2006). Racism, discrimination, and oppression continue to be realities for minorities in American society, making cultural competence an important component of the education of social workers (Krenzman & Townsend, 2008).

Social workers play a critical role in interdisciplinary hospice teams (Bosma, et al., 2010; Kovacs & Bronstein, 1999; Luptak, 2004), helping to meet the multifaceted psychosocial, economic, and medical needs of patients at the end of life (Raybould & Adler, 2006). The role of social workers and the competencies required of social workers working in hospice, palliative, and EOL care are designated in the Medicare Hospice Benefit (MHB) and National Association of Social Workers (NASW) Standards for Palliative and End of Life Care. Interdisciplinary collaboration geared toward work in healthcare settings should be taught in schools of social work, and modeling and teaching teamwork through interdisciplinary classroom experiences and opportunities for participation in joint degree programs should be expanded (Kovacs & Bronstein, 1999). EOL conversations should become “a routine, structured intervention in healthcare” (Roff, 2001, p. 60), and part of that conversation requires a thorough knowledge of the contexts of practice.
Middle Eastern Cultures and End-of-Life Care

This study examines training experiences and knowledge of social workers working in EOL care, and focuses specifically on social work practice with people of Middle Eastern cultures. Middle Eastern cultures were selected for this study in order to explore cultural diversity and contrasts in customs and beliefs surrounding EOL decision-making, death rituals, and family dynamics. The approach of selecting one specific ethnic group to illustrate culturally competent EOL care rather than to attempt to examine all ethnicities represented in the United States was chosen with the intention of providing a richer, more thorough view of the importance of cultural competence in healthcare settings as it relates to one, rather than many, different ethnic groups. This research is especially timely given the current political climate in the United States. Due to ongoing global conflicts, Middle Easterners are increasingly experiencing prejudice and racism (Al Abed et al., 2013), and mass media and popular culture are saturated with misleading stereotypes and images of Middle Easterners (Salari, 2002).

The most recent U.S. Census data regarding Americans of Arab ancestry was published in 2013, based on data collected by the 2006-2010 American Community Survey (ACS). The ACS brief *Arab Households in the United States: 2006-2010* reported that during that time period, 1.5 million Americans claimed Middle Eastern ancestry, more than 32% of whom were of Lebanese ancestry, 9.9% Egyptian, 9.7% Syrian, 5.5% Palestinian, 5% Moroccan, 4.9% Iraqi, 4% Jordanian, and 1.9% Yemeni (2013). The remaining approximately 27.1% responded that their ancestry was “Arab,” or “Arabic,” and did not specify their family’s country of origin.

Middle Eastern cultures found among Palestinians, Israelis, Jordanians, Syrians, Egyptians, and Lebanese have many similarities. They are cultures with patriarchal family structures that value their elders, live in households that include extended family, and tend to
make healthcare decisions as a family (Stein et al., 2009). Family ties and traditional values are especially important to Middle Easterners, who strive to pass conservative family values on to their children, making acculturation to the U.S. often a slow and difficult process for many (Aprahamian et al., 2011). Unfamiliarity with distinctive characteristics of Middle Eastern cultures has led healthcare professionals to frequently label Middle Eastern patients as “difficult patients to work with” (Aboul-Enein & Aboul-Enein, 2010, p. 20), and this lack of knowledge and understanding of their Middle Eastern patients and their families hinders communication processes and provision of healthcare services (Al Abed et al., 2013).

**Research Questions**

Three questions guided this research. First, how do social workers obtain the skills necessary to provide culturally appropriate EOL care to clients and families of Middle Eastern descent? Secondly, what are common intervention strategies employed by social workers who provide EOL care to clients and families of Middle Eastern descent? Finally, what recommendations do social workers who provide EOL care to clients and families of Middle Eastern descent have for social workers who anticipate encountering this population in their own practice?
CHAPTER 2: LITERATURE REVIEW

The purpose of this literature review is to present the current state of knowledge on social workers’ preparation to provide culturally competent care to racially and ethnically diverse populations of clients utilizing EOL services. Definitions and explanations of concepts germane to the field of EOL will be covered, and illustrations using a specific ethnic minority group will be presented.

Need for Better Preparation of Social Workers Working in End-of-Life Care

Given the likelihood of working with death and dying, particularly in the healthcare setting, a setting in which more and more older adults will be present, it is essential that education for social workers, especially those entering the healthcare field, includes EOL issues such as hospice and palliative care in the body of knowledge and range of skills offered in their training programs (Christ & Sormanti, 1999). Social work has long held a prominent role in hospice care, yet despite this, the roles and functions of social work practitioners providing care in this field are not clearly defined (Bosma, et al., 2010). Many social work practitioners and educators believe that a combined generalist and specialist focus in training is needed for social workers who primarily work with dying clients and their families (Bosma et al., 2010). The discussion in the literature, however, remains focused on generalist versus specialist training for social workers in healthcare settings (Kovacs & Bronstein, 1999).

Christ and Sormanti (1999) investigated social work training in EOL care through surveys, interviews, and focus groups with social work practitioners and concluded that the majority of social workers, even those in medical settings such as cancer centers and teaching hospitals, spent a fairly small amount of their workdays conducting bereavement counseling, providing assistance in EOL decision-making, and negotiating ethical dilemmas related to these
issues. The authors suspected that lack of training or emotional avoidance were contributing factors in the social workers’ apparent reluctance to involve themselves in these duties, although most of those participating in the study cited time management issues being the primary reason. The exception regarding this distribution of time was hospice social workers, who reported that their primary job description was caring for the dying and the bereaved (Christ & Sormanti, 1999).

Both personal and professional challenges have been reported by individuals from a variety of professions whose work brings them in contact with persons who are dying (Manis & Bodenhorn, 2006). For inexperienced professionals, client interactions that involve issues surrounding death and loss have been shown to be uniquely challenging, often triggering a level of personal distress greater than that associated with other varieties of presenting problems (Kirchberg, Neimeyer, & James, 1998). Significant correlations between a counselor’s level of empathy for the client (found to be related to the counselor having a higher comfort level when working with client issues related to death and bereavement) and the counselor’s years of formal education and experience working with these issues were discovered. Additionally, counselors who exhibit higher levels of comfort and therefore more empathy toward their dying or bereaved clients exhibit lower levels of secondary trauma as a result of their interactions with their clients. Aversion and discomfort addressing client issues associated with death and bereavement were two problems frequently observed among those counselors whose formal training and contact with dying or bereaved clients was limited (Kirchberg et al., 1998).

In his 2004 evaluation on the subject, Wass (2004) concluded that death education for health professionals and counselors is of great concern citing the many indications of avoidance and ambivalence proliferating from the greater cultural context in which efforts to educate these
professionals are made. He observed that advances in medicine and the biological sciences are factors in often unrealistic hopes of extending human lives, further reinforced by an anti-aging industry that is flourishing in the persistent avoidance of death (Wass, 2004).

The Open Society Institute and the Soros Foundation identified “improving health care practitioners’ abilities to deal with death and dying” as a key objective of the 2004 collaborative project, The Project on Death in America, with the goal of transforming the culture of dying in the United States. Also in 2004, NASW released their document Standards for Palliative and End of Life Care, defining 11 standards to serve as a guide to assessment, treatment, resource linkage, advocacy, and leadership for social workers regarding their work with clients at the end of life (NASW, 2004; Raybould & Adler, 2006).

**Call to Increase End-of-Life Course Content/Curriculum Revision**

Medical social workers and social work educators have been discussing best practices for the preparation, supervision, and continual education necessary for effective social work practice in healthcare settings for decades (Kovacs & Bronstein, 1999). The 2005 Social Work Summit on End-of-Life and Palliative Care recommended infusing palliative care principles into the curriculum of generalist social work practice, especially for those who are training with the intention of working in healthcare settings and urging social workers to make ongoing learning a priority through continuing education (Altilio et al., 2007; Roff, 2001). Regarding social work credentialing, the summit participants advised that in order to establish more consistent means of training practitioners and attain more consistency of EOL care, professional social work organizations need to collaborate with one another to create certifications that are less specific and more applicable across practice settings (Altilio et al., 2007).
Faculty of MSW programs have reported that high student demand exists for courses focusing on care of the dying and bereaved and have noted, moreover, that “this is very charged work and students would benefit from additional personal and professional work to assist them in working effectively with dying persons and their loved ones” (Christ & Sormanti, 1999, p. 94). The need for practical and emotional support for students while developing their counseling skills has also been cited as an important factor in training professionals to work in EOL care (Maguire, Elliott, & Jones, 1996).

The EOL care provided by social workers is clinical in nature (Berzoff, 2008) and therefore requires advanced training that is unfortunately absent or limited in the majority of social work programs (Christ & Sormanti, 1999; Walsh-Burke & Csikai, 2005). For example, social workers working in a hospice setting provide the clinical services of a counselor, context interpreter, advocate, and team member (Fort & Lois, 2003). EOL issues such as the right to refuse, withdraw, or withhold life-sustaining measures; discussions of assisted suicide; truth-telling (honest communication with patients regarding medical prognoses); futile treatments; and racism in medical service delivery all have the potential to pose ethical dilemmas (Raybould & Adler, 2006), and social workers need self-awareness of their personal belief systems, values, and feelings regarding such matters to effectively handle these issues in practice (NASW, 2004). A survey of hospice social workers by Kovacs and Bronstein (1999) found that a need exists for social workers to learn how to best thoughtfully integrate personal experiences with losses experienced in their professional work.

A 2005 initiative by Kramer, Christ, Bern-Klug, and Francoeur proposed a national agenda for the social work profession for research in palliative and EOL care. Notable among the numerous objectives mentioned was the need for the development of age-specific and culturally
sensitive means of measuring client grief and bereavement outcomes, and the creation of effective interventions applicable for use in a variety of social service settings to address grief and bereavement related to profound loss, including trauma-mitigating interventions. Kramer et al. (2005) identified specific objectives for social work curriculum development, training, and evaluation addressing current deficiencies in learning objectives and competencies regarding EOL and palliative care. Recommendations included also considering the current educational initiatives of nursing and other medical fields when defining and evaluating curriculum and dissemination approaches to these topics in social work. An assessment of an assortment of educational strategies needs to be made to craft the skill, attitude, and knowledge competencies needed within the social work profession. Also cited as high priorities were the identification of risk factors associated with complicated grief and the development and testing of interventions for its treatment. A body of research on grief and loss as related to developmental issues in palliative care, such as the deterioration of one’s health and losses in autonomous functioning, also needs to be established as distinct from the more traditional focus of grief research on mortality (Kramer et al., 2005).

Offering courses with content regarding social work in healthcare settings, family intervention, and crisis intervention is another proposed solution. To counter the claim that many social work programs lack time or opportunity to teach these skills in their curriculum, many new training programs are developing as post-graduate continuing education programs, such as the one developed by Columbia University’s School of Social Work, which integrates continuing education with on-the-job training (Kovacs & Bronstein, 1999).
Culture and Cultural Competence in End-of-Life Care

Culture is a “unified set of values, ideas, beliefs, and standards of behavior shared by a group of people; the way a person accepts, orders, interprets, and understands experiences throughout the life course” (Thomas, 2001, p. 40). It is an important aspect of a person’s identity throughout life and becomes especially important as death approaches. Folk values, beliefs, and practices associated with one’s culture may provide meaning and comfort when the end of life is near (Bonura et al., 2001).

Cultural competence is “the ability to engage in actions or create conditions that maximize the optimal development of client and client systems” (Sue, 2001, p. 802).

Multicultural counseling competence, a similar concept, is defined as “the counselor’s acquisition of awareness, knowledge, and skills needed to function effectively in a pluralistic democratic society (ability to communicate, interact, negotiate, and intervene on behalf of clients from diverse backgrounds)” (Sue, 2001, p. 802).

Acculturation is the process of integration into mainstream culture (Duffy et al., 2006) and has been identified as an important concept to consider when assessing the psychological well-being of individuals who have emigrated from another country (Baltas & Steptoe, 2000). It describes how members of a minority culture adjust their original cultural beliefs, values and behaviors on both the individual and group levels, as a result of contact with a dominant culture (Baltas & Steptoe, 2000). When working with ethnic or racial minorities, it is important that practitioners can assess levels of acculturation among the patient and family members (Thomas, 2001). The ability to accurately assess acculturation requires the practitioner to gain cultural sensitivity through acquisition of intercultural knowledge, with the goal of achieving cultural competence.
Importance of Cultural Competency in End-of-Life Care

Multiple studies have shown that members of minority groups are receiving poorer quality health care, and less of it, than members of the dominant culture, and that the experience of minorities in overall healthcare settings is comparable to that specifically observed in hospice care (Reese, 2011; Stein, Sherman, & Bullock, 2009). Hospices that lack adequate, culturally appropriate services, such as interpreters and community outreach to minority groups, and staff diversity tend to have fewer referral sources of minority patients and less community understanding of hospice services, both of which contribute to the under-utilization of hospice services by minority populations (Reese et al., 2010). Minority clients may see the hospice philosophy of care as intrusive and in conflict with cultural norms (Duffy, 2006). The concept of hospice care may be best introduced to minority populations through education presented by key community leaders and presentations facilitated at places of worship.

The need for increased levels of cultural competence among healthcare providers, including social workers, is an important factor when considering how under-represented racial and ethnic minorities are among nursing home residents, hospice patients, and those receiving long-term and palliative care (Schim, Doorenbos, & Borse, 2006; Thomas, 2001). Barriers to culturally competent hospice care have been identified, including lack of funding needed for the provision of culturally competent services (i.e., community outreach, cultural competence training), lack of applications for EOL employment from racially and ethnically diverse job-seekers, barriers to care created by the organizational culture of the hospice itself, and failure to identify which cultural groups are not being adequately served by the hospice (Reese, 2011). Culturally competent care has been found to increase cost effectiveness in EOL care (Duffy et al., 2006). When providers streamline their service offerings based on the acceptance and
utilization of specific services by the minority groups they frequently serve, service efficacy improves (Duffy et al., 2006).

Standards have been developed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the U.S. Department of Health and Human Services Office of Minority Health (HHS/OMH) to guide hospice staff in the provision of culturally and linguistically appropriate services (Schim, Doorenbos, & Borse, 2006). Additionally, Medicare has recently included in their Conditions of Participation (CoP) that hospices document measures taken to provide culturally competent care. Unfortunately, due to the varying levels of healthcare providers’ cultural competence, these models of care are not adequately utilized (Reece, 2011).

The NASW Standards for Cultural Competence in Social Work Practice, originally published in 2001 and updated in 2015, place emphasis on the importance of values and self-awareness, cultural sensitivity and awareness of biases, knowledge, and practice skills as they relate to work with diverse clients (NASW, 2015). There exists general agreement among healthcare researchers that increased cultural competence leads to better communication, higher rates of patient satisfaction, and better compliance with treatment (Khanna et al., 2009).

Methods of Teaching Cultural Competency in Social Work Education

Learning about cultural differences means exploring differences in attitudes and personal values (Weissman, 2000). Cultural competency requires self-reflection and confrontation of fears and other feelings, especially regarding attitudes and values associated with EOL. Through the use of experiential learning techniques such as role play, small-group case-based discussions, and personal narratives, learners may be led to self-reflection that helps them better understand the values and attitudes of other cultures (Weissman, 2000), which is the foundation of culturally competent social work practice.
Various methods of training social workers about specific cultures may result in practitioners who are knowledgeable and understanding, but have not learned how to relate empathetically with individuals belonging to cultures other than their own (Lu, Dane, & Gellman, 2005). Many programs use traditional methods of teaching social workers about cross-cultural practice, which didactically focus on informational content regarding minority groups, a method that has been proven to be ineffective in changing attitudes, an important component of cultural competency. Lu et al. took a different approach to training in cultural competence, one which emphasizes interpersonal sensitivity and skill development over informational content. In a pilot study targeting attitudes, Lu et al. (2005) used experiential learning techniques with a group of 24 foundation-year MSW students in an attempt to teach cross-cultural empathy. Students were led through exercises such as breath awareness, mirroring activities, and discussion groups with the intent of imparting increased awareness and mindfulness of attitudes regarding one another throughout the 2-day workshop. The researchers later coded the videotaped discussions and performed a qualitative cross-case content analysis of the verbalizations of the participants. Participants verbalized an increased sense of attunement, heightened awareness, and a state of “being present” (Lu et al., 2005, p. 98), suggesting that the workshop had met its objectives.

Another cultural competency training program for practicing healthcare professionals was developed and evaluated by Khanna, Cheyney, and Engle (2009). The researchers conducted a 4-hour cultural competence workshop, focusing on knowledge and skill development. Sixty healthcare professionals including physicians, nurses, and hospital administrators attended. Workshop content included an introduction to cultural and linguistic competency, health disparities among ethnic and racial minorities, discussion of how culture affects health beliefs,
and a presentation of the importance of cultural competency in effective patient/provider communication. Directly following the workshop, participants completed the 29-item Cultural Competency Assessment (CCA), a survey instrument created by the researchers to assess training outcomes. The instrument employed a post-then-pre method retrospectively to assess participants' self-reported knowledge and skills in regards to the provision of care to racially and ethnically diverse populations, using a Likert-type scale with choices ranging from never to always for each question. The presentation of the questions pertained to the participants’ knowledge or skills both after and before the training. For example, participants would respond to the item “I can effectively work with health care interpreters” (Khanna, Cheyney, & Engle, 2009, p. 888) under the column header “After Training” and then again under the column header “Before Training.” Results indicated a positive shift in the self-reported knowledge and skills of the participants regarding cultural competence in the healthcare setting (Khanna, Cheyney, & Engle, 2009). While such a self-report method is expedient, its validity is questionable since respondents were not surveyed independently at two different time-points.

Middle Easterners and End of Life

Middle Easterners in the U.S.

The U.S. government has struggled to accurately classify the racial, ethnic, and ancestral identities of Americans of Middle Eastern descent (Kayyali, 2013). The U.S. Census Bureau attempts to classify members of the American population according to federal racial classifications, as defined by the Office of Management and Budget (OMB), and operates under the assumption that federal and state laws and public policy may be accurately created based upon these classifications. People from the Middle East and North Africa (MENA) region may self-identify racially as Black or White, and Arabic-speaking people may choose to classify
themselves as Asian or African if using their continental origins as the basis for self-identification (Kayyali, 2013). Approximately 82% of Arabs living in the U.S. are citizens; a large majority was born in the U.S. (Salari, 2002). There is some controversy regarding the size of the Middle Eastern, or Arab population in the United States. The long version of the U.S. census form, which is sent to less than 20% of U.S. households and contains census questions regarding ancestry, has been blamed for a severe census undercount of the Arab population. The U.S. Census’ 2006-2010 American Community Survey (ACS) reported that 1.5 million people of Arab ancestry live in the U.S. (Asi & Beaulieu, 2013), while the Arab American Institute (AAI; 2012) has estimated the population to stand at approximately 3.67 million.

Arabs have been identified as:

those who have descended or immigrated from one of 22 Arabic speaking countries stretching from Morocco to the Persian Gulf, and including such countries as Algeria, Bahrain, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen. (Suleiman, 1999, p. 1)

They have also been described as “Arabic speaking people of Semitic origin, who were born in an Arab country and migrated to the United States, or whose parents were born in an Arab country and therefore consider themselves of Arabic origin” (Aboul-Enei & Aboul-Enei, 2010, p. 20).

