A MIXED METHOD EXPLORATION OF VIEWS OF HOSPICE AND PALLIATIVE CARE AMONG SEXUALLY DIVERSE WOMEN

by

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A Mixed Method Exploration of Views of Hospice and Palliative Care among Sexually Diverse Women

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The aims of the present study were to explore whether end-of-life health care attitudes are different among sexually diverse women, to understand how healthcare system distrust, willingness to seek help, religiosity/spirituality, and beliefs about alternative medicines are related to one’s beliefs about hospice and palliative care, and to further elucidate these findings with interviews with lesbian older adults about perceived barriers of using hospice and palliative care. Self-identified lesbian older women (n = 30; M age = 66 years), heterosexual older women (n = 31; M age = 64.8 years), lesbian middle-aged women (n = 35; M age = 50 years), and heterosexual middle-aged women (n = 49; M age = 50.5 years) were recruited for this study. The results indicated that lesbian women did not endorse a different level of distrust than heterosexual women but other empirical research studies have found higher levels of discrimination, fear, and distrust. However, health care system distrust was significantly related to comfort discussing pain management among all populations and significantly related to hospice beliefs among the middle-aged women, suggesting the potential for this to be a strong barrier to end-of-life health care services. Overall, lesbian women held more positive beliefs about hospice and palliative care services than heterosexual women, a finding that may be related to a perception that hospice is more counter-culture health care with its emphasis on comfort over cure, and therefore more sensitive. In the qualitative analysis of the interviews, age emerged as an important factor in understanding beliefs about hospice, pain management,
and preferences for life-sustaining treatments. Also, recognition of partnerships and messages of inclusiveness were important to these women in a hospice and palliative care service provider.
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CHAPTER 1

Introduction

The goals of palliative and hospice care are to achieve the best quality of life for patients during the dying process, and to assist their families with direct care needs and with saying goodbye to their loved one. According to the National Hospice and Palliative Care Organization’s September 2010 edition of *NHPCO Facts and Figures: Hospice Care in America*, in 2009 approximately 41.6% of all deaths in the United States were under the care of a hospice program with 83% of these hospice patients aged 65 years or older, and 38% aged 85 years or older. This end-of-life care is most often provided by an interdisciplinary team of health care workers including nurses, physicians, and social workers, though with increasing frequency it also includes psychologists, chaplains, pharmacists, dietitians, occupational or physical therapists, and volunteers (Haley, Larson, Kasl-Godley, Neimeyer, & Kwilosz, 2003).

A standard of care for this team (and healthcare at large) is being sensitive to how diversity impacts decision-making at the end of life. Recent research efforts have been made to understand how marginalized or diverse populations use and think about end-of-life care to help guide these teams. A solid foundation of information exists for guidance with ethnic and racial diversity but relatively little information exists about sexual minorities and how their beliefs and culture influence end-of-life decisions. And there is a very real need; by 2030, approximately one in five people will be sixty five and older, and roughly 4 million of those will be lesbian, gay, or bisexual. Because older women
significantly outnumber older men, one could also argue that most older members of the sexual minority population will be lesbian women rather than gay men, bisexuals, or transgendered persons (Barker, 2004). The purpose of the present study was to explore attitudes and beliefs about pain management, hospice, and other factors that may influence accessing end-of-life health care services for sexually diverse women. The following literature review describes the disciplines of hospice and palliative care and differences in service utilization, highlights research on possible reasons for these differences by diverse populations, overviews the sparse literature on sexual minorities and end-of-life care, summarizes the available research on lesbian women and health care utilization, and stresses the importance of learning more about lesbian women’s views and beliefs across the range of adulthood to best serve this important population.

**Palliative and Hospice Care**

The goals of palliative and hospice care are to achieve the best quality of life for patients during the dying process, and to assist their families with direct care needs and with saying goodbye to their loved one. This includes management of physical, psychological, social, spiritual, and existential needs of individuals with advanced disease. Although exact definitions of palliative and hospice care may vary, it is generally accepted that *palliative care* is focused on treatment of conditions that are life-limiting whereas *hospice care* refers to a special type of comprehensive palliative care provided during the last 6 months of life (Haley et al., 2003). Conditions for which hospice and palliative care are appropriate include cancer, chronic obstructive pulmonary disease, end-stage