Many Arabic-speaking people from the MENA region prefer to differentiate themselves from the broad term “Middle Eastern,” instead claiming the identity of “Arab,” despite the fact that the region also includes countries that, while having a large Arab population, are not technically considered Arab countries, such as Iran, Turkey, and Israel. These individuals cite pride in their Arab cultural heritage as reason for resisting taking on the identity of “Iranian,” “Turkish,” or “Israeli” (Kayyali, 2013). Furthermore, activists and researchers specifically
interested in Arab populations tend to avoid the blanket term “Middle Eastern,” as the broader MENA region encompasses many non-Arab countries including Cyprus, Afghanistan, Armenia, Azerbaijan, and Georgia. Nonetheless, the terms “Middle Eastern” and “Arab” tend to be used interchangeably, whether or not they technically identify the same group of people (Kayyali, 2013).

**Older Middle Eastern Populations**

An individual’s age at the time of immigration to the U.S. is important to take into consideration when examining members of a population such as older Middle Eastern Americans (Al Abed, Davidson, & Hickman, 2013). Older immigrants may be identified as belonging to one of two groups: those who immigrated to the U.S. early in life, and those who immigrated late in life. Less flexibility and motivation to adjust to the culture of their new surroundings is one characteristic of those who immigrated later in life. In addition to potentially poor English communication skills, the desire to maintain the ethnic lifestyle of their country of origin can contribute to social isolation experienced by those who immigrate later in life, which ultimately affects their overall well-being (Al Abed et al., 2013).

**Considerations for Working with Middle Eastern Clients at the End of Life**

The 1991 implementation of the Patient Self-Determination Act in the United States brought to the forefront a number of assumptions regarding the values of those receiving EOL care (Giger, Davidhizar, & Fordham, 2006). Among those assumptions are those of patient autonomy, which in many cases is in conflict with an individual’s family-centered culture; truth-telling, the practice of conducting frank discussions with patients and their families regarding disease progression and prognosis, which may be in direct conflict with the communication style of some cultures; and control over the dying process, the practice of which can be seen as
“playing God” to those whose religion dictates that life must be sustained at all costs and the belief in miracles is key. Hospital admission itself may be feared by older Middle Easterners due to their fear that hospitals are where people go to die (Aboul-Enei & Aboul-Enei, 2010).

Most Middle Easterners wish for heroic life-saving measures and aggressive treatments to be withheld once death is considered imminent and state a preference to die at home (Old & Swagerty, 2007). The implementation of formal hospice care or placement in a residential hospice is not common among those of Middle Eastern descent. A nursing home placement for an elderly relative would not be preferred by typical Middle Eastern families, who traditionally care for their dying or sick family members at home (Old & Swagerty, 2007). Suggesting placing a family member in a nursing home can be seen as offensive to many Middle Eastern families, as this may be interpreted as a suggestion that the family member is a burden to them. Avoiding nursing home placement may be a significant dilemma for new immigrants, who may not have extended family available to assist with care (Duffy et al., 2006).

Hospitals are often accused by non-Western cultures of having unreasonable restrictions in regards to visiting times and the number of visitors a dying patient is allowed in his or her room at one time (Gatrad, Brown, Notta & Sheikh, 2003). Duffy et al. 2006 interviewed members of five racial/ethnic groups in Michigan, inquiring about EOL care. Christian Middle Eastern women in particular indicated that restricted visiting hours are problematic due to their family members’ profession, stating, “Our men are storekeepers and cannot come until late” (p.155). Jewish Middle Eastern families are required to show respect for their dying family member by keeping vigil at the bedside when death is imminent (Bonura et al., 2001). Insistence that the dying person is never left alone has often proven to be a source of conflict when hospital visiting hours are restrictive.
Many Western EOL considerations that are likely to be applicable to those of Middle Eastern heritage are cultural, and practically universal to all Middle-Easterners; however, many are based on religious practices such as funeral rituals and last rites (Gebara & Tashjian, 2006). Three religions—Islam, Christianity, and Judaism, all monotheistic Abrahamic religions—will be discussed further as they relate to EOL care for Middle Eastern clients. These three religions possess carefully developed guidelines regarding medical ethics (Clarfield et al., 2003). Medical decision-making is often implicitly or explicitly influenced by the cultural and religious backgrounds of not only clients and their families, but clinicians as well. Medical care providers who are not of the same religion as their clients may not have a thorough understanding of their clients’ religious beliefs and how they relate to health care, which may cause misunderstandings, unintended conflict, or confusion regarding provision of health care (Clarfield et al., 2003).

**Middle Eastern Muslims.** The earliest waves of Middle Eastern immigrants to the U.S., who began immigrating in the late 1800s, were primarily Christian, and acculturated without great difficulty (Nassar-McMillan, Lambert, & Hakim-Larson, 2011). More recent waves of immigrants have been predominantly Muslim and have not adjusted to life in the U.S. as easily, due in part to a tendency to associate most closely to a close-knit community of other Middle Eastern Muslims in their area.

In the Islamic faith, which may be unfamiliar to social workers in the U.S., followers are instructed to pray five times a day while facing east, toward Mecca, the holy city of Islam. Medical caregivers should be made aware that physical modesty is important to Muslims; therefore, when possible, procedures that may involve exposure of or physical contact with a Muslim patient’s genitals should be done by a caregiver of the same sex (Gebara & Tashjian, 2006). Muslim women in particular have reported feeling uncomfortable in a hospital setting,
stating that maintaining modesty is challenging due to the frequent visits by clinicians who require them to uncover for examinations and procedures (Duffy, 2006).

Knowledge of the formal hierarchy for family decision-making as prescribed by Islamic law is especially important for care providers (Clarfield et al., 2003). According to these laws, a husband is considered the surrogate decision-maker for his wife, regardless of her mental status.

Islam also dictates that offering nutrition and hydration are mandatory and considered a component of basic care, at least via mouth, unless feeding and offering liquids would shorten life. Every moment of life is considered precious, so if a treatment will extend life, it should be pursued, unless an individual is in the final stages of a terminal illness. Islam recognizes death as a part of life; therefore, once death is seen as imminent, the dying process should not be hastened nor prolonged through medical intervention (Clarfield et al., 2003).

An Islamic spiritual leader, an Imam, is likely to visit the dying person and his or her family to provide support and to say prayers with them. Family members may wish to place a copy of their holy book, the Qur’an, on their loved one’s pillow or at their bedside. It is important that non-Muslims do not handle this book unless they cover it with a clean piece of cloth (Gatrad & Sheikh, 2002). Muslims may prefer to have their bed facing east as they are dying (Nazarko, 2006) and once a Muslim has died, Islam requires that any non-Muslim who touches the deceased wear gloves (Nazarko, 2006). Soon after death, according to Muslim tradition, family members perform a ritualistic bathing of the body of the deceased, and burial should occur as soon as possible.

**Middle Eastern Christians.** Middle Eastern Christians tend to express that spirituality is very important to them (Duffy et al., 2006). Roman Catholics will likely ask their priest to visit a dying parishioner to administer the Sacrament of the Sick, also referred to as “last rites,” and
Holy Communion (Nazarko, 2006). Orthodox Christians similarly receive final sacraments, which they call “Holy Unction.” In many Middle Eastern communities, the rituals and beliefs of the Orthodox and the Catholic, although very different in practice and dogma, may often overlap more than differ. For example, an Orthodox man may be seen handling rosary beads, which are seen as traditionally utilized by Catholics during prayer; however, in the Middle East, they tend to be utilized by both denominations (Nazarko, 2006).

Middle Eastern Christians prefer to die at home, surrounded by family and friends, but are avoidant of direct discussion of death prior to it occurring (Duffy et al., 2006). Relief of suffering for the terminally ill, specifically in the form of pain management, is encouraged, even if its provision may hasten death (Clarfield et al., 2003). Likewise, a treatment that is provided with the intent of prolonging the dying process may be declined by Middle Eastern Christians. This includes providing nutrition and hydration to the dying individual, mechanical ventilation, or any other treatment meant to prolong life without adding additional comfort.

Middle Eastern Jews. Devout, Orthodox Jews pray three times a day, practice ritualistic morning hand washing, wash before each meal, and observe a kosher diet (Bonura et al., 2001). Jewish Law, known as Halacha, or “the way,” guides medical decision-making for followers of Judaism (Clarfield et al., 2003). Unlike Islam and Christianity, religions with theological differences among denominations, Middle Eastern Jews share common beliefs and religious laws; the primary differences are in the degree of religious observance between Jews.

Jews believe that human life is of infinite value and the saving of life, one’s own or the life of another, is a duty of the devout. Illness and death are acknowledged as part of life, as is the dying process, which Judaism believes must be respected once death is deemed imminent (Clarfield et al., 2003). Jewish values are congruent with the hospice philosophy of care (Bonura
et al., 2001)--once it is determined that a cure is no longer possible, priorities of Jews and their family shift to support and palliation.

Jewish families are obligated to sit by the dying family member’s bedside as a sign of respect and to ensure that the individual is not alone when death occurs. A person who is expected to die within three days or less is referred to as a goses, and according to Judaism, no treatment or movement of the person may be performed if it would cause the dying process to be accelerated. Actions such as shifting the individual’s body in bed or removing a pillow from under the head of an individual in this state is forbidden if it would cause discomfort or hasten death (Clarfield et al., 2003).

Judaism dictates that no funeral preparations are made until death occurs (Clarfield et al., 2003). The body of the deceased must not be left alone to ensure that it is not desecrated in any way. A ritualistic washing of the body takes place shortly after death, and the deceased is dressed modestly, wrapped in a linen shroud, and buried in a simple pine coffin (Clarfield et al., 2003).

**Middle Easterners as Targets of Racism, Discrimination, and Hate Crimes**

The effects of prejudice against Middle Eastern immigrants, refugees, and their descendants, such as racial profiling and hate crimes, often increase drastically following acts of global and domestic terror and with the volatile politics Middle East (Salari, 2002). Immediately following the September 11, 2001 attacks on the World Trade Center in New York and the Pentagon, the FBI reported a 1,600% increase in hate crimes against Middle Easterners and Muslims in the U.S. This surge in hate crimes has yet to drop below or return to the pre-9/11 rate and has increased higher still in the months following global media coverage of recent terror attacks such as those in San Bernardino and Paris (AAI, 2015).
Scapegoating, or racial profiling of minority communities by the government or other institutions, can be harmful to both the physical and psychological health of those in the targeted group (Salari, 2002). On January 27, 2017, the current presidential administration placed limitations on travel to the U.S. from seven Muslim-majority countries and suspended all refugee admissions to the U.S. for 120 days via an Executive Order (EO), entitled “Protecting the Nation from Foreign Terrorist Entry into the United States” (EO No.13769, 2017). This EO was referred to by media and other sources as a “Muslim Ban” (AAI, 2017, paragraph 3) due to selection of the countries that were named as “terror prone” regions by Homeland Security. The provision of the order indefinitely suspending the entry specifically of Syrian refugees into the U.S. stated:

the entry of nationals of Syria as refugees is detrimental to the interests of the United States and thus [I will] suspend any such entry until such time as I have determined that sufficient changes have been made to the USRAP to ensure that admission of Syrian refugees is consistent with the national interest. (EO No.13769, 2017, section 5, c)

This EO was challenged as unconstitutionally targeting Muslims. On February 13th, 2017, U.S. District Judge Leonie Brinkema ordered a primary injunction declaring the order unconstitutional and stated, “The president himself acknowledged the conceptual link between a Muslim ban and the EO” (Barakat, 2017, para. 6).

On March 6th, 2017, the U.S. president issued Executive Order 13780 (2017), a revised version of Executive Order 13769. This revision excludes Iraq from the list of banned countries, removes provisions excluding religious minorities from the six countries included in the travel ban, includes a waiver process available on a case-by-case basis, and is not applicable to green-card holders or anyone inside the U.S. with a valid visa (Thrush, 2017). At the time of the submission of this dissertation, temporary injunctions to EO 13780 have been filed by district courts of Maryland and Hawaii, to specifically prevent enforcement of the Section 2(c) 90-day
entry bar (National Association of Foreign Student Advisers, 2017). Further appeals to this EO are currently pending.

**Conceptual Foundations**

**Western Culture and End-of-Life Considerations**

Advances in modern Western medicine such as antiseptics, antibiotics, and improvements in surgical techniques have added years, if not decades, to the average American lifespan (Krisman-Scott, 2003). Our ability to treat diseases such as heart disease, cancer, and stroke has lengthened the amount of time from diagnosis of a terminal illness and actual death. Fatalities caused by acute illness have been replaced with deaths caused by chronic or debilitating diseases such as heart disease and cancer (Krisman-Scott, 2003; Richardson & Barusch, 2006) and developments in medical technology have created life-sustaining measures for even the most advanced illnesses (Roff, 2001). Even today, according to the medical model of care, chronic and terminal illnesses are often seen as the personal failures of physicians (Fort & Lois, 2003).

The traditional female caregiver to the ill and the presence of friends and family at a dying person’s bedside at home has become a thing of the past for most Westerners, due to lifestyle changes such as population mobility and an increasing number of women entering the workforce post-World War II (Krisman-Scott, 2003). Furthermore, cultural changes brought on by advanced media technologies, particularly television, have brought images of quick, violent, and impersonal death into homes of millions, but no depictions of how most deaths actually occur—such as the slower deaths of chronic diseases. The increase in the number of hospital beds brought on by the enactment of Medicare (Kulesher, 2005) has encouraged a shift in care settings from homes to institutions such as hospitals, and long-term care skilled nursing facilities. With
no real contact with the dying and inaccurate depictions of death, many Americans have lost touch with what dying is like (Krisman-Scott, 2003).

Even as the topics of death and dying became frequently avoided, they again became topics of discussion in the United States in the 1960s and 1970s, a time when organized societal attempts to broaden individual rights such as the rights of women, African Americans, and other oppressed groups were paramount in society (Krisman-Scott, 2003; Sloan, 1992). Parallels may be drawn between issues within the women’s movement of the 1960s and those discussing the right to die (Sloan, 1992). Advocating for choice regarding where and how to give birth or where and how one dies have been debated at the same time.

A number of prominent publications regarding death and dying emerged—Herman Feifel’s *The Meaning of Death* in 1959, Glaser and Strauss’ *Awareness of Dying* in 1965, and Kübler-Ross’ *On Death and Dying* in 1969 (Krisman-Scott, 2003). Credit is given to Kübler-Ross’ *On Death and Dying* for introducing the philosophy of hospice care to the mainstream and spurring the U. S. hospice movement (Miller & Mike, 1995; Sloan, 1992). The five stages of grief as presented by Kübler-Ross both challenged the medical model of death and became well-respected and widely taught. According to Kübler-Ross (1969), individuals approaching EOL tend to move through a series of five stages: denial, anger, bargaining, depression, and finally, acceptance.

Dame Cicely Saunders, a British physician who was also a nurse and a medical social worker, is credited as the founder of the modern hospice movement, which is said to have begun with the establishment of St. Christopher’s Hospice in London in 1967 (Fort & Lois, 2003; Krisman-Scott, 2003; Miller & Mike, 1995; Remington & Wakim, 2010). At St. Christopher’s, a world-famous research and teaching center for hospice care, Saunders developed pain
management approaches and models for meeting the total needs of dying patients using an interdisciplinary team to provide palliative care (Connor, 2007; Fort & Lois, 2003). Palliative care is a form of specialized medical care focused on providing “comfort care” to individuals for whom aggressive, curative therapies are no longer desired or feasible; on pain and symptom management allows them to focus on quality of life (Fort & Lois, 2003; Remington & Wakim, 2010) and on the patient and family’s psychosocial and spiritual needs (Kovacs & Bronstein, 1999).

U.S. interest in the hospice movement augmented in 1963 when Saunders delivered her ground-breaking lecture to the Yale School of Medicine (Connor, 2007; Remington & Wakim, 2010; Sloan, 1992). This lecture on the concept of holistic hospice care was attended by medical students, nurses, social workers, and chaplains and resulted in an invitation to Saunders by Florence Wald, the dean of Yale’s School of Nursing, to become a visiting faculty member in the spring of 1965. Subsequently, in 1968, Wald took a sabbatical to work at St. Christopher’s to learn about hospice from Saunders (NHPCO, 2010). Saunders’ methods of pain management for the terminally ill, the family involvement she encouraged, and her insistence on open communication with dying patients regarding their condition were then carried over to the first U.S. hospice, opened with Wald’s guidance in 1974 in Branford, Connecticut (Connor, 2007; Fort & Lois, 2003; Miller & Mike, 1995).

Although the first U.S. hospices frequently referred to England’s model of hospice care for guidance (Sloan, 1992), there are a number of distinct differences between the two. For example, the hospice movement in the United States differentiated itself from the European model of hospice by focusing on home-based care (Chapman & Bass, 2000; Fort & Lois, 2003). The word “hospice” in Europe refers to a specific facility for providing care, whereas in the U.S.,
hospice is a philosophy of care that may or may not involve a specialized care facility. The length of time a disease is defined as terminal also varies; in the U.K. hospice system, a patient is considered terminal if the physician predicts that his or her disease will result in death within 12 months, whereas in the U.S., terminal illness is defined as predicting death will occur within 6 months (Chapman & Bass, 2000). This difference reflects the more general difference in approaches to healthcare between the two countries, with the U.S. consistently having fewer public benefits. Hospice care practice, therefore, as in all forms of health care, is a reflection of the political systems governing it.

Until the initiation of the hospice movement, institutionalized death in the hospital was for many the only option available (Krisman-Scott, 2003). Because of the hospice movement, the field of caring for the dying became a recognized medical specialty. Holistic care and adequate pain control became paramount to the care of the terminally ill (Remington & Wakim, 2010). Palliative care as a specialty is growing and becoming integrated into an expanding number of healthcare professions and institutions (Altilio et al., 2007), and “what began as a small rebellion has evolved into a large healthcare industry” (Connor, 2007, p. 89).

**History and Analysis of Medicare and the Medicare Hospice Benefit**

In many ways, being older in the United States has meant being privileged in regards to a universal delivery of healthcare access (Richardson & Barusch, 2006). Through Medicare, seniors were until very recently the only age group in the country who were eligible for universal health insurance. But of course this has not always been the case. Prior to Medicare’s establishment in 1965, only 56% of those over age 65 had hospital insurance. Hospital insurance as an employment benefit only become prevalent in the 1940s and ’50s as companies, competing for workers, began offering benefits such as pensions and company-sponsored health insurance
but did not extend these health insurance benefits to their retiring employees (Richardson & Barusch, 2006). When President Lyndon Johnson signed Title XVIII of the Social Security Act, Medicare was established as a comprehensive health insurance for all Americans eligible for retirement benefits under Social Security and was intended to be an incremental first step toward national healthcare (Kulesher, 2005).

Earliest discussions of hospice at a federal level were spurred by Senator Frank Church, a Democratic senator from Idaho, who chaired the 1972 hearings of the Senate Special Committee on Aging, “Death with Dignity: An Inquiry into Related Public Issues” (Miller & Mike, 1995). This three-day hearing, which included testimonies from prominent leaders in the hospice movement such as Dr. Elisabeth Kübler-Ross, did not immediately result in concrete progress for the terminally ill and their families, but it did bring recognition to the movement at a federal level as well as media coverage, thereby raising awareness of EOL issues in the general public (Miller & Mike, 1995).

In 1978, the Hospice Task Force was established by Health, Education and Welfare Secretary Joseph Califano to study the cost, use, and quality of hospice care in the United States (Mahoney, 1998). At the time, 28% of all Medicare costs were accounted for by persons in the last year of life (Lubitz & Riley, 1993). Debate surrounding the financial reimbursement and the core services requirement ensued. Interestingly, the task force’s resulting National Hospice Study report was not released until after the Medicare Health Benefit (MHB) was signed into law. The MHB, through an amendment to the Social Security Act written by Pennsylvania Senator John Heinz, was signed into law in 1982 and became permanent in 1986 (Connor, 2007; Mahoney, 1998; Remington & Wakim, 2010).
In order for an individual to enter hospice care covered by the MHB, he or she must meet the following eligibility criteria:

(a) The patient must be eligible for Medicare Part A; (b) The patient’s physician and the Hospice Medical Director must diagnose the patient with a terminal illness with a 6-month or less life expectancy; and (c) The patient must sign a consent to receive the hospice care benefit and forgo all other Medicare benefits in treatment of the terminal illness. (Centers for Medicare & Medicaid Services, 2015, Chapter 9, section 10, paragraph 1)

According to Medicare hospice regulations, services are to be provided by an interdisciplinary team whose core members must include a physician, a registered nurse, a social worker, and a pastor or other counselor providing pastoral care (Kovacs & Bronstein, 1999; NHPCO, 2015). Generous levels of services are provided to the recipient primarily in the home, but may also be provided in a nursing home or inpatient hospice, and include durable medical equipment at no extra cost and minimal copayments for medications and inpatient respite care (Mahoney, 1998).

Hospice has been increasingly more accepted in the U.S. healthcare system and is the fastest growing Medicare benefit (Connor, 2007). Approximately 84% of hospice care in the United States is funded by the MHB, making it the primary insurer for hospice services (Remington & Wakim, 2010). Prior to the introduction of the MHB in 1983, hospices were dependent on private donations and grants to meet operational costs. Today, in addition to Medicare, most hospices also accept reimbursement from Medicaid, the Veterans Administration, and private insurance (Chapman & Bass, 2000).

Hospice care greatly reduces the costs of caring for a patient in the last 6 months of life (Mahoney, 1998; Remington & Wakim, 2010). Despite these cost-saving benefits, far fewer Americans are accessing this service than qualify for it due to barriers such as the reluctance of medical staff to communicate with patients regarding hospice care, resulting in nonexistent or
untimely referrals to hospice (Roff, 2001). In 2014, the median length of service for hospice patients was 17.4 days (NHPCO, 2015).

At the time of the signing of the MHB in 1982, there were approximately 500 hospices nationwide (Mahoney, 1998), when the American hospice movement was still in its first 10 years of existence. More recent figures suggest that there are now about 6,100 hospices operating in the United States (NHPCO, 2015). There has been debate regarding whether hospice in the U.S. has been helped or harmed by the MHB (Sontag, 1992). Both the funding and the recognition Medicare has given to the service are of great benefit to hospices. However, Medicare regulations governing hospice have potentially weakened the hospice philosophy through excessive medicalization and by shifting the unit of care squarely to the patient and away from the family. These regulations often cause vulnerable populations such as homeless individuals who are in need of hospice care, to be turned away because they do not have a primary caregiver or lack healthcare benefits.

**Medical Social Work in Hospice**

Hospice, with its holistic approach to patient care, is a natural fit for social worker practice; social workers are essential members of interdisciplinary hospice teams (Bosma, et al., 2010; Kovacs & Bronstein, 1999; Luptak, 2004). The philosophies of social work and hospice complement one another, each taking into account the dying individual in the full context of his or her life (Bosma et al., 2010); quality of life should include quality of death (Roff, 2001). Using the biopsychosocial approach to assessment, “taking into account the entire person in his or her environment” (Berkman, 1996, p. 543), social workers view patients holistically, providing patients and families assistance with emotional reactions, therefore aiding them in making difficult medical decisions later (Snow et al., 2008).
Chapter nine of the Medicare Benefit Policy Manual, Coverage of Hospice Services Under Hospital Insurance, declares that the services of medical social work “must be provided by a social worker who has at least a bachelor’s degree from a school accredited or approved by the Council on Social Work Education (CSWE), and who is working under the direction of a physician” (Centers for Medicare & Medicaid Services, 2015, section 40.1.2, first paragraph). Services provided by social workers in hospice include psychosocial assessment, supportive and bereavement counseling, referral, brokerage, and general problem-solving (Luptak, 2004).

Cherlin, Schulman-Green, McCorkle, Johnson-Hurzeler, and Bradley (2004) identified five outstanding practices of clinicians providing EOL care. These practices include non-abandonment, defined by being present for the patient and family, sitting and listening, and paying attention to their needs; respect for the patient, exhibited by giving the patient choices, not forcing anything on the patient such as treatments or activities, and honest communication; care of the family, demonstrated when clinicians relate on a personal level with family members, create a welcoming environment for the family, and anticipate needs of family members; facilitation of the family process, by helping to create opportunities for quality family visitation and assisting in making family time more meaningful, and meeting the family’s needs when the patient’s death appears to be approaching, which the clinicians have prepared the family to anticipate and recognize; and finally, follow-up with the family after the patient’s death, offering support to the bereaved family through gestures such as sending a card or note, calling to check in, attending the patient’s funeral, and providing referrals as necessary (Cherlin, et al., 2004).

**Overview of NASW Standards for Palliative and End of Life Care**

In 2004, NASW released their document *Standards for Palliative and End of Life Care*, defining 11 standards for social workers to serve as a guide to assessment, treatment, resource
linkage, advocacy, and leadership regarding their work with clients at the end of life (NASW, 2004; Raybould & Adler, 2006). These standards are as follows:


NASW Standards 2 and 5 will be discussed further due to their specific applicability to the Medicare Hospice Benefit requirements and social worker preparation for working in hospice care.

**Standard 2—Knowledge.** Social workers require a thorough understanding of the current social and political climate surrounding EOL care in order to provide care successfully in this realm of practice (Roff, 2001). They must understand the extent to which health policies do and do not address issues regarding healthcare as it applies to older individuals (Richardson & Barusch, 2006). The NASW *Standard for Palliative and End of Life Care* regarding Knowledge states, “Social workers in palliative and end of life care shall demonstrate a working knowledge of the theoretical and biophysical factors essential to effectively practice with clients and professionals” (NASW, 2004, p. 4). Knowledge about medical systems and how access to healthcare services may be impeded by barriers, as well as an understanding of social systems, such as the socioeconomic, cultural, and spiritual aspects of family life (Raybould & Adler, 2006), are essential for a social worker practicing with clients at the end of life. Social workers working with EOL issues need an awareness of patients’ potential mistrust of their healthcare providers, how language and cultural differences may complicate the treatment process, and the challenges of providing appropriate care to patients whose values and beliefs may vary from that of the mainstream (Bosma et al., 2010; Raybould & Adler, 2006).
Standard 5 - Attitude / Self-Awareness. The NASW Standard for Palliative and End of Life Care regarding Attitude / Self-awareness states,

Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients’ rights to self-determination and dignity. Social workers shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice. (NASW, 2004, p. 4)

Social workers also need to be aware of their personal biases such as racism, sexism, and classism. Ageism, or discrimination based on age, for example, a term first introduced in 1969 by Robert Butler, can be seen as a barrier to effective care for older adults at the end of life. The concept of ageism not only includes discriminatory behaviors based on a person’s age, but also prejudices through stereotyping (Butler, 1969). Discrimination may occur on an institutional level through policies and practices as well as on a personal level and may be distinguished as negative or positive behaviors (Allen, Cherry & Palmore, 2009). In a recent study, self-reported ageist behaviors and ageist attitudes were detected among graduate and undergraduate social work students and social service providers in current practice in mental health and nursing homes. Through use of the Relating to Older People Evaluation (ROPE), an instrument that focuses on personal discrimination, both negative and positive attitudes and behaviors were detected in these groups (Allen, et al., 2009).

Social Ecological Theory and Acculturation

The processes underlying acculturation and mental health among Middle-Eastern Americans can be understood best by applying major concepts of social ecological theory (Aprahamian, Kaplan, Windham, Sutter, & Visser, 2011). Social ecological theory, an adaptation of Bronfenbrenner’s ecological systems theory, considers the interaction between the individual and his or her environment (Kirst-Ashman & Hull, 1993). Ecology is a term originally used by biological scientists to describe interdependencies among organisms in nature (Unger, 2002).
Social ecology emerged as a field in the 1960s and 1970s, adding to the ecological model the social, institutional, and cultural contexts of human relationships with their environment (Stokols, 1996). Drawing from the “related fields of ethology (the study of animal behavior), ecological psychology (the study of the effects of the physical environment on human psychology) and ethnology (the study of social knowledge in everyday contexts)” (Unger, 2002, p. 482), social workers embraced ecological theory, and specifically social ecological theory, as an integral component of their practice.

Bronfenbrenner’s ecological systems theory views individuals as existing within micro-, meso-, exo-, and macrosystems (Bronfenbrenner, 1977). These systems refer, respectively, to the person’s immediate environment (e.g., family, peer group, neighborhood), the interactions among microsystems (e.g., family and peer group), formal and informal environments with an indirect or direct influence (e.g., government agencies, mass media), and the larger cultural context in which one lives (e.g., culture, governing laws, public policies), respectively. Social ecological theory similarly considers individuals in their environment, with a focus on the interplay among factors such as the individual’s unique personal characteristics and history; his or her close relationships with family, peers, and partners; his or her community involvement in the workplace, school, and neighborhood; and with the greater society’s social and cultural norms, and public policies (Kloos & Shah, 2009; Stokols, 1996).

The processes of immigration and acculturation to a new country are known to be filled with stressors (Aprahamian et al., 2011). Despite the 2010 U.S. Census finding that approximately 1.5 million persons of Middle Eastern descent live in the U.S. (2013), few studies focusing on the specific experiences of Middle Eastern Americans exist. Aprahamian et al. (2011) used 2003 Detroit Arab American Study (DAAS) data in an attempt to determine if, in
addition to level of acculturation, the mental health of Arab American immigrants was influenced by factors such as age at time of migration, amount of time in the U.S., and religious affiliation. Although neither the researchers who collected the original DAAS data nor the researchers who conducted the current study explicitly approached their studies from the social ecological perspective, both studies can be easily understood with this model.

Participants of the DAAS consisted of 1,016 adults of Arab descent, ages 18 and older, living in the Detroit, Michigan, metropolitan area surveyed during a 6-month period. Demographic and historic participant data collected included age, place of birth, age at time of migration to the U.S., religious affiliation, highest educational level achieved, family income, and marital status (these factors are relevant at the individual and relationship levels of the social ecological model). The Kessler Psychological Distress Scale, a 10-item self-report questionnaire developed to measure nonspecific psychological distress (relevant at the individual level), was used to measure the mental health of the survey respondents. Survey items derived from previously validated instruments (relevant at the individual and societal levels) were utilized to measure acculturation. Questions regarding experiences of discrimination due to race, ethnicity, or religion captured whether or not the respondents had ever experienced discrimination in the form of verbal insults, threatening language or gestures, physical assault, vandalism, or loss of employment (relevant at the individual, relationship, community and societal levels). The researchers conducted a sequential multiple linear regression to examine the association between level of acculturation and mental health including family income, age, age at migration to the U.S., length of time in the U.S., gender, education, religion, and experience with discrimination as covariates. The regression model utilized for the analysis involved the researchers adding clusters of variables in three blocks for the full sample: “Mental health = [gender age education...
income] [age-at-migration length-of-time-in-US discrimination religion] [acculturation]” (Aprahamian et al., 2011, p. 86).

The study by Aprahamian et al. 2011 found, contrary to the results of previous studies regarding the relationship between acculturation and mental health among Arab Americans, that acculturation alone did not significantly affect the mental health of Arab Americans, but rather, mental health was affected by a number of other variables, most significantly age at the time of migration, length of time in the United States, religion, and experiences with discrimination. These factors parallel the levels outlined in the social ecological model, emphasizing the point that the mental health of Arab Americans is likely not merely accredited to the individual’s level of acculturation to society, but that other factors such as the person’s individual characteristics, his or her close relationships, and interactions with his or her community as well as greater society must be accounted for.

**Summary of the Current State of Knowledge**

Based on a review of the literature, it appears that cultural competency in EOL care is not being taught in many schools of social work. Additionally, post-MSW training of social work professionals is of questionable value due to the methods in which the material is being presented. Future research needs to explore various pedagogies used to teach cultural competence in EOL care in both academia and the professional field. Gaps exist in the social work educational system’s ability to produce culturally competent practitioners and the profession’s ability to measure the desired level of cultural competence needed to care for clients at the end of life (Boyle & Springer, 2001). Course work in grief, loss, and bereavement/EOL care in general needs to be a mandatory part of Master’s-level social work education if the
profession of social work is to adequately address the ever-growing needs for care among elder populations (Snow et al., 2008).

Cultural competence when working with clients in the end of life is a skill set that will be highly necessary within the next several years, as great numbers of the ethnically diverse Baby Boomers reach retirement age and beyond. Various pedagogies for teaching this difficult-to-teach topic must be evaluated, and those proven effective implemented in schools of social work and among continuing education providers. This study proposes to address some of these issues by interviewing and observing social workers who currently work in EOL care providing services to Middle Eastern patients and their families.
CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

Qualitative methods were chosen for this study over quantitative methods due to the researcher’s desire to identify and describe the following: 1) how social workers learn to provide culturally appropriate EOL care to Middle Eastern patients and their families, 2) intervention techniques frequently utilized by social workers when working with this population in the EOL, and 3) recommendations social workers have for other social workers who provide or will provide EOL care to this population in the future. Qualitative inquiry is a valuable contributor to the knowledgebase of social work (Lietz & Zayas, 2010) and is a useful method for researchers who seek to better understand a phenomenon within its natural context (Lincoln & Guba, 1986).

After conducting a thorough examination of the five traditions of qualitative inquiry as identified in Creswell (2007)—ethnography, phenomenology, narrative, grounded theory, and case studies—the researcher chose interpretive qualitative methodology rather than utilizing one specific tradition to guide the research. When conducted in a systematic manner, studies employing interpretive qualitative methodology have proven useful in contributing to the existing knowledge base without embracing a recognized qualitative approach (Caelli et al., 2003).

The researcher’s desire to better understand the subject matter was driven by both her life experiences as a first-generation Arab American of mixed heritage, and her work as a medical social worker. The researcher grew up in a household headed by an Arab father who immigrated to the United States from Israel as an adult in the late 1960s, and an American-born mother of primarily Dutch and German ancestry. Her professional experience as a medical social worker includes practicing in multiple healthcare settings in which she provided EOL care: the emergency room, outpatient hospice, home health, and on an inpatient hospital unit dedicated to care of patients with HIV/AIDS. Throughout her career, her personal experience as the daughter
of an immigrant has shaped the way she has approached her social work practice, especially when working with racial and ethnic minorities. Given that the researcher is a member of the ethnic group upon whose care the research questions focus, the researcher carefully considered how she would position herself when approaching the participants for interviews and throughout the interview process. For the purpose of this study, with the goal of remaining focused on the participants’ diverse experiences and to avoid placing herself too closely with the experience of the client and family, rather than the experience of the social worker, the researcher chose not to divulge her ethnic identity to the participants unless specifically asked.

Data collection consisted of in-depth, semi-structured interviews with 12 social workers in the greater Houston area. The researcher received IRB approval and began interviews in January 2016. Interviews were concluded in June 2016, when data collection efforts ceased to gather new data and information began to overlap, indicating that data saturation had been reached (Padgett, 2008).

With the assistance of Atlas.ti software (http://www.altasti.com), the interview transcripts were analyzed through qualitative content analysis using a directed approach. Qualitative content analysis is a method of coding written, oral, or other forms of communication and classifying them according to a conceptual framework (Rubin & Babbie, 2008) with the goal of providing “knowledge and understanding of the phenomenon under study” (Down-Wamboldt, 1992, p. 319). A directed approach to content analysis is utilized when seeking to validate or conceptually extend a previously established theory or theoretical framework (Hsieh & Shannon, 2005). Initial, a priori themes, are identified by referring to existing theories or previously conducted research (Potter & Levine-Donnerstein, 1999).
A number of *a priori themes* were woven into this research. These included:

1. Social workers are not adequately learning EOL care in their MSW programs.
   Most learning regarding EOL is happening through field supervision and on-the-job training (Christ & Sormanti, 1999; Kovacs & Bronstein, 1999; NASW, 2004; Raybould & Adler, 2006).

2. Social workers are learning to become culturally competent in their MSW programs (Boyle & Springer, 2001; Kramer et al., 2005).

3. Culturally appropriate EOL care is not being taught in MSW programs (Duffy et al., 2006; Raybould & Adler, 2006; Stein et al., 2009).

4. Social workers are unsure how to interact with various cultures regarding EOL (Duffy et al., 2006, Nazarko, 2006; Weissman, 2000).

5. The greatest stumbling block to working with Middle Eastern patients and their families is lack of knowledge regarding how to build initial rapport (Aboul-Enein & Aboul-Eein, 2010; Salari, 2002).

6. Many social workers are intimidated and at a loss due to the language barrier and lack of knowledge of Islam, which is clouded by the current political climate surrounding Middle Eastern Muslims (Al Abed et al., 2013; Gatrad & Sheikh, 2002).

7. Nursing home care is not frequently utilized by the Middle Eastern community. Family members care for their elders at home (Aboul-Enein & Aboul-Eein, 2010; Al Abed et al., 2013; Salari, 2002).
Research Site

The research interviews were conducted in the greater Houston area. This area was selected as the research site for three primary reasons:

1. Houston, TX, has the 4th largest Middle Eastern population in the United States (U.S. Census, 2003).

2. Texas Medical Center (TMC), located in downtown Houston, is the largest medical center in the world. According to Texas Medical Center Corporation (2015), TMC is comprised of “21 renowned hospitals, 14 support organizations, ten academic institutions, eight academic and research institutions, seven nursing programs, three public health organizations, three medical schools, two pharmacy schools, and a dental school” (Facts and Figures, para.1). Prominent institutions within TMC include the University of Texas MD Anderson Cancer Center, Houston Methodist Hospital, Baylor College of Medicine, Rice University, Texas Children’s Hospital, and Shriners Hospital for Children–Houston. Also included in TMC is Houston Hospice, the Institute for Spirituality and Health, the City of Houston Department of Health and Human Services, Memorial Hermann--TMC, Texas Heart Institute, the Michael E. DeBakey VA Medical Center, and both the Texas A&M and the University of Texas Health Science Centers.

3. Houston is within a reasonable proximity of the residence of the researcher, Baton Rouge, LA, and multiple trips to the research site were necessary to conduct interviews. Houston is a drivable distance from Baton Rouge, LA--approximately 270 miles, or 4 hours by car. The researcher has personal contacts in Houston, who provided housing accommodations at no cost, which reduced travel expenses significantly.
Pilot Study

In order to refine the interview questions and test data collection methods, the researcher conducted a pilot study before proposing the current research. The researcher created a set of guiding interview questions following a review of the social work literature that yielded no standardized measures appropriate for use in identifying methods of training social workers to provide culturally appropriate EOL care. A colleague of the researcher, an LSU School of Social Work alumnus with professional connections in the local hospice community, referred participants to the researcher for the pilot study. Three MSW-level social workers with experience working in EOL care were identified and recruited via email. Participants each received written informed consent forms. Each interview lasted approximately one hour. The researcher conducted two face-to-face interviews using digital recorders and conducted one by phone using the iPhone application TapeACall (http://www.tapeacall.com). The researcher then transcribed and reviewed the three recorded interviews. Review of the transcripts led the researcher to revise several questions, add probing questions, and eliminate redundancies in the question set.

Sampling and Recruitment

The researcher’s focus when recruiting participants for this study was to find social workers with an understanding of the research topics who reside within the chosen geographic area. Criteria for participation in the study included an MSW degree and experience working in social work within the greater Houston area in a position that includes providing a significant amount of EOL care. Examples of hospital departments and outpatient facilities housing jobs that meet these criteria include critical care, transplant services, emergency medicine, cardiology,
oncology, palliative medicine, hospice, and nephrology. Social workers of all levels of experience were sought out for an interview.

Participants for this study were primarily recruited via snowball sampling strategy (Anastas, 1999; Miles & Huberman, 1994). Upon initial contact, the researchers asked participants to provide contact information for colleagues who met the sampling criteria or for assistance communicating with their supervisor to request permission to circulate a recruiting email from the researcher (Appendix A). No monetary payment was offered in exchange for participation; however, as an incentive for participation, participants received a summary of the research results upon conclusion of the project.

Prior to beginning the recruitment process, the researcher attended the 19th Annual Interdisciplinary Conference on Supportive Care, Hospice and Palliative Medicine, held at the University of Texas MD Anderson Cancer Center, on October 16-17, 2015. This provided a better perspective of the culture and facilities of the TMC and additional information about the palliative care and hospice community in the Houston area. Two social workers in attendance were recruited as future participants. Networking at the conference with interdisciplinary team members from targeted departments within the TMC yielded contact information for MSWs on their teams. The researcher later contacted these MSWs via email or phone. Mentioning the name of a coworker and citing the context of the researcher’s acquaintance with the coworker proved to be a useful way of recruiting participants. The researcher was also able to recruit participants online through the use of LinkedIn (http://www.linkedin.com), a social networking website with a focus on professional networking and job-seeking. Sending private messages via LinkedIn to social workers in the greater Houston area, who were identified using the website’s
search feature, was an effective method of personally inviting social workers to participate, and yielded a few participants.

Recruitment methods that proved unsuccessful included joining the Houston Chapter of NASW’s Facebook group and making posts soliciting participation, and emailing a national listserv for social workers working in palliative care and hospice to request participation. While these posts did garner interest in the research by social workers, they did not yield any participants. Attempts to access potential participants through personal connections at a major university in the greater Houston area were also not successful.

**Demographics of Participants**

Twelve social workers were interviewed for this study, of which, 83.3% \((n = 10)\) were female. The participants ranged in age from 28 to 66, with a mean age of 45 \((SD = 12.73)\). Racially, 75% \((n = 9)\) of the participants were Caucasian, 16.7% \((n = 2)\) were African American, and 8.3 % \((n = 1)\) were Asian. Ethnically, 16.7% \((n = 2)\) of the Caucasian participants identified as Hispanic, specifically Mexican American, and 8.3% \((n = 1)\) identified as Lebanese American. The one Asian participant ethnically identified as Vietnamese American.

The sample represented a wide range of experience levels. Participants completed their MSWs 3 (2013) to 41 (1975) years before the interview, the average being 14 years prior \((SD = 10.76)\). Twenty-five percent \((n = 3)\) of the participants reported that their current position included both supervising and training other social workers, and 41.7 % \((n = 5)\) indicated that their current position did not require supervising, but did require that they train others.

The participants all have experience working in EOL care with Middle Eastern patients and their families in the greater Houston area. Nine of the 12 participants currently work in the field of medical social work in a setting where they frequently work with Middle Eastern patients.
in the EOL. Many of the participants work on hospital units within the TMC. One works in a cardiovascular intensive care unit (ICU), three work in an outpatient cardiovascular transplant clinic, one on an inpatient palliative care unit, one on a geriatric skilled nursing unit, one on a kidney transplant unit, and one in a medical ICU. One participant works for a for-profit hospice agency, providing services to patients and their families at home and in nursing homes.

Three of the participants were not working in the social work field at the time of the interviews. One participant is a senior international services representative at a large cancer specialty hospital, and although she does not formally provide social work services, she often utilizes her social work skills in her current position, which involves working closely with the social work department of her hospital. Another participant worked for several years as a social worker on an inpatient oncology unit of a cancer specialty hospital within the TMC, but at the time of interview worked as a health education specialist in the health and medical library for patients and their families, located within the same hospital. One participant was unemployed at the time of the interview. Although he has many years of experience working in hospice, he reports that since completing his doctorate in social work in 2015, many potential employers are turning him away from clinical social work positions, stating that he is over-qualified for the positions available. He was last employed as a contracted social worker for one month in a skilled nursing facility. Presently, he is searching for an academic position in the Houston area and is writing a book.

In regard to the licensure status of the social workers interviewed, 50% ($n = 6$) held in-state LMSW licensure, and 41.7% ($n = 5$) held in-state LCSW licensure. One of the participants did not hold a current state social work licensure. Her position in the hospital was outside of the field of social work and did not require her to maintain licensure. Two of the participant also
maintained licensure in states other than Texas: one maintained LMSW licensure, and one maintained LCSW licensure in an additional state. Along with holding LCSW and LMSW credentials, 25% \((n = 3)\) of the participants in the sample also held Academy of Certified Social Workers (ACSW) certification, and 16.7% \((n = 2)\) earned the title of Certified Clinical Transplant Social Worker (CCTSW). Two completed degrees in addition to the MSW: one completed a DSW, and one completed a Master’s degree in sociology.

**Data Collection**

Data collection included a brief demographic survey (Appendix B), a written measure of perceived multicultural counseling competency (Appendix C), and a semi-structured interview consisting of 13 interview questions developed by the researcher (Appendix D). Protocols for conducting phone interviews were established in the pilot study, but did not prove necessary. All interviews were conducted face-to-face and primarily took place at the participants’ place of employment, with the exception of one interview that was conducted in a private meeting room of a university library due to the participant’s unemployment. Follow-up interviews were scheduled with select participants as needed for clarification and confirmation of the interview data. The recorded interview times for individual participants, including follow-up interviews, ranged from 30 minutes to 1 hour and 39 minutes \((M = 48 \text{ minutes}, SD = 21.59 \text{ minutes})\). In all, 577 minutes of interview data were collected and transcribed verbatim.

The researcher used the 32-item version of the Multicultural Counseling Knowledge and Awareness Scale (MCKAS; Ponterotto et al., 2002), a paper-based self-report inventory, to gauge the participants’ perceived multicultural counseling competency, as a means of screening participants. The MCKAS measure perceived multicultural counseling competence in two dimensions: multicultural knowledge and multicultural awareness (Ponterotto et al., 2002).
Ponterotto (2002) credits Sue et al. (1982), for the MCKAS’ conceptual base, which is derived from Sue’s multicultural counseling competency report defining multicultural counseling competence as comprising of three distinct, yet interrelated, components: awareness of one’s own cultural socialization and accompanying biases, knowledge of the worldviews and value patterns of culturally diverse populations, and specific skills for intervention with these populations. (Ponterotto et al., 2002, p. 154)

The revised, 32-item version of the MCKAS was extracted from the 45 earlier-created items on the Multicultural Counseling Awareness Scale (MCAS) (Ponterotto & Alexander, 1996), and combined the dimensions of knowledge and skills into the MCKAS subscale of multicultural knowledge.

Permission to use the measure was obtained from the author (Appendix E). The instrument includes 20 knowledge-related items and 12 awareness-related items, each rated using a 7-point Likert scale in which 1 = Not at all true, 4 = Somewhat true, and 7 = Totally true. Per the author’s instructions, participants were informed that the instrument would not be used as an evaluative tool, as it is still undergoing validation research. Its limitations and psychometric strengths are currently under study, and no formal cutoff scores of multicultural counseling knowledge or awareness yet exist (Ponterotto et al., 2003).

The measure produces two mildly correlated scores ($r = 0.36$) of perceived knowledge (ranging from 20 to 140) and awareness (ranging from 12 to 84). Higher scores indicate a higher perceived knowledge and awareness of multicultural counseling issues (Ponterotto et al., 2002). Research of the measure has found both knowledge and awareness to be internally consistent. Coefficient alphas for the knowledge subscale have been calculated at about 0.92 and 0.78 for the awareness subscale (Ponterotto et al., 2003).
Knowledge scores for participants of the current study \((n = 12)\) ranged from 77 to 136, with a mean score of 100 \((SD = 18.36)\). Awareness scores ranged from 36 to 77, with a mean score of 63 \((SD = 11.24)\). Cronbach’s alphas for the scores recorded from this study’s participants were 0.88 for knowledge and 0.90 for awareness. These scores are comparable to the scores reported by a study conducted by Cummings (2010), which utilized the same 32-item version of the MCKAS to measure the perceived multicultural counseling competency of 33 residence life professionals, the majority of whom held graduate degrees in Student Affairs and were of comparable racial and ethnic diversity to the sample in the current study. The residence life professionals’ scores for the knowledge subscale ranged from 59 to 127, with a mean score of 92 \((SD = 15.22)\). Their scores on the awareness subscale ranged from 40 to 78, with a mean score of 66 \((SD = 8.74)\).

**Confidentiality, Consent, Recording, and Transcription Procedures**

In order to ensure confidentiality of the participants, the researcher changed all participant names to pseudonyms. Names of the universities the participants attended and mention of their current or past places of employment were also removed from the interview transcripts. The researcher obtained informed consent from each participant via an informed consent form (Appendix F). Participants were provided with a copy of the form at the time of the interview. Interviews were recorded using two digital audio recorders simultaneously, to reduce the risk of loss of data due to equipment failure. The researcher also took handwritten notes throughout the interviews.

The recorded interviews were transcribed verbatim by a team of two Master’s-level and a PhD social work student recruited from LSU’s Social Work department. The transcriptionists all signed confidentiality agreements (Appendix G) and were paid for their work. To assure data
security, the researcher trained each transcriptionist on methods of keeping the interview data confidential, such as only transcribing using headphones, not making copies of any interview recordings or completed transcripts, and always performing data transfers on secure internet connections. All interview data was saved on a shared Google Drive and only transferred to and from that drive via secure internet connection. Transcripts were double-checked for accuracy by the researcher, who corrected them while listening to the digital recordings.

Data Analysis

Directed content analysis of the interview transcripts was conducted using Atlas.ti. The researcher’s approach to analyzing the research data involved the following tasks as outlined by Ryan and Bernard (2003): discovering coding categories and subcategories, reducing the codes, and linking the codes to the applicable literature. To begin the data analysis, the researcher immersed herself in the data by listening to the digital recordings of the interviews shortly after each was completed. The researcher listened to the recordings a second time in order to carefully check the transcriptions submitted to her by the transcriptionists. The corrected transcripts were then uploaded to Atlas.ti and reread multiple times, facilitating further immersion into the data. The researcher made notes in a research diary and began creating memos in Atlas.ti throughout this listening and reading process.

To continue the data reduction process (Miles & Huberman, 1994), initial codes were created based upon a priori themes (Potter & Levine-Donnerstein, 1999). The researcher did this by parsing through the interviews and developing specific codes that referred to these themes in the data. Codes were then created to categorize significant statements and quotes and interesting quotes that well-articulated the commonalities in the participants’ answers. From those quotes, code groupings were created, consisting of similar quotes, based on how they answered the
research questions. The researcher then condensed the codes into larger groupings, sorting by subject matter.

A total of 42 codes were ultimately used to categorize the 868 quotes that were identified as meaningful for answering the research questions. These 42 codes were sorted into larger groupings as they related to the research questions and ultimately into three to four major code groupings per research question.

**Ensuring Analytic Rigor**

The analytic rigor of the research was maintained by focusing on the confirmability, credibility and transferability of the research findings.

**Confirmability**

The confirmability, the degree to which the research findings may be verified (Drisko, 1997; Lincoln & Guba, 1985), was enhanced through literature searches, the creation of audit trails, and peer debriefing. Audit trails, the detailed documentation of the research procedures maintained throughout the course of the research process (Lincoln & Guba, 1985), increase the auditability of a study, the degree to which an outsider could follow and critique the process of conducting the research (Padgett, 2008). The components of this research project’s audit trail include a research diary, handwritten notes taken during interviews, memos containing initial impressions of the data, the digital recordings and transcripts of the interviews, and a codebook created while analyzing the data. The digital and handwritten components of the research diary document the entire research process, including the development of research protocols, meetings with committee members, participant recruiting efforts, notes on pertinent conference attendance, and miscellaneous observations or ideas the researcher wished to document for
future reference. This diary was made available to dissertation committee members for review by request.

The use of peer debriefing (Lincoln & Guba, 1985; Padgett, 2008) further added to the confirmability of the research by ensuring that should the research later be questioned, the researcher could attest to collaborating with committee members while collecting and analyzing the data. Peer debriefing occurred via regular meetings with the researcher’s dissertation committee members to discuss the progress of the data collection and to ensure that data collection efforts were effectively answering the research questions. Although the committee members did not directly participate in the data collection efforts, they provided feedback based on their reviews of the interview transcripts and in face-to-face discussions with the researcher regarding the data collection experience.

**Credibility**

The credibility, the degree to which the findings of a study represent the views expressed by the research participants (Lincoln & Guba, 1985), was enhanced through the use of member checking, seeking participant feedback regarding the research findings (Miles & Huberman, 1994; Padgett, 2008). Member checking was employed through the researcher’s contact with participants to review conclusions drawn from the interview transcripts and to solicit input on alternative wording when necessary.

**Transferability**

The transferability of the research is the degree to which the findings of the research may apply to or be useful in practice, theory, or future research projects (Lincoln & Guba, 1985). This research may be extended to study social work practice in the EOL with many different populations. The research questions may be modified to study other ethnicities and
socioeconomic classes, varying age groups, persons with disabilities, and special groups such as veterans, refugees, and homeless populations. The results of this study and of any additional study conducted using this research’s basic premises may be used in the development of courses to prepare social workers and other healthcare professionals to work with various populations in the EOL.
CHAPTER 4: RESULTS

This chapter presents the findings of the study. Three primary questions guided the research, each exploring facets of providing culturally appropriate EOL care to patients of Middle Eastern descent and their families. The skill set necessary for providing culturally appropriate social work services to Middle Eastern patients in the EOL and their families includes two specific components. The first involves skills needed to work with patients and families in the EOL. The second is the ability to provide culturally appropriate social work interventions.

In order to improve the flow of data presentation, the original ordering of the research questions in the Introduction and Methodology sections of this document have been modified in the Results and Discussion sections. Upon review of the data, it became apparent that the data supporting question 2 directly build upon the data supporting question 3. Therefore, participants’ recommendations to other social workers working in EOL care with Middle Eastern patients and their families will be discussed before common intervention strategies used by participants when working with Middle Eastern patients and their families.

How is the Skill Set Obtained?

The first research question asked, how do social workers obtain the skills necessary to provide culturally appropriate EOL care to clients and families of Middle Eastern descent? Participants of the study reported that they developed components of the skill set through three primary methods: formal social work education through their MSW program, on-the-job training, and personal life experience.
Educational Preparation

While all of the participants expressed that the MSW programs they attended prepared them to work in the field of social work, none of the participants reported that culturally appropriate social work practice was integrated with EOL care in such a way as to prepare them to provide culturally appropriate EOL care. Keeping in mind that learning to provide culturally appropriate EOL care requires that a social worker is proficient in both working with patients and families in the EOL and also practicing social work with diverse cultures, few participants expressed that they felt that their program provided them the specific coursework necessary to fully develop their EOL skill set. All of the participants reported that they took at least one course dedicated to multicultural social work practice, citing that their MSW programs infused culturally appropriate generalist practice throughout their curriculum. Some mentioned that EOL content was embedded within courses such as Human Behavior in the Social Environment (HBSE), and others reported that specific courses on death and dying and EOL care were offered as electives, not required courses in their programs. Among those who reported receiving EOL instruction, a few mentioned that a particular instructor’s expertise, rather than the program’s curriculum provided the most memorable learning experience contributing to the development of their EOL skill set.

Curriculum content on cultural diversity. All of the participants reported that cultural diversity was an important topic throughout their MSW coursework. None of the participants said that their education was deficient in multicultural practice; however, there was no mention of the integration of culturally appropriate practice with EOL care in the MSW programs attended by any of the participants.
Patricia, who works on an inpatient transplant unit, discussed her MSW program’s content regarding cultural diversity. “There was a lot about cultural diversity, and how to be aware…. But at the same time my focus was on political [macro focus], so I didn't get a lot of clinical exposure in school.” Elaine, who also works in transplant services, but in an outpatient clinic, attributed her school’s overall cultural focus for her ability to provide culturally appropriate social work interventions:

My school really focused on anti-racism, so we did a lot of processing of cultural awareness and in terms of practicing and using Westernized theories and applications to other settings of populations of patients… the first thing we learned in our practice in my MSW program was to be aware that yes, you want to be [culturally competent] you know they say “cultural competency,” but no one is ever competent. You want to be culturally sensitive because everyone is very different in their process of where they are in their culture… I would say school had the biggest in terms of setting that foundation for me in terms of how I view it.

Stephen, a social worker on an inpatient palliative care unit, described a particular class he took in his MSW program:

I don’t think anything helped as far as Middle Eastern patients in particular. But I did have a class that focused basically on social work with different ethnic groups. And we all had to do presentations about different ethnic groups… from that what came up was the whole thing about being more culturally aware, culturally sensitive, and culturally just more accepting and open to seeing things from different perspectives.

**EOL-specific coursework.** A vast majority of the participants reported that their MSW program did not adequately prepare them to work in EOL care. Participants who completed their MSW before the 1980s in particular claimed that their programs did not cover EOL issues at all, or stated that HBSE and other courses only briefly touched upon the topic. To highlight the changes in the amount of EOL coursework included in MSW programs over the last four decades, the interview findings are presented here in chronological order by date of completion of the MSW, beginning with the 1970s and concluding with the present day.
1970s. Charlotte, who works for an outpatient transplant clinic associated with a large hospital system, completed her MSW in the 1970s. She does not remember EOL care being mentioned at all in her social work education.

I don't remember we had any [EOL training]. I mean, we didn't talk about dying in the 70s … You didn't even say the word “cancer” when I was first working in hospitals. You wouldn't tell people they had cancer… there were no hospice programs when I first started working in hospitals… it was not unusual not to tell someone, because they were going to die, why bother them. Of course, they knew, people always know. Kübler-Ross came out with On Death & Dying, and that's when the conversation started. And the end of life, palliative care, that all started then so that it was all on the job training, nothing from [my MSW program].

While she felt that her program provided her excellent preparation to practice social work, Charlotte expressed that she felt her younger colleagues received better EOL training than she did.

Now, I was extremely well prepared at [my university], excellent program, but when it comes to, I mean 40 years later, you're going, “okay what did I learn then, what do the [students] learn now?” … the [EOL] skill sets that the two younger social workers I have who worked for me are so…so surpassed mine.

Nancy, a social worker on a geriatric, skilled nursing unit of a large hospital, also completed her MSW in the 1970s. Like Charlotte, she reported that she did not have any EOL content in her program, echoing the sentiment that EOL was not talked about in the 1970s and cited Kübler-Ross as her earliest exposure to working with death and dying as well.

1990s. Rhonda, a hospice social worker, completed her MSW in the early 1990s. She stated that although her coursework covered EOL, she did not feel that her MSW program prepared her for her current work in hospice. “Not really, no. I bet my internships I think [prepared me to work in EOL care]…but not, um, not specifically with different cultures I would say. [EOL was covered in] probably one of the human behavior classes.”
2000s to present. More recent MSW graduates reported that their programs had some EOL content infused throughout the curriculum, and many learned skills in their coursework that they later translated into EOL skills. Amanda, a social worker in a medical intensive care unit (MICU), completed her MSW training in 2006. While she did not take a particular course about EOL, Amanda says she did learn the skills she needed in her generalist practice coursework.

I don't believe I took any specific class; I don't remember if there was an elective for death and dying or anything like that… I remember learning the stages of grief, but that was probably in a theory class or something like that… theory was helpful, mainly because you can pick and choose from a bunch of different theories and in the hospital setting a lot of times it's going to be a brief task oriented type stuff. Other things that were helpful - I did take the medical social work elective.

Colleen, who works as a social worker in an outpatient clinic for patients with advanced cardiac failure, including heart and lung transplant, completed her MSW in 2009. She did feel that her MSW program prepared her for the work she currently does, also due to a theories course she took.

There was one course in particular… it was a theories course, and they broke it up into two semesters. One with individuals and then one with families. So you got the one on one, and then you also got the larger systems approach or slightly larger systems approach. I would have to say that that really helped prepare me because we did a lot of role play in that class.

Several of the participants who reported that the MSW program they attended contained EOL-specific coursework, said that it was offered either as an elective or as a part of the curriculum for their concentration. Examples of concentrations mentioned that included courses such as death and dying in their curricula were medical social work and gerontology. Elaine, who is a social worker in the same outpatient clinic as Colleen, completed her MSW in 2010. She felt that her program did prepare her for her current position, due in part to her personal course selections.
I knew I would become a medical social worker, so I chose courses knowing that end of life would be a part of it. … I think I took one course…about social work care in a medical setting. I felt that course helped quite a bit because we had to focus on looking at the transitions of care of patients when they come through the ED [emergency department] and different acuity levels and stages of care as well as the life process of that as well.

**Instructor expertise in end-of-life care.** In a few cases, it was not the coursework or the curriculum offered by the MSW program that made the most impact on specific participants. Rather, an instructor’s expertise received credit for providing the majority of the skills learned to provide effective EOL care. One adjunct instructor in particular was mentioned by almost every participant who obtained their MSW from one large local university. Alex is a social worker on an inpatient critical care unit, and finished her MSW in 2013. She spoke of this instructor extensively in our interview.

My program specifically did offer a grief and bereavement course, and a trauma course. We had a fantastic social worker who has been experienced for years and actually does outside trauma counseling… she’s been a social worker for, I want to say, over 20 years. Her grief and bereavement class actually were very helpful for that, because I could help clients better understand some of the behaviors that they were witnessing. Or prepare them for potential behaviors that they would see… I took grief and bereavement, and then I also took trauma…very difficult course work as far as the emotional aspect because we get into real cases…people that she's counseled, situations she's worked in. I felt like I got a lot of benefit from that…she's a fantastic speaker. She's a fantastic social worker… she's very well rounded. And she would be somebody I would certainly look to for any type of training for trauma or grief and bereavement.

Renee, who last practiced social work on an oncology unit, graduated with her MSW in 2001 from the same university Alex attended. She took the same instructor’s death and dying course, and mentioned that it “greatly prepared” her for working in EOL care, including providing culturally appropriate EOL care.

If you interview anybody who went to [the university I attended], they probably will talk about that class. She's everybody's favorite social worker in Houston… So I took that class, and it was just not so much that I learned specific tasks or knowledge, but just learning to be comfortable with death and dying as part of my role as a social worker. And openness to different meanings for different people and traditions and rituals.
Rhonda, a hospice social worker who completed her MSW in the early 1990s, praised the instructor of a death and dying course she took as an elective while an undergraduate social work student at a small university that generally offered small-sized classes. She described this instructor’s death and dying elective as “the biggest class I have ever taken at the university… it was a fabulous professor.” The content and format of the class especially made an impact on her - “He brought in a lot of great speakers. I’ll never forget, we went to a funeral home, and toured, and he really took us through death and dying culturally. And then the grief process with different people.”

**On-the-Job Training in End-of-Life and Culturally Appropriate End-of-Life Care**

Overwhelmingly, the participants expressed that they did not receive enough instruction in the classroom to adequately develop the skill set needed to provide culturally appropriate EOL care. For many, these skills were learned in the field. Their MSW internships, “trial by fire,” learning from other social workers and employees from other disciplines at their worksite, patient inquiry, and researching topics independently were the primary methods by which the participants reported obtaining the necessary knowledge once working in the field.

**MSW internship.** Quite a few of the participants credited their MSW internships as the means of learning the skills needed to provide culturally appropriate EOL care. A skilled internship supervisor was often mentioned as having made a large impact on their development of this skill set. Alex had a unique experience, as she was supervised by multiple social workers throughout her internship placement, which allowed her to rotate through multiple departments in the hospital she currently works. “I did a one-year internship here [at my current work site]… My first semester I worked primarily in rehab… then the second half of my internship I worked with acute care social workers and ICU social workers.”
Other social workers. The participants frequently reported that they received training for their position from other social workers, either in their department or from a social work supervisor. Patricia mentioned that her training for providing culturally appropriate interventions came from mentoring of other social workers, and she is now a mentor to new social workers in her department.

[I trained] the other two that are here. I've been here the longest, so that's kind of the way the department works. So whoever we bring in, that person who has been there the longest is kind of the mentor and kind of trains until they are ready to go out on their own… Everything that I learned about working with different cultures was really just based on experience and being mentored by other social workers who had been in a field for a long time.

Charlotte is the lead social worker in her department. She trained Elaine, who now provides training to incoming social workers and social work interns, as well as new employees in other disciplines. Both Charlotte and Elaine have provided Colleen, the department’s newest social worker, with her training.

Nancy felt that she was particularly well trained for her current position on a skilled nursing unit by her supervisor, who was Middle Eastern herself. “Our former director was Lebanese. And she, being Lebanese, she understood that culture.”

Renee found that talking with other social workers in her department helped her to learn the skills she needed for to work with Middle Eastern patients and their families in her most recent social work position.

One of the great things about working [in this hospital], it’s a huge department of social workers, so you always have all these colleagues you can work things out with. You know, you go back to your office and there’s eight other [social workers] there you can discuss it with.

Stephen described his role in the development of a specific training for working with Middle Eastern patients and their families. The initial training, which he developed for
physicians to help them communicate with families of all cultures dealing with a terminally ill family member, was overcome with questions specifically about working with Middle Eastern families. This led to the development of Samera's presentation. This training evolved to include other disciplines in the hospital, continues to be offered, and is well-attended.

I interviewed the different [medical] fellows that year. The new training doctors. And I said, "What are the biggest challenges for you with family meetings?" And one of them said "international families" and in particular, Middle Eastern patients. So we had Samera come. My presentation was going to be about an hour, and I had [planned for] Samera to talk about just for five minutes. I started out with the international families. She came up, [with the intention of talking] just a couple of minutes, and that meeting went the whole hour. Just with Samera… There were so many questions from the doctors just about Middle Eastern families … So there's a huge need…Especially back then before they had a lot of training. There's a big need for how to handle, how to work with international families.

Samera, who immigrated to the United States from Lebanon, is considered one of the resident experts on Middle Eastern cultures within her hospital system. In her interview, she provided more information about her goals for her presentation within the training program:

I did this presentation to inform, because [I’ve been involved in situations where] the patient is totally frustrated, the family is frustrated, and from the other side, you have the medical team as well, who is really upset, because they want to give the care, they want to do the correct approach, but they are not allowed, because the patient doesn't want to listen, or to deal with them anymore. So here, we created this presentation, so I will instruct the medical team how [the patients and their families] think based on their culture and background… We told them how to talk [to their Middle Eastern patients], how to say “hi,” [in Arabic] to [appropriate] physical contact and eye contact.

Employees in other disciplines. Participants mentioned receiving formal and informal training in their workplace from employees of other disciplines. Physicians, nurses, translators, chaplains, and international patient service representatives were cited as coworkers who helped participants develop their EOL and culturally appropriate care skill sets, and to merge the two skill sets to provide culturally appropriate EOL care. Alex credited the global services department of her hospital for the majority of her training in culturally appropriate EOL care.
[We social workers] heavily rely on our global services for being culturally competent …They work with us in translation, but they also advise us about what we can recommend as far as goals of care…they'll typically be with family first, or they've been working very heavily with them. Because [the patients] come here specifically for care in a lot of cases. And they'll come from their native country to get care here. So, they've already worked with global services before they've ever even shown up [at the hospital].

Stephen had two primary mentors. He described receiving training for his role as the social worker on a palliative care unit by another social worker on his unit and the team's chaplain. He described receiving minimal training from the previous social worker in his position - two weeks of shadowing her, “and then also, training from different doctors on what they want. Things like that.”

**Trial by fire.** Many of the participants referred to the training they received for their current position as "trial [or initiation] by fire" or "trial and error," indicating that they received little or no training as a new employee. These participants attributed their lack of training to the new employer's expectation that they were hired based on their level of experience, and therefore did not need much training. Often, participants expressed feeling that they received little or no training due to staffing issues; either the outgoing social worker was only available for a limited time--2 weeks to a month--or had already left the worksite and was not available at all. Additionally, high caseloads were often cited as a factor that restricted the amount of time supervisors or coworkers could dedicate to training the newly hired social workers.

Rhonda described the training received for her current position with a hospice agency as “initiation by fire!” She attributed her level of experience at the time she was hired for the scant amount of training that she received. The main focus of the training that she did receive was on the agency’s operating procedures

There was training specific to anything specific that they want me to do here. Or a certain way that they want it done. We just changed [our charting system], all on iPads and so,
there was training provided to that. But not anything on my social work role. They expect you to know, and I think that's why they only usually hire experienced people.

Russell also felt that his employer's expectation that he came fully prepared to perform his role in his most recent social work position contributed to the lack of training he received. “Nobody [trained me]… Oftentimes social work just throws you in and expects you to adapt. That’s just what it is.”

Charlotte is the supervisor of her department, and developed her own position, as well as the positions of the social workers she supervises, so she did not have anyone to train her. She describes her preparation:

It's a conglomeration of forty plus years in social work… I was hired as an expert. As a content expert to just develop the program, so I came in to develop the social work program…I've worked in transplant for quite a while. I've worked in hospitals for many years; 35 years… when I came here, I was given carte blanche to do what I felt was proper to establish a program that is value added.

**Patient inquiry.** Participants described learning how to provide culturally appropriate EOL care by asking their patient or the patient’s family for assistance. Amanda described a candid conversation she had with a Christian Iraqi woman:

I remember just asking her about what life was like where she came from. I'm not really scared to delve into things like that. "Tell me why you do this?" or "I'm curious, I would love to know." I tend to do it in a more non-threatening way… "I'm really interested in you, in your culture."

Samera, who is Middle Eastern herself, was raised a Christian, and primarily learned about Islam from both patient inquiry and by talking to a close personal friend. “I don't know the Muslim culture very well, but I learned it as well, from them, from the patients. By asking them. … I did my research and asked my Muslim friend.”
Rhonda described learning a great deal about Middle Eastern cultures from Middle Eastern patients and their families. One of her patients’ family members, in particular, was especially helpful.

[I learned primarily by] observing patients and families. And asking questions. We had one lady a long time ago, and she was taking care of her father, and he passed away. And [while he was a patient of our hospice], she was very open to talking with me, and she would always prepare food for us when we came... And so, I would sit down with her, and she was really one that I could kind of just ask questions because she had lived here [in Houston] a long time and so she knew Western culture and so I just asked her a lot of questions… She was a great resource.

**Self-directed research.** When the necessary training for working with a specific culture was not provided by the participant’s department, and colleagues or employees from other departments could not provide assistance, many of the participants did their own research, primarily via the internet. Russell described independent research he performed online and in bookstores to learn about the cultures of patients he encountered in his work in hospice. “I was dealing with diverse populations, I, on my own, studied the individual cultures. So it was more a self-taught and self-education than what was actually provided in the courses themselves…” He felt that there were many different situations that he encountered in his work in hospice that he was unprepared for, and did not have a mentor available to teach him what he needed to know.

I would go to Barnes and Noble and Borders and just study everything about [a topic], read Social Security books for Dummies from cover to cover, Medicare from cover to cover, and just learn it on my own. There was nobody to really go to… And to me, if you're going to step in the shoes of a hospice healthcare worker, you have got to study [your patients] and know them… if I don't know something, I'm going to go home, I’m going to spend two or three hours studying their religion, studying where they came from.

Rhonda also reported independently researching her patients’ cultures and recommends those whom she trains to perform "reading and research" to fill in gaps in knowledge about cultures he or she encounters in hospice work.
Life Experience

Participants drew from their own life experiences to enhance their EOL practice with their patients and families of Middle Eastern descent. Growing up in a multicultural household themselves and the influence of their religious affiliation were the two most commonly cited ways the participants’ lives influenced their ability to provide culturally appropriate EOL care.

Growing up in a multicultural household. A few of the participants discussed the influence of their experiences growing up in a multicultural household as having had an effect on their EOL work with Middle Eastern patients and their families. Russell, an African American man in his 60s, grew up in a household that included many foster children of various ethnicities. He credits his parents and his upbringing for much of his understanding of diverse cultures.

My mother took in 50 foster kids over a 10-year period... And they were Caucasian; they were Hispanic, a few African American, and some Asians... to me, that opened up the floodgates of caring for others, of loving others, of not looking at the pigmentation or the amount of melanin in the skin, but feeling their pain and understanding their heart... I often say that the greatest lesson I have ever learned was not from the Bachelor's or the Master's or the Doctorate, or from some CEU [continuing education unit] program, but was watching two people, [my parents], love people that were so much different than them. And that's where I learned my empathy to care about others genuinely.

Patricia, a second-generation Mexican American, expressed that she felt that her culture and Middle Eastern cultures shared many characteristics, which helps her relate to Middle Eastern patients and their families.

I think a lot of [Middle Eastern] values mirror those of Hispanics. So I kind of get it - the values of the men in the family who kind of are the bread winners and they make the decisions and things like that. I think that personal experience has helped me not to be closed minded about that way they make decisions or the way they work with each other within the family.

Elaine, a first-generation Vietnamese American, found similarities between her experience growing up in the United States as an Asian with the experiences of Middle Easterners in the
United States. She described her frustration with being stereotyped, and the lack of understanding she often encountered as a Vietnamese American:

One Middle Eastern family may be very different from another family… Because you have religion that plays into it too. And then you have where they are located in the Middle East is different too. Because [people] lump everything together, like Asians, same way, and it’s really frustrating … just because you may have an interaction with one population doesn’t necessarily mean it may apply to everybody.

EOL wisdom learned from religious affiliation. A number of the participants mentioned that their personal experiences with their own religious affiliation influenced their practice with Middle Eastern patients and their families in the EOL. Amanda grew up in south Louisiana, in a primarily Catholic family. She attributed her Catholic upbringing to her views regarding EOL and provided an interesting parallel to a biblical story and her experience as a social worker learning to work in EOL care.

I was very lucky with my upbringing and my understanding of death and everything, that [death] doesn't traumatize me. Um, but a lot of people don't have that luxury. Even social workers don't have that luxury…And the way I do things is very dependent on my ability to go into another person's personal hell and that's a really difficult thing to do and another way I describe it that might be a little bit nicer than a personal hell is being a Christian talking about Good Friday. That journey to the cross and I'm just walking with you down that road like Simon of Sarine. Nobody wants that job. But it is a very blessed job. It's very personal, and you're seeing a very personal side of someone.

Russell had a unique perspective on religion. He is not only a social worker, but also an ordained minister. He has translated his experience as an African American and a pastor into ways of relating with his Middle Eastern patients and families.

I have pastored two churches, so I understand the spiritual perspective and [I have gained insight because I am] African American. African Americans, when they come into hospice, tend to see things through a God lens, or spiritual lens [as Middle Easterners tend to do], so I’m very familiar with the judgment that comes along with that.
What Recommendations Do the Social Workers Have for Others?

The next research question asked what recommendations social workers who provide EOL care to clients and families of Middle Eastern descent have for social workers who anticipate encountering this population in their own practice? Recommendations from participants focused on Middle Eastern cultures, Middle Eastern views on EOL, and the participants’ own self-awareness developed through working with this specific population.

Middle Eastern Cultures

The participants had many recommendations regarding Middle Eastern cultures for other social workers who anticipate working with Middle Eastern patients and their families in EOL care. The recommendations primarily focused on issues of acculturation, body language, and family values.

Take acculturation level into consideration. The patient and family’s level of acculturation makes a difference when planning social work intervention strategies. Whether the family has been living in the United States for generations, has recently immigrated, or is only traveling to the United States for medical treatment, the family’s level of acculturation will guide the social worker’s interventions with a Middle Eastern family.

Rhonda has found in her practice, there are a few clues that a social worker can use to determine a patient and family’s level of acculturation.

I’ve found that if they have young kids in the public school system, [this is an indication that the family has a higher level of acculturation than if the family has their children in a private school]. All that makes a difference….Especially if it’s a multigenerational home, where you’ve got maybe mom and dad, who have been here a while, [if] their kids are going to public school, [this is an indication that the family] interact with a lot of other people in the community, but [you may see that] the grandparents have come over and [the grandparents may not] have that level of comfort.
Charlotte compared and contrasted the differences a social worker encounters when working with an “Americanized” (highly acculturated) versus a “non-Americanized” (less acculturated) family.

Well, “non-Americanized” you’re looking at old-school, you’re looking at the old world. You're looking at their culture as it would exist in their country… and here, [with an “Americanized” family], they have assimilated, so I don't have to worry so much about their cultural differences because we are all in the same boat…So that those cultural norms that you would see with their parents or grandparents, you're not going to see with them because they have grown up here…we are going to be talking about the younger patients in their now 20s, 30s, getting up into the 40s you're still probably looking at first-generation-born immigrants…“do they speak English? How long have they lived here?” You have to sort of know where they are on that continuum… the key is “where are you on that developmental spectrum, what generation are you, what does your generation expect?”…the [adult children] may be able to work with you, completely face-to-face, upfront, because they’ve grown up here.

**Appropriate body language is important.** Participants, especially female social workers who may be unfamiliar with the traditional protocols for communicating within a Middle Eastern family, expressed that they often find establishing relationships with key family members daunting. Middle Eastern cultures are known for their strong patriarchal family structure, which many of the female participants expressed took time to acclimate to. Renee discussed her strategy for working with Middle Eastern families, taking her gender into account in the interactions. “[I was not taught this skill] in any formal way, um… just with practice. Just learning to present myself very assertively. I don't know if that was for good or for bad, but that's how I did it.”

In her work as a hospice social worker, Rhonda expressed that she has learned that, as a woman, touching Middle Eastern patients or their family members is seldom appropriate.

I don’t have to touch the patients like the nurses do. I do if maybe they’re not Middle Eastern, if they’re crying or if there’s something else, I will pat them, or give them a touch, or touch their hands. But, with Middle Eastern, I’m more sensitive to that.
A common misconception regarding interacting with Middle Eastern patients and their families is that women should not make eye contact with a Muslim man. Samera explained the importance of eye contact when interacting with Middle Eastern patients and families who are observant of the Islamic faith:

Eye contact is very important, but just with the male. You don't [make] eye contact with wives or the daughter, and you talk only to the male…you always make eye contact and talk to the oldest male in the room, even if the patient is a female and the patient is there. First, you talk to the male in the room…He doesn't want you to ignore him, and he thinks that you are ignoring him if you are not talking to him.

*Be sensitive of what the family values.* Knowing what is important to a family is especially crucial when working with Middle Eastern families who are caring for a family member in EOL. Amanda described her experience with Middle Eastern families negotiating discharge planning:

As far as success goes, I would say success lies in if you are really considering what the family values. They’re not necessarily going to be valuing hospice, that’s not of value [to them], at least not in my experience. What’s going to be of value is to be able to go home, be comfortable…What they’re going to value is being able to keep those relationships with those who they trust [doctors, nurses, social workers and other members of the team who cared for their loved one during their stay in the hospital], to go home with their family members… From my perspective, they are at the end of life, there is nothing else we can do. A successful scenario would be me getting them home in a situation that they are comfortable in.

**End of Life**

Recommendations from the participants specifically surrounding the topic of EOL as it is approached by Middle Eastern patients and their families focused on EOL planning as taboo, resistance to hospice care, and EOL traditions.

*Planning for end of life may be seen as taboo.* Participants reported that efforts to initiate conversations surrounding EOL with Middle Eastern patients and their families frequently met with resistance, which can sometimes lead to the family rejecting social work
services altogether. According to the participants’ experiences, other members of the care team – doctors and nurses – also experience difficulty with these conversations and experience resistance and rejection when approaching Middle Eastern patients and their families to discuss EOL.

Charlotte stressed that social workers need an understanding of their Middle Eastern patient and family’s view of death and what their expectations are for medical treatment in the course of dying. The social worker will then be better able to work with the patient and family, having “the awareness of where your limitations are so that you don’t breach any kind of rules that you shouldn’t breach…you can’t go in and say ‘well now let’s talk about end of life.’” Because that doesn’t exist, that conversation doesn’t exist.”

Samera explained her understanding of why discussing EOL may be seen as taboo for many Middle Easterners:

For them, a lot of our patients, from the Middle East… end of life is not for a doctor to decide. End of life, only God decides it, this end of life. So they couldn’t accept that a doctor would tell them “I’m sorry you only have one month to live,” they cannot accept it, there will be a conflict with the doctor just because he said that. They directly, they say “I need to change the doctor, I don't trust this doctor, he is not a good doctor, he doesn't believe in life.” All this is related to the culture and to the religious beliefs.

Discussion of the establishment of Do Not Resuscitate (DNR) orders, whether regarding a patient who is being cared for inpatient or outpatient, was frequently mentioned as a difficult topic in EOL care with this population. Alex described that in her experience, other members of the patient care team, who have already met a Middle Eastern patient and their family, have advised her to avoid the topic of DNR altogether.

In some cases we’ve even been told “don’t even mention a Do Not Resuscitate.” That’s not culturally something that would be appropriate for specific families that we’ve worked with. In some cases when we’ve talked about it with families, they immediately shut the conversation down. But we’ve even been warned in some cases, don’t even address it with the family. Because we, we already know their stance on that. They’re not
going to even talk about that. Everything should be done. Even when we’ve explained what that would look like and how traumatic that can be physically. The family are insistent that we do everything…We should not try talking with them, typically about Do Not Resuscitate, or you know limiting medical care for them.

In Amanda’s work in the MICU, she has learned that some Middle Eastern families

“believe in doing everything…that means that if you are doing CPR and the patient flat lines, then it’s fine because you did everything.”

Samera further clarified these sentiments, regarding DNR:

They struggle to do the best thing for the patient by not accepting DNR, by not accepting that this is the last days or this is the end of life. They truly believe they are doing the best thing for the patient. They always believe in miracles, always. They always say, “you don't know, you never know, maybe she will wake up, just like that.” They always say, “it’s not up to you.” They always say, “a miracle, it can happen,” from the religious point of view…For them, as long as there is a soul in your body, it’s against God’s will, to finish or to stop the oxygen, to stop the machine, as long as the soul is there.

She has found this to even be applicable regarding brain death:

For them, this, not death…They want to keep [the patient on life support] as long as the heart is beating - even though the patient has been pronounced officially and legally brain dead. The Muslim patient really cannot accept that. That's how and when our role comes in, to instruct that “this is how it is here” and “the patient is already pronounced dead.” It’s very hard for them from the religious point of view, from the family, the support and the love, and everything. And even they have fear toward God [that] they intentionally ended the life of the patient.

**Resistance to hospice care.** Overall, the general consensus among the participants regarding referring Middle Eastern patients to hospice care was that it was futile. Due to the cultural taboos surrounding the topic of EOL care and the religious and cultural beliefs surrounding EOL, the participants overwhelmingly expressed that Middle Eastern patients and their families “don’t believe in hospice.” Samera clarified these beliefs:

For them hospice means that a son is putting away his sick mom if he is puts her in hospice... so we don't do it really often… they are not familiar with hospice [as we know it in the United States]…when you put a patient, back home, in a hospice it means that you are not a good family member, that you just [left the family member] to die by himself. It's different than the hospice here. [In their home country], they don't accept
hospice…Even the services back home. They don't have, like, the quality. Back home the hospices are not like here, not at all…the concept is “who is there? It’s a person who doesn't have anyone.”… If the patient [needs] hospice but still have brothers, a father, they will never put him in hospice…They will keep him at home, or in a hospital as long as they accept him.

**End-of-life traditions.** Participants mentioned the value of being familiar of their Middle Eastern families’ EOL traditions, specifically surrounding the patient’s actual death. Rhonda described the protocol for handling the body of a Muslim patient, based on her experience as an outpatient hospice social worker:

They have the group at the [mosque] that comes in after [the patient] dies and they take care of the body… when the nurse goes in and they die, you don’t touch the body really. The nurse will lay the stethoscope and listen, and she can do what she needs to do to pronounce the death, but that is it. [The family doesn’t] want any touching, cleaning. [Usually, with other hospice patients] our nurses and aides will prepare the body to be picked up by the funeral home or to be seen by the family…just as a sign of respect. But with the Muslims, you don’t want to do that. And so they have their own group own group that comes… And then they usually dress [the deceased] in all white.

Russell described his typical experience as a social worker in an inpatient hospice, taking his gender into account as he described an interaction with a Middle Eastern family’s reaction to a patient’s death:

When their loved one passes away, the men will come out. I’m a man, so the men will come out and shake your hand and hug you and embrace you…They are so grateful and they bow, they are so respectful… I know Middle Easterners, from my perspective, seem to have great respect for healthcare professionals, physicians and nurses, and they are very respectful. So, and we see that demonstrated in their comments and in their body language and the way they treat us after the death. Thanking us. So it’s pretty publicly expressive from that vantage point.

**Self-awareness**

Participants stressed the importance of becoming aware of their own personal views on the EOL – the dying process, reactions to the death itself, and views on the afterlife. Many discussed experiencing distress when working with Middle Eastern patients and their families who insisted that “everything be done” for patients who the medical team see as no longer
benefitting from curative treatment. Amanda spoke of self-awareness when working in EOL care -“You have to be able to handle your own stuff, not stuff it back, but actually deal with it in order to enter into that picture or walk down that road with another person.”

Stephen shared his experience working with patients who meet hospice criteria, but continue to receive curative treatment:

So a part of the Qur’an is to seek a cure until you’re definitely sure, you know, there’s nothing else left. And pretty much that’s treatment, treatment, treatment, until the person is sure the person is going to die. Until they’re just about dead and even, you know, ‘til they die…And that’s just not my belief, so it’s hard to watch that in other people. Um, and then, the other thing is that one of my roles is to, before anybody leaves here, we give them the option of completing an out-of-hospital DNR. Um, so that’s pretty much counter-culture to Muslims. Because it would be stopping care. And so even though people are on their last leg and they’re going to be taking this trip back to the Middle East, they don’t want an out of hospital DNR. So we just don’t even bring it up with families anymore because it’s just distressing to them…And I know that’s not right in my mind. But, not one patient or family has ever signed an out-of-hospital DNR that I’ve worked with. None. Not one yet. Not one Middle Eastern family…Oh and that’s the other thing that is tough is that Middle Eastern patients do not do hospice, at all. It’s morally distressing because I see that hospice would be so good for them but they don’t want it. They don’t want it talked about at all. And also it’s tough because many Middle Eastern patients or some, some are doing fine.

Alex discussed the frustration and feelings of helplessness she experiences when working with Middle Eastern patients who come directly to her facility from other countries in order to receive medical care. She is often dismissed by the families, who have already developed relationships with other members of the care team prior to admission. Due to their socioeconomic status, the families may not need the tangible resources that she normally offers as a means of initiating contact and developing the relationship that leads to later providing emotional support to the family.

I think it’s just hard for me when I’m working, typically with a Middle Eastern patient, because I feel like the support that I want to be able to offer them, I feel is limited. For one thing, they’re usually not from Houston. So, any resources, any immediate resources I can’t provide them. Which in most cases isn’t an issue, because like I said their government typically will pay for everything for them, including their stay here, the
family’s stay as well, not just the patient. So, they don’t typically need resources or anything, but as far as giving emotional support, I feel like, to me it feels more cultural, I can’t relate to them. From the medical perspective, we don’t want to put somebody through a lot of pain and trauma and all if we can help it, but they still want us to go full course with everything. I think it’s just very difficult to offer support in that respect, because even though I want to be able to help with any emotional support, they typically don’t want anything to do with social work. You know, as far as, asking about any kind of grief support or anything I can offer them, they usually just say they’re fine, they don’t need anything.

Russell also shared his personal thoughts on EOL and how they shape his practice of social work in EOL:

I believe you die like you live. You die like you live. And if those things were significant and important during your life, why should they be discontinued as your life is ebbing out in its final chapter, final sentence, final punctuation mark, period, the end of life? Those things ought to be allowed to be practiced and to be celebrated and memorialized. And so that's very personal to me, but also in terms of our profession we need to understand that and we need to allow that. And oftentimes through ignorance, or we have that big term "ethnocentrism," where we kind of think that our way is the superior way or the only way…And we impose that.

What are Common Intervention Strategies Utilized?

The final question was, what are common intervention strategies employed by social workers who provide EOL care to clients and families of Middle Eastern descent? Most frequently mentioned were rapport building, educational interventions, teamwork, and EOL discussions.

Rapport-Building Techniques

Initial interactions with Middle Eastern patients and their families was a topic that brought about many common issues for participants. Reoccurring themes were the importance of first impressions, figuring out who the plays the role of family spokesperson, demonstration of knowledge of Middle Eastern cultures, and the importance of building the working relationship slowly.
First impressions are important. First impressions are important when working with Middle Eastern patients and their families. How the social worker presents herself or himself when first meeting a Middle Eastern family can shape the entire course of the working relationship with a family before even speaking a word. Russell succinctly made this observation, stating “Just one offensive body posture can destroy the entire thing.”

Samera explained this viewpoint more thoroughly:

As soon as you walk in the door, the first impression is so important… [When] you start the conversation saying "please help me to understand your culture, help me to understand what the message that you want me to understand or to present to the doctor," when we tell them that we need their help and we are open to understand their culture, then [interacting with them] will be easier.

Samera suggested, when working with Middle Eastern families who are minimally acculturated to the United States, a social worker will likely experience resistance or be outright rejected by a family if their approach lacks consideration for the family’s level of acculturation.

When they feel that someone is here to judge him - "you are coming from a different country." You cannot do that. This is the biggest mistake, when an employee or a doctor will tell the patient "this is not your country we are different, you cannot do this here." That's it! And once this happens, that's it; there is no connection at all.

Learn who the family spokesperson is. Stephen has learned that he can avoid problems communicating with Middle Eastern families by asking them up front, in their first interaction, how they would prefer to receive information from the palliative care team.

Every family is different; some families like to get information directly from the doctor. Other families would rather have us speak to their spouse or other family member and let them talk to the patient and then ask them the question directly. [Ask them] “What are you most comfortable with?” so we know right off the front and then, you know, act that way going forward.

Demonstrate knowledge of their culture. Demonstrating knowledge of their culture can be a meaningful way to build rapport with a Middle Eastern family. Whether it is speaking a few key words of their language, showing knowledge of geography, the region’s weather, or
mentioning a historic landmark in their country, the effort put forth and the acknowledgement of their cultural heritage is beneficial when developing a relationship with Middle Eastern patients and their families.

Russell cited this as an intervention strategy, specifically when introducing the idea of hospice to a Middle Eastern family:

To be effective, you have to understand their traditions, their culture...how they see, touch, God, medicine, healthcare professionals, the Imam, the minister; all of those things are important. Funeral, burial, rituals...We’ve had many Middle Easterners come in and say "we don't want any healthcare professional to touch the body after death. We wash, we clothe, we bury without embalming"...We had to set up [transportation for the body, sometimes out of state] in advance so that the body could be in the ground without embalming as soon as possible...So once they saw that we were sensitive to that, and understanding of that, they signed on because they saw cultural sensitivity. I think the skill is cultural knowledge, sensitivity, and awareness. You gotta have it. "Well, no we don't do that in America, you know, we wait a week, and we have a wake, and they come and view the body." That's not gonna fly.

Samera described including this type of information in the presentation she gave to the palliative care department:

I did a brief overview of the Arabic and Middle East countries, for them to have some point of common conversation with the patient. If you know that the patient from Saudi Arabia, ask him about Mecca ... If they know someone is from the Emirates, Dubai, they will ask about Burj Kalifa, you know, there is something to do the ice breaking here.

Stephen, who learned this strategy from Samera’s presentation, puts this into practice with the Middle Eastern patients he works with in palliative care. “Be very aware that there are certain things that can help connect with family members. Like Middle Eastern patients, what can open a lot of doors is just leading in with as-salāmū ʿalaykum [peace be upon you].”

Build the working relationship slowly. Participants shared the importance of getting to know Middle Eastern patients and their families before “getting down to business.” Colleen takes her own race and ethnicity into account when she first begins building a working relationship with a Middle Eastern patient and their family.
I'm Caucasian, and so going into it…it's a little harder for the client or patient to trust me... And so establishing that trust and taking a little longer... The problem I face in this setting, especially in my previous setting [critical care]…you came in, and "you have an anoxic brain injury, and we got to make a decision now," and boom, boom, boom, boom, boom. And that's the reality of medical social work. You are working against the clock, and you do not have multiple visits to establish trust, so how do you do that in a time crunch scenario? I'm still learning that. But the big thing is knowing you’re going to need to take a little more time and a little more effort to establish trust so that they’re comfortable making that decision and opening up to you about that.

Rhonda spoke of common responses Middle Eastern families may give her when she initially meets with them in hospice:

[They may say] “Yes, we have everything we need, we’re fine. We’ll call you if we need something.” So that’s why when you do go in initially you try to be always non-threatening... And there may be some questions even on the assessment that, I may not choose to ask at the initial assessment. Or I may have to work, and gain some of their trust…I’m not necessarily going to ask about funeral home on the first visit.

Nancy shared that social workers who work with Middle Eastern families in particular need to provide “a lot of patience, a lot of support. Because they tend to move slower than the Americans do. They tend to move much slower.”

**Educational Interventions**

The use of social work interventions with the primary objective of providing information to patients, their families, as well as the care team serving them, were a frequently mentioned by the participants. In addition to providing information about disease processes, EOL, and culture, participants often provided educational interventions defining their role on the care team.

**Educate patients and their families.** Samera spoke of the importance of providing patient and family education, especially preparing families for the dying process. She refers to especially addressing fears the family may experience based on hearsay, such as “morphine makes them crazy.” Hospital policy is another area Samera discussed that educational
interventions by the social worker on the care team can be useful, but must be approached with their culture in mind.

We need to educate them about the policy and the process of the hospital, because they are here [as a patient]. But at the same time, we need to gain their confidence while educating them. If you tell them, “this is our policy you have to go with it,” they will not accept it, they will be defensive and offensive more. So we will tell them, what I do, “based on our experience with patients from your area, from the Middle East, we thought that this is the best approach we can help you with.” We tell them in a way, “that this is the process,” but in a more diplomatic [way]... They don't like [the approach] “these are the rules you have to follow.”

Stephen, like many social workers who work in palliative care, often educates patients and their families regarding the difference between palliative care and hospice. He typically frames this by focusing on the differences in the services offered.

So you could just get more with palliative care, and palliative care would also include radiation, fluids, if you need any physical therapy, occupational therapy, things like that. So you just get more things… labs can come down … You wouldn’t get treatment, curative treatment... there’s just more services in palliative care. There’s more benefit services than in hospice.

Educate coworkers. Rhonda spoke of how, in her role of a social worker on a hospice team, she often taught culturally appropriate interactions to other team members and advocated for her clients through educational interventions with her team.

I think [we need to be] very culturally sensitive. Being aware of their rights and their beliefs, and also educating the team. Because our chaplain (laughs) is wonderful, but it really is hard for him to understand that [Muslim patients and their families] don’t want to meet with him [laughs]. They don’t. And so educating our staff, as well, about what their wants and desires may be…And that’s where I find that social workers even now, that we have to educate the people that we work with. And the nurses are great here, and my administrator’s great, but, we really have to educate them, that “no, they don’t have to sign it and have a hospital Do Not Resuscitate order.” They have the right to choose not to do that. And then setting our boundaries, too, because I don’t want to do a disservice to a family when our marketer may say, “Oh they need a power of attorney. They need a power of attorney then.” Well, there’s a lot more involved than just a power of attorney. I really want to give them the resources to sit down with someone and say “okay what type of situation is your family in? Do you need just a power of attorney [POA]? Do you need a specialist in elder law?” I really just don’t want to see, “here slap a POA form in their
face.” I really want to see the bigger picture, which, I think social workers are great at. And give them the resources they need.

Likewise, Samera described how she would in turn “translate” the staff’s interactions to the patients and their families, often smoothing out difficult interactions between patients and fellow medical team members. One example she provides is educating staff on setting boundaries with patients and family members.

Sometimes they allowed themselves to do things because they can do it at back home. But they don’t know that this is here. [We have] zero tolerance for it. Abuse - physical, verbal abuse. For us, verbal abuse is zero tolerance. For them, verbal abuse is okay. You see? So this thing that [staff] need to understand. This is part of the education, culture education that we highlight on.

**Define the social worker’s role on the care team.** Charlotte spends time with each new patient describing the role of the social workers on the care team.

One thing we do when we meet people is we introduce our role. I say, “I don’t work for the state, I don’t work for child welfare, I don’t give out food stamps, I work for the hospital and this is what I do” to separate myself from any kind of government bureaucrat that might have treated them poorly in the past or threatened them.

Samera describes how she both maintains her professional boundaries with Middle Eastern patients and their families and at the same time, gains their trust by defining her role in the hospital.

Part of helping them is for them to respect our role and our knowledge because this is what we do to help them. If they don’t respect our role and knowledge and responsibility, they will delay or interfere, make it difficult for treatment and the way we can help them with.

**Teamwork**

Working in EOL care, whether in an inpatient or outpatient setting, requires that social workers function as the member of a multidisciplinary care team. Participants discussed strategies for providing culturally appropriate EOL patient care as a member of a team.

Examples included utilizing team members in other disciplines as liaisons, asking for assistance
from other social work team members, and calling on the services of religious leaders in the community.

**Utilize team members in other disciplines as liaisons.** Alex advises new social workers and student interns in her department to work closely with the Middle Eastern patient’s liaison from the Global Services department, if the patient has traveled to the United States specifically for medical care and/or requires translation services.

Typically, I just work very heavily with the liaison [from Global Services] that that family's working with. Because that's going to be that family's touchstone…That's the person that they're going to put a lot of trust in, as far as ensuring that they're getting everything that they need when they're here, aside from obviously their physicians and, those that are caring for their loved one… That person's going to be communicating and they're putting all their faith in that person. Giving appropriate translation and explanation... I'll tell them “just make sure that you speak a lot with your liaison”…Even though families or even the patient may state that they don't really need anything from our department or from the social worker, we should still make sure that they know that we're available to them. And so, I just encourage the students that I've worked with and certainly new hires, just to continue to reach out to the liaison so that the family does still at least know that you're there. You're still trying to at offer support and certainly so that you know what's going on. If there's been any change with how the family is coping, or if there's something that maybe will present itself that we can assist with. So yeah, we rely very heavily on our liaison, who's working with the family or that patient…But, it certainly helps to know that [social work is] in contact. They're reaching out. They're offering support. And even if you're kind of an absent person in the situation, because you're not able to do it yourself it, it does help to work with them and to know what's being afforded to the family.

**Ask for the assistance of another social work team member.** Sometimes, if a social worker is having a difficult time working with a family, or meeting a great deal of resistance from them, a strategy used by a few of the participants was to ask for assistance from another social worker from their team. At the hospital where Samera works, she is most frequently the person who is called in to assist.

They would call me from [the palliative care unit] saying “we have a problem with the patient and the family”…mostly it was the family, more than the patient…so they would page me, the palliative medical team, even though Stephen, the social worker will be there, but they would always page us and especially me, because I'm the social worker.
here [in International Services] and I'm the senior. Anyway, so they would page me and I would go.

Nancy conveyed that she has called upon her departmental supervisor, who was Middle Eastern herself, to help her to “recover” interventions with Middle Eastern patients when she was having difficulty making progress in areas such as discharge planning. She expressed she felt that someone who was intimately familiar with the family’s culture could help her to bridge gaps in communication, especially when working with a family who was less acculturated and unfamiliar with the American healthcare system.

**Call on the services of religious leaders in the community.** When working with Middle Eastern families, specifically Muslim families who are facing difficult EOL decisions such as removing a loved one from life support, Samera routinely brings in a religious leader from the community to counsel the family regarding the Islamic faith’s beliefs about EOL.

So a lot of time I started this by saying “what if we invite a Muslim Sheikh or Imam to be with you and to help you to understand that this is not against God’s will?” …we met Sheiks and Imams, so every time I have this case, I will call him and he will come. We have here chaplaincy department, so they helped me [connect with religious leaders in the community]…so we established this relationships so that will help them to make it easier to accept the end of life recommendation from our doctor…you know the patient and the family [they don’t] want to feel guilty, they are already hurting…They don't want to do anything against God’s will, against the instruction of the Qur’an, because this is all written in Qur’an. So they don't want to live with the guilt. So when an Imam comes and tells them “it’s okay”… for them, they look up to the Imam, the Imam is the one who puts the Shariah, the law… we notice that they feel safer once the Imam comes and tells them “it’s ok to do that, it’s not against Allah’s law”…It seems they are giving them, if I may say, the permission or they make it easy for them to say “okay” to accept this is end of life…It makes the patient and the family feel safer and less guilty when they have to make this decision, and they feel the support that “it’s not our decision, we took the approval from the Imam.”
End-of-Life Discussions

EOL discussions, entered with any patient and family, must be entered carefully. Participants shared stories about entering EOL-related discussions with Middle Eastern patients and their families regarding topics such as DNR, POA, and hospice referrals.

Enter discussions about end-of-life issues cautiously. Many of the experiences were shared as “interventions that went poorly,” primarily because the topic was not approached correctly or the social worker had not established a solid working relationship with the family. Colleen provided an example of an intervention that went poorly due to a physician’s assertive approach to initiating an EOL conversation with a patient’s family:

We had a family meeting [regarding] this patient… It was with her sons, she was a female patient, and her sons were the ones making the decisions. And the physician asked “if this particular treatment doesn’t work, we have a couple more options, but have y’all discussed end of life?” And that was the only time it was ever brought up and they said “absolutely not. In our faith, it is Allah’s decision to withdraw, to end life. And so it is not our decision to make, and with that, we do not discuss end of life.” They were very clear “please DO NOT bring that up again.” And everyone in the room, their reaction was, “got it, okay.” They were very, very kind and respectful about it, but very clear that this will be the last time we discuss it.

Nancy’s advice to other social workers for avoiding breeching the topic too soon or at all with a patient and family included exploring their expectations about EOL.

What is important to them? [Find out] how they view end of life, and what do they see it as, and if they see that the [patient] is at the end of life, because sometimes family members don’t see it. They just don’t. And so therefore you know that it’s end of life, but they’re not willing to accept it so sometimes, many times, you have to go along with that…sometimes they’re just not ready to accept it. And I tell them don’t push it, just go with what the family wants.

Charlotte’s approach focuses on providing support while respecting the family’s belief when they express that “end of life occurs when God wants end of life to occur” and has found in her experience that when working with less acculturated, religious, Middle Eastern families “there’s no prepping people for withdrawal, there’s no prepping them for phase 1, phase 2, phase
3, to be ready for withdraw of equipment, because it’s all in the hands of God.” She draws from her experience working with patients in EOL in the 70s and 80s and “you sort of go back to the old days where you don’t talk about it.”

“Find out what they will go for.” When faced with difficult decisions, such as discharge options, and wishes for EOL care, Amanda discussed exploring multiple options with Middle Eastern families:

Any student of mine or any social worker who I’m precepting, I want to be able to teach them instead of just kind of writing them off and saying “well, they’re never going to go for that.” Okay, find out what they will go for. A lot of my cardiac patients are no different. You know? There are so many people who are suspicious about hospice because when it first came out there was a lot of craziness going on and they don't want to do hospice either. “Well, find out what it is that they want, what are their wishes.” And I think we can empower people to do that just by having conversations, you know? … You don't have to go in there [to see the patient and say] “Have you thought about dying?” that's kind of scary. [You could start with] “What is it that you want? You've got this medical condition - what is your understanding of it? Has the doctor told you that he can cure you? No? You realize that your heart is not going to get better, so have you thought about the future of that? What are you afraid of? What do you think about with regard to your future and what is it that you want for the rest of your life, knowing that you have this condition?” I think that we can get a lot of answers that way…It’s actually something that can be translated to other cultures as well; there are actually a lot of people who aren’t able to be approached about the end of life.

Amanda shared one strategy in particular that she has found helpful when discussing discharge options. While a Middle Eastern family may be unwilling to accept their family member’s discharge from the hospital to hospice, they will often agree to go home with palliative care.

We have a couple of home health agencies [here in Houston] that have palliative care programs, which has been tremendously helpful…[the patient] wants to go home, and you know, if you just send them home with regular home health they'll be back in the ER in a day. And so that's a conversation I can have with them… "This is a home health agency, and their primary focus is to keep you comfortable, it's not hospice, okay, they are still going to be treating you, they're going to treat your symptoms, and they're going to be giving you all of your normal medications."
CHAPTER 5: DISCUSSION

The purpose of this research was to examine how social workers learn how to provide culturally appropriate EOL care to Middle Eastern patients and their families, find out what social workers working with this population recommend that other social workers need to know, and discover intervention strategies that are frequently used by social workers working in EOL care with Middle Eastern patients and their families.

Summary of Research Findings

Attainment of the Skill Set

Participants reported that the skillset needed by social workers to provide culturally appropriate EOL care to patients of Middle Eastern descent and their families was primarily developed through formal educational preparation, on-the-job training, and life experience. As discussed by Raybould and Adler (2006) and Roff (2001), many of the participants agreed that their MSW programs did not contain much EOL content and when it was covered, participants often stated that it was covered when discussing late adulthood in human behavior courses, which was congruent with the findings of Kovacs and Bronstein (1999). It appears that participants who were more recent graduates of MSW programs—those who graduated after 2000 as opposed to those who completed their MSW in the 1970s—did take coursework specifically covering EOL issues, demonstrating that recent efforts, such as those of Kramer et al. (2005), to increase EOL content in social work education have had some level of positive impact.

Participants frequently stated that they gained the skills they needed through on-the-job training, during their MSW internship, and while on the job from other social workers and employees in other disciplines. Many gained skills through what they described as “trial by fire,” through patient inquiry, and through self-directed research, consistent with the findings of
Berzoff (2008) and Snow et al. (2008) that on-the-job training continues to be the means most commonly cited by social workers for obtaining the skills necessary to perform psychosocial work with the dying.

The participants’ own life experiences such as growing up in a multicultural household and the EOL wisdom learned from their religious affiliation were also sources of development of the skillset, congruent with the NASW Standards for Cultural Competence in Social Work Practice, originally published in 2001 and updated in 2015, which places emphasis on the importance of values and self-awareness, cultural sensitivity and awareness of biases, knowledge, and practice skills as they relate to work with diverse clients (NASW, 2015).

**Recommendations from the Participants**

Participants made many recommendations that they considered useful for other social workers entering the field of EOL care working with patients of Middle Eastern descent and their families. The general recommendations were not necessarily EOL-specific, and included taking the patient and family’s acculturation level into consideration, the importance of appropriate body language and being sensitive of what the family values.

EOL-specific recommendations included being aware that discussing EOL may be seen as taboo to some Middle Eastern cultures, and that many Middle Eastern cultures tend to be resistant to embracing hospice care. These views were consistent with those of Old and Swagerty (2007), who stated that the implementation of formal hospice care or placement in a residential hospice is not common among those of Middle Eastern descent and a nursing home placement for an elderly relative would not be preferred by typical Middle Eastern families, who traditionally care for their dying or sick family members at home. Duffy (2006) further explained
that minority clients may see the hospice philosophy of care as intrusive and in conflict with their cultural norms.

Learning about the EOL traditions of Middle Eastern cultures was also recommended. Aboul-Enein and Aboul-Enein (2010) reinforced this in their discussion of how unfamiliarity with distinctive characteristics of Middle Eastern cultures has led healthcare professionals to frequently label Middle Eastern patients as “difficult patients to work with” (p. 20). Al Abed et al. (2013) also mentioned how lack of knowledge and understanding of Middle Eastern patients and their families may hinder communication processes and the provision of healthcare services.

Gaining self-awareness of one’s own views regarding EOL was frequently mentioned by participants as important for social workers working in EOL care, demonstrating knowledge of the objective of the 5th standard of NASW Standards for Palliative and End of Life Care (NASW, 2004) regarding Attitude and Awareness: “Social workers shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.” (p. 4)

**Common Intervention Strategies Utilized**

Participants identified common intervention strategies used when working with Middle Eastern patients and their families in the EOL. Strategies for rapport building, educational interventions, the use of teamwork, and conducting EOL discussions were most often cited. Regarding rapport building strategies, participants emphasized the importance of first impressions, learning who the family’s spokesperson is, demonstrating knowledge of the patient and family’s culture, and building the working relationship slowly. This was consistent with Weissman (2000), who discussed the importance of practitioner awareness of the value many non-Western families place on the opinions of the collective family unit and greater community when faced with EOL decision-making.
Educational interventions utilized by the participants include educating patients and their families, and coworkers, and stressed the importance of defining the social worker’s role on the care team. As a member of an interdisciplinary team, as described by Kovacs and Bronstein (1999), social workers must define their role to patients and their families and educate them about the services available to them.

Strategies cited for promoting teamwork mentioned were utilizing team members from other disciplines as liaisons, asking for assistance from other social workers, and calling on the services of religious leaders in the community. Gatrad and Sheikh (2002) also specified that for patients of the Islamic faith, arranging a visit from an Imam to the dying person and his or her family may be a helpful way to provide support.

When conducting EOL discussions with Middle Eastern patients and their families, participants recommend entering discussions about EOL issues cautiously and “finding out what they will go for.” Knowledge such as awareness that Middle Eastern Christians are likely to prefer to die at home, surrounded by family and friends, but tend to be avoidant of direct discussion of death prior to it occurring, as expressed by Duffy et al. (2006) is helpful when approaching Middle Eastern patients to conduct difficult EOL discussions such as discharge planning.

Other relevant findings

There exists general agreement among healthcare researchers that increased cultural competence leads to better communication, higher rates of patient satisfaction, and better compliance with treatment (Khanna et al., 2009). The need for increased levels of cultural competence among healthcare providers, including social workers, is an important factor when considering the under-representation of racial and ethnic minorities among nursing home
residents, hospice patients, and those receiving long-term and palliative care (Schim, Doorenbos, & Borse, 2006; Thomas, 2001). Consistent with NHPCO’s data, the participants reported low usage of hospice services by Middle Easterners patients (2015). Hospice utilization by Middle Eastern populations, as with other minority groups, can be increased through community outreach efforts (Reece et al., 2010). Encouraging Middle Eastern cultural centers, churches and mosques to invite palliative care and hospice providers in their community to facilitate educational gatherings about EOL care options available in their community would be beneficial in increasing hospice usage by patients of Middle Eastern descent. Including community members in the facilitation of these educational sessions, especially community members who work in healthcare or have experience with hospice or palliative care can help to bridge cultural gaps between providers and the Middle Eastern community they serve.

Participants echoed what the literature has emphasized regarding the conflict between Western and Middle Eastern values regarding EOL care such as personal autonomy and open communication between patients and healthcare providers (Weissman, 2000). Many Middle Eastern cultures tend to communicate bad news to the patient and the rest of the family incrementally, a small bit at a time. Participants discussed ways around the approaches used by Western healthcare to “sit down and talk about this bad prognosis” and have found that patients and families from Middle Eastern cultures respond better when healthcare workers place more value on the opinions of the collective family unit when approached with EOL decision-making. The Medicare requirement that a patient be diagnosed with a terminal illness with a life expectancy of 6 months or less in order to be covered by the Medicare Hospice Benefit (Centers for Medicare & Medicaid Services, 2010) is a stumbling block for many Middle Eastern patients who may medically qualify for hospice, but are unwilling to stop curative treatment due to their
perceived religious obligation to continue treatment or their unwillingness to talk about EOL due to their cultural or religious beliefs (Old & Swagerty, 2007). When facilitating EOL discussions such as DNR status or hospice referral, calling in an Imam to help negotiate religious concerns with Muslim patients can be helpful.

Many of the participants reported perceiving the response of “we’re fine, we have everything we need” as a rejection of social work services. Others stated understanding, knowing that this is more likely due to a Middle Eastern family’s desire to take care of problems privately, and feeling shame in admitting that they need help (Salari, 2002). This may also occur because the social worker has not taken the time to get to know the family. According to Salari, many Middle Easterners become annoyed at many Westerners’ tendencies to “get right to business” without first making small talk (2002), and the family may want to know more about the social worker than his or her title. Additionally, in a first meeting with a family or in formal family meetings, if possible, it is helpful to have a staff member who is familiar with Middle Eastern cultures to act as a “cultural translator” like Samera was for her colleagues. Formal translation services should be strictly reserved for translating language.

**Implications for Social Work**

**Increase Opportunities for Experiential Learning**

One of the clear messages taken from the discussions with participants about their MSW curricula is that course content matters. Many social work programs use traditional methods of teaching about cross-cultural practice, which didactically focus on informational content regarding minority groups, a method that has been proven to be ineffective, however, in changing attitudes, which is an important component of cultural competency (Lu, Dane, & Gellman, 2005). Consistent with the literature, participants expressed that role play and other
experiential learning techniques are effective in developing the skill set needed to provide culturally appropriate EOL care. Courses that include presentation of case studies, small group discussions, or role play (Weissman, 2000) lead to self-reflection, which is beneficial to the development of better understanding of other cultures’ values and attitudes.

The attention that MSW programs give to issues such as EOL is influenced by environmental factors that vary over time, such as the addition of new knowledge, and the shifting values of greater society. Meaningful educational experiences help students gain a deeper understanding of important issues central to their future practice as social workers.

**Generalist Practice Social Work Skills**

Many social work practitioners and educators believe that a combined generalist and specialist focus in training is needed for social workers who primarily work with dying clients and their families (Bosma et al., 2010) and have recommended infusing palliative care principles into the curriculum of generalist social work practice, especially for those who are training with the intention of working in healthcare settings (Altilio et al., 2007; Roff, 2001). Some of these skills mentioned by participants include compassion, empathy, and starting where the client is. Social work training must challenge students to stimulate their curiosity, encourage openness to the experience of others, develop willingness to admit lack of knowledge, and learn empathic responsiveness to his or her clients. Social workers also need to be able to extend sensitivity to cultural norms other than their own, for example, respectfully interacting first with the oldest male in the family, and being able to set aside his or her own cultural values, such as the value of gender equality.
Continuing Education

MSW graduates should be made aware that their ongoing education and the development of expertise will depend on their assertiveness in identifying needs for knowledge and locating sources for training. Participants frequently reported doing their own research regarding working with patients in the EOL from cultures with which they are unfamiliar. Online CEU courses may help bridge these gaps in knowledge for practicing social workers. Providers of CEUs may also develop workshops to teach EOL care to specific populations. Once general knowledge of how to best provide EOL care to a population is established, it can be presented using a template to create an online course or a workshop including information about the size of the population in the U.S., the history of the population’s immigration, their most prevalent religious beliefs, their family structure, their common health problems, and their views about EOL.

Limitations

The sample consisted of social workers who all worked in the greater Houston area and most attended the same university for their MSW. Because of this, the researcher did not generalize the results to the greater population of social workers who work with Middle Eastern patients in EOL care in the U.S. Inclusion of participants from multiple U.S. cities would provide a richer view of the state of culturally appropriate EOL care.

Another limitation associated with only including one major metropolitan area as the research site is that the population of Middle Easterners present in greater Houston area may not be representative of the Middle Eastern population of the rest of the U.S. The participants who worked in inpatient care within the Texas Medical Center reported frequently encountering Middle Eastern patients who traveled to Houston specifically to receive medical treatment. Participants who work in outpatient healthcare settings reported that the Middle Eastern patients...
they work with primarily live within the greater Houston area. Social workers who work in other large cities are likely to encounter different Middle Eastern populations, and utilize different skill sets when working with these populations.

The significance of the participants’ scores on the MCKAS, the measure of perceived cultural competency, cannot be given much weight with such a small sample \((n = 12)\). Another significant limitation of the 32-item version of the MCKAS is that, as a self-reporting measure, it does not produce a measurement of the participants’ level of competence with regards to multicultural counseling skills. The MCKAS measures perceived multicultural counseling competence in two dimensions: multicultural knowledge and multicultural awareness (Ponteretto et al., 2002). A larger group with more ethnic diversity, a wider range of experience levels, and a broader base of universities attended could make better use of the MCKAS by comparing knowledge and awareness scores to other factors such as years of experience (Cummings, 2010).

**Recommendations for Future Research**

The present research could be improved by including more participants and expanding the sampling criteria to include participants from several U.S. cities with large Middle Eastern communities. A well-funded research project with multiple researchers to recruit and interview participants could reach a broader range of experience levels and include a representative sample of the social work workforce in multiple geographic areas.

Any of the three broad research questions from this study could be expanded into a larger-scale study. For example, question one regarding the participants’ educational preparation could include a more in-depth examination of the participants’ formal training through reviewing their transcripts, requesting a detailed account of all post-MSW CEUs completed and records of
conferences attended, and a focused interview specific to how they developed their EOL skill set could be conducted.

Using the premise of immersing a researcher in a community and ultimately dispersing the information gained through their experience into the community, this research could be developed to benefit both a healthcare community and a local university simultaneously. A grant-funded researcher, who could be a research associate from a university or a post-doctoral intern, could greatly benefit a community through a larger scale study of this type, implemented with the objective of improving EOL care to a specific group in a geographic area through educating current healthcare workers at their place of work and teaching a course at the affiliated university based on the research findings. The research findings could then be disseminated through an academic publication, a training manual for healthcare workers, an interdisciplinary workshop conducted at the medical center, and a course taught at the university.

Social work practice in the EOL with many different populations can be studied using the research methods developed for this study. The research questions may be modified to study other ethnicities and socioeconomic classes, varying age groups, persons with disabilities, LGBTQ populations, and special groups such as veterans, refugees, and the homeless. The results of this study and of any additional study conducted using this research’s basic premises may be used in the development of courses to prepare social workers and other healthcare professionals to work with various populations in the EOL.

**Conclusion**

This study utilized an interpretive qualitative methodological approach to learn about the experiences of MSWs working in EOL care with patients of Middle Eastern descent and their families. The three research questions examined (1) how social workers obtain the skills
necessary to provide culturally appropriate EOL care to clients and families of Middle Eastern
descent, (2) the common intervention strategies social workers employ while providing this care,
and (3) the recommendations they offer to others who anticipate encountering this population in
their own practice.

Research participants most frequently cited formal educational preparation, on-the-job
training, and their own life experience as the means by which they attained the skillset needed to
provide culturally appropriate EOL care to Middle Eastern patients and their families. Although
cultural competence itself is being taught, participants expressed that it is covered separately
from EOL care. While EOL care is being taught more in MSW programs than it has been in
previous decades (Raybould & Adler, 2006), consistent with previous findings in the social work
literature, (Berzoff, 2008; Snow et al., 2008) on-the-job training continues to be the means most
commonly cited by social workers for obtaining the skills necessary to perform psychosocial
work with the dying.

Assessing the patient and family’s level of acculturation to U.S. society, the use of
appropriate body language, and demonstrating sensitivity regarding the family’s values were
common recommendations the participants made for other social workers who work with Middle
Eastern patients and their families. The implementation of formal hospice care or placement in a
residential hospice is not common among those of Middle Eastern descent and a nursing home
placement for an elderly relative are not typically preferred by less acculturated Middle Eastern
families, who traditionally care for their dying or sick family members at home (Old &
Swagerty, 2007). Additionally, communication processes and the provision of healthcare
services may be hindered by practitioners’ lack of knowledge and understanding of Middle
Eastern patients and their families (Al Abed et al., 2013), and practitioners need to gain self-
awareness of their personal views regarding EOL, consistent with the NASW *Standards for Palliative and End of Life Care* (2004) regarding attitude and awareness.

Rapport-building strategies, educational interventions, interdisciplinary teamwork, and conducting EOL discussions were identified as common intervention strategies used by the participants when providing EOL care to Middle Eastern patients and their families. Noteworthy techniques used for building rapport include demonstrating awareness of the value many non-Western families place on the opinions of the collective family unit and greater community when faced with EOL decision-making (Weissman, 2000), recognizing the importance of first impressions, learning who the family’s spokesperson is, utilizing knowledge of the patient and family’s culture, and building the working relationship slowly. Defining the social worker’s role on the care team (Kovacs and Bronstein, 1999), arranging a visit from a religious leader (Gatrad & Sheikh, 2002), and cautiously approaching EOL discussions with the understanding that many Middle Eastern patients and families tend to be avoidant of direct discussions of death (Duffy et al., 2006) were also mentioned as important intervention strategies utilized by the participants.

Implications for social work practice and education include recommendations to increase opportunities for experiential learning, infuse palliative care principles into the curriculum of generalist social work practice, and develop CEU workshops to teach practitioners how to best provide EOL care to specific populations.
REFERENCES


TO: Timothy Page  
Social Work  

FROM: Dennis Landin  
Chair, Institutional Review Board  

DATE: January 25, 2016  

RE: IRB# 3658  

TITLE: Social Work Practitioner Competence in End of Life Care: The Development of the Skillset  


Review type: Full X Expedited ____ Review date: 12/11/2015  

Risk Factor: Minimal ______ X Uncertain _______ Greater Than Minimal______  

Approved ____X____ Disapproved ________  

Approval Date: 12/11/2015 Approval Expiration Date: 12/10/2016  

Re-review frequency: (annual unless otherwise stated)  

Number of subjects approved: 12-25  

LSU Proposal Number (if applicable):  

Protocol Matches Scope of Work in Grant proposal: (if applicable)_______  

By: Dennis Landin, Chairman  

PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING – Continuing approval is CONDITIONAL on:  

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU's Assurance of Compliance with DHHS regulations for the protection of human subjects*  
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.  
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.  
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.  
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.  
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.  
8. SPECIAL NOTE:  

*All investigators and support staff have access to copies of the Belmont Report, LSU's Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at http://www.lsu.edu/irb  

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APPENDIX B.
REQUEST FOR PARTICIPANT PARTICIPATION EMAIL

Laura S Meiki

From: Laura Meiki
Sent: Monday, January 04, 2016 10:25 AM
To: RE: Interview request for dissertation research
Subject: Good morning, Ms. [REDACTED],

Happy New Year! Thank you for your quick response to my request to interview members of the SW team at Houston Methodist. I greatly appreciate your willingness to help with my recruiting efforts.

Please send the following information to your SW team members:

Dear colleague,

My name is Laura Meiki, I am an MSW and a doctoral student in social work at LSU. I am reaching out to you today because I am interested in interviewing you for my dissertation research.

The focus of my research is the process by which MSWs obtain the necessary skillset to provide culturally appropriate end of life care to patients of Middle Eastern descent. I am targeting MSWs in the Houston area due to the large Middle Eastern population in your city, and the presence of the Texas Medical Center, which I understand treats many international patients originating from Middle Eastern countries.

The interview will last about one hour, and with your permission, will be digitally recorded (voice only, not video). Your responses to my interview questions will remain confidential and no identifying information about either you or your employer will be used in my dissertation or any publications that may result from my research. I would prefer to meet with you at your place of employment, but if that is not practical, I am willing to meet elsewhere, at your convenience.

I plan to make multiple visits to Houston to conduct my research, and hope to meet and interview you on one of these visits during January or February.

Please send me an email at lmeiki@lsu.edu to let me know if you are willing to participate in my research and I will send you a few dates and times to choose from. I look forward to meeting you!

Best regards,
Laura

Laura S. Meiki, MSW
Graduate Assistant
Office of the Associate Vice President
for Institutional Effectiveness & Academic Planning
University Administration
Louisiana State University
3810 West Lakeshore Drive
Baton Rouge, Louisiana 70803
lmeiki@lsu.edu
APPENDIX C.
PARTICIPANT PROFILE SURVEY

Participant Profile

Please be aware that while the results of this study may be published, no names or identifying information will be included in the publication. The identity of the participants interviewed will remain confidential unless disclosure is required by law.

Name: _______________________________________

Age _____

Gender
☐ Male
☐ Female
☐ Transgender

Are you of Hispanic descent?
☐ Yes
☐ No

Race
☐ African American/Black
☐ Asian/Pacific Islander
☐ Caucasian/White
☐ Native American/First Nations

Ethnicity/ethnic heritage (please be specific)
____________________________________________________________________________

Current employer and department ________________________________________________

How long have you been employed here? ________

Job title ________________________________________________

Do you supervise other social workers in your current position?  YES  NO

Do you train others in your current position?  YES  NO

If yes, whom do you train? (New SW employees? MSW students? Students/employees from other departments?)
____________________________________________________________________________
**Licensure status** (check all that apply)

- [ ] LMSW State: __________
- [ ] LCSW State: __________

- [ ] Other _________________________ State ___________________

**At what university did you complete your MSW?**

______________________________________________________________________________

Month/year completed __________________________

**Additional certifications or degrees earned**

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

Have you ever participated in continuing education workshops or in post-MSW coursework that focused on providing culturally appropriate end-of-life care?  YES  NO

If yes, please provide specific information about the workshop or course (workshop/course title, when and where taken, who led or taught it)

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________
# APPENDIX D. MULTICULTURAL COUNSELING KNOWLEDGE AND AWARENESS SCALE (MCKAS)

Multicultural Counseling Knowledge and Awareness Scale (MCKAS)

Copyrighted © by Joseph G. Ponterotto, 1997

A Revision of the Multicultural Counseling Awareness Scale (MCKAS)

Copyrighted © by Joseph G. Ponterotto, 1991

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Using the following scale, rate the truth of each item as it applies to you.

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<td>Not at</td>
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1. I believe all clients should maintain direct eye contact during counseling.

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2. I check up on my minority/cultural counseling skills by monitoring my functioning – via consultation, supervision, and continuing education.

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3. I am aware some research indicates that minority clients receive “less preferred” forms of counseling treatment than majority clients.

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4. I think that clients who do not discuss intimate aspects of their lives are being resistant and defensive.

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5. I am aware of certain counseling skills, techniques, or approaches that are more likely to transcend culture and be effective with any clients.

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6. I am familiar with the “culturally deficient” and “culturally deprived” depictions of minority mental health and understand how these labels serve to foster and perpetuate discrimination.

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Using the following scale, rate the truth of each item as it applies to you.

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7. I feel all the recent attention directed toward multicultural issues in counseling is overdone and not really warranted.

1 2 3 4 5 6 7

8. I am aware of individual differences that exist among members within a particular ethnic group based on values, beliefs, and level of acculturation.

1 2 3 4 5 6 7

9. I am aware some research indicates that minority clients are more likely to be diagnosed with mental illnesses than are majority clients.

1 2 3 4 5 6 7

10. I think that clients should perceive the nuclear family as the ideal social unit.

1 2 3 4 5 6 7

11. I think that being highly competitive and achievement oriented are traits that all clients should work towards.

1 2 3 4 5 6 7

12. I am aware of the differential interpretations of nonverbal communication (e.g., personal space, eye contact, handshakes) within various racial/ethnic groups.

1 2 3 4 5 6 7

13. I understand the impact and operations of oppression and the racist concepts that have permeated the mental health professions.

1 2 3 4 5 6 7

14. I realize that counselor-client incongruities in problem conceptualization and counseling goals may reduce counselor credibility.

1 2 3 4 5 6 7
Using the following scale, rate the truth of each item as it applies to you.

1 2 3 4 5 6 7  
Not at All True Somewhat True Totally True

15. I am aware that some racial/ethnic minorities see the profession of psychology functioning to maintain and promote the status and power of the White Establishment.  

1 2 3 4 5 6 7

16. I am knowledgeable of acculturation models for various ethnic minority groups.  

1 2 3 4 5 6 7

17. I have an understanding of the role culture and racism play in the development of identity and worldviews among minority groups.  

1 2 3 4 5 6 7

18. I believe that it is important to emphasize objective and rational thinking in minority clients.  

1 2 3 4 5 6 7

19. I am aware of culture-specific that is culturally indigenous, models of counseling for various racial/ethnic groups.  

1 2 3 4 5 6 7

20. I believe that my clients should view a patriarchal structure as the ideal.  

1 2 3 4 5 6 7

21. I am aware of both the initial barriers and benefits related to the cross-cultural counseling relationship.  

1 2 3 4 5 6 7

22. I am comfortable with differences that exist between me and my clients in terms of race and beliefs.  

1 2 3 4 5 6 7
Using the following scale, rate the truth of each item as it applies to you.

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23. I am aware of institutional barriers which may inhibit minorities from using mental health services.
   
   1 2 3 4 5 6 7

24. I think that my clients should exhibit some degree of psychological mindedness and sophistication.
   
   1 2 3 4 5 6 7

25. I believe that minority clients will benefit most from counseling with a majority who endorses White middle-class values and norms.
   
   1 2 3 4 5 6 7

26. I am aware that being born a White person in this society carries with it certain advantages.
   
   1 2 3 4 5 6 7

27. I am aware of the value assumptions inherent in major schools of counseling and understand how these assumptions may conflict with values of culturally diverse clients.
   
   1 2 3 4 5 6 7

28. I am aware that some minorities see the counseling process as contrary to their own life experiences and inappropriate or insufficient to their needs.
   
   1 2 3 4 5 6 7

29. I am aware that being born a minority in this society brings with it certain challenges that White people do not have to face.
   
   1 2 3 4 5 6 7

30. I believe that all clients must view themselves as their number one responsibility.
   
   1 2 3 4 5 6 7
Using the following scale, rate the truth of each item as it applies to you.

1  2  3  4  5  6  7
Not at  Somewhat  Totally
All True  True  True

---------------------------------------------------------------------------------------------------------------------------------

31. I am sensitive to circumstances (personal biases, language dominance, stage of ethnic identity development) which may dictate referral of the minority client to a member of his/her own racial/ethnic group.

1  2  3  4  5  6  7

32. I am aware that some minorities believe counselors lead minority students into non-academic programs regardless of student potential, preferences, or ambitions.

1  2  3  4  5  6  7

Thank you for completing this instrument. Please feel free to express in writing below any thoughts, concerns, or comments you have regarding this instrument:
APPENDIX E.
INTERVIEW QUESTIONS

1. Describe your current social work position.

2. Who trained you to perform your role at (name of current employer)?

3. Please describe the types of social work settings that you have worked in throughout your social work career. In which one do you feel you were able to develop your EOL care skillset? How about with Middle Eastern clients?

4. To what extent do you feel that your MSW program prepared you to work in EOL care? What courses did you find most helpful?

5. How do you see that race, ethnicity or minority status of the client plays a role in providing EOL care?

6. Who are your Middle Eastern clients? What countries are they from originally?

7. What have you found to be the most difficult skill to develop as a social worker who works with Middle Eastern clients at the end of life? How have you learned this skill? How do you think other social workers may best learn this skill?

8. What specific personal characteristics, if any, do you feel that you have that help you when working with Middle Eastern clients?

9. What skills does a social worker need in order to provide effective care at the end of life to Middle Eastern clients? Do you feel that you possess these skills?

10. Can you provide an example of an interaction that either you or a social work colleague has had with a Middle Eastern client and or their family that went poorly? What was the outcome? How do you think this could have been done differently?

11. How do you know when you are providing effective EOL care to a Middle Eastern client and their family? How do you know when the intervention you are providing is ineffective?

12. If or when you train a new member of your department or institution’s social work staff, what do you think is the most important piece of advice to give them to assist in providing effective interventions with Middle Eastern clients and their families dealing with the EOL?

13. Is there anything that we did not cover that you feel social workers or social work educators need to know about providing EOL care to Middle Eastern clients and their families?
Good afternoon, Dr. Ponterotto,

Thank you. My signed utilization form is attached. Please let me know if further information is needed.

Best regards,
Laura Meiki

-----Original Message-----
From: Laura Meiki <lmeiki@lsu.edu>
To: jponterott@aol.com
Sent: Thu, Mar 3, 2016 11:20 am
Subject: Request to use MCKAS for dissertation research

Good morning, Dr. Ponterotto,

I am a doctoral student in Social Work at Louisiana State University. My dissertation research focuses on how social workers learn to provide culturally appropriate end of life care, specifically to Middle Eastern clients and their families. I’d like to use the MCKAS in my research.

How do I go about obtaining your permission to use the instrument?

Best regards,
Laura Meiki

Laura S. Meiki, MSW
Graduate Assistant
Office of the Associate Vice President
for Institutional Effectiveness & Academic Planning
University Administration
Louisiana State University
1. **Study Title**: Social Work Practitioner Efficacy in End of Life Care: The Development of the Skillset

2. **Performance Site**: Participant work sites in the Greater Houston, TX area.

3. **Investigators**: The following investigators are available for questions about this study, M-F, 8:00 a.m. – 4:30 p.m.
   
   Tim Page, Ph.D.  (225) 578-1358  
   Laura S. Meiki, MSW (225) 772-3712

4. **Purpose of Study**: The purpose of this study is to gain a better understanding of how master’s level social workers who primarily practice with clients in the end of life learned the necessary skillset to effectively serve Middle Eastern clients and their families.

5. **Subject Inclusion**: Licensed Masters-level social workers who currently or have in the past worked primarily with Middle Eastern clients in the end of life.

6. **Number of Participants**: 12-20

7. **Study Procedures**: You will be interviewed by an Investigator in a private setting such as your office, or on the phone. The primary focus of the semi-structured, hour to hour and a half long digitally recorded interview will be your educational training and the process of skill development related to your social work practice with Middle Eastern clients in the end of life. The Investigator may request to observe your interactions with a client and/or their family in the field. Appropriate institutional permission from your place of employment must be obtained prior to any observations of client/practitioner interactions.

8. **Benefits**: This study may increase the field of social work’s understanding of how social workers can be best prepared to provide end-of-life services with Middle Eastern clients.

9. **Risks**: There is no known risk to participating in this study. Should you experience emotional distress due to the sensitive nature of the interview questions, the Investigator will provide you with resources to assist in coping with the emotional distress.

10. **Right to Refuse**: Your participation is voluntary. Should you at any time choose not to participate or would like to withdraw from the study; you may do so without penalty or loss of any benefit to you.

11. **Privacy**: Results of the study may be published, but no names or identifying information will be included in the publication. Subject identity will remain confidential unless disclosure is required by law.
12. **Compensation**: Participants will be provided a written summary of the research findings upon the conclusion of the data analysis.

13. **Participants’ Rights**:

   The study has been discussed with me and all my questions have been answered. I may direct additional questions regarding study specifics to the investigators. If I have questions about subjects’ rights or other concerns, I may contact Robert C. Mathews, Chairman, LSU Institutional Review Board, (225)578-8692, irb@lsu.edu, www.lsu.edu/irb. I agree to participate in the study described above and acknowledge the researchers’ obligation to provide me with a copy of this consent form if signed by me.

   Signature _________________________________  Date ________________________________
Confidentiality Agreement

Transcriptionist

I, ______________________________ transcriptionist, agree to maintain full confidentiality in regards to any and all audio files received from Laura Meiki, related to her dissertation research.

Furthermore, I agree:

1. To keep all research data confidential by not discussing or sharing the information in any form or format (e.g., audio files, transcripts) with anyone other than Laura Meiki.

2. To keep all research information in any form or format (e.g., digital audio files, transcripts) secure while it is in my possession. This includes:
   a. using closed headphones or earbuds when transcribing audio-taped interviews;
   b. keeping all transcript documents and digitized audio files on a password-secured device;
   c. closing any transcription programs and documents when temporarily away from my computer;
   d. keeping any printed transcripts in a secure location such as a locked file cabinet; and
   e. permanently deleting any e-mail communication containing the data;

3. To submit all transcriptions to Laura Meiki in a complete and timely manner.

4. To delete or otherwise destroy all research information in any form or format that is not returnable to the primary investigator (e.g., information stored on my computer hard drive) upon receipt of payment for completion of the transcription.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audio files to which I will have access.

Transcriber’s name (printed) __________________________________________________

Transcriber’s signature ______________________________________________________

Date _____________________
VITA

Laura Meiki received her Master’s Degree in Social Work from the University of Illinois at Chicago (UIC) in 1997. She has held teaching, research, and administrative positions at Louisiana State University’s main campus in Baton Rouge, and at LSU in Shreveport. Prior to her work in academia, she practiced medical social work for many years, primarily focusing on crisis intervention and end of life care. She anticipates graduating with her Ph.D. from Louisiana State University in August 2017 and plans to pursue a faculty position teaching social work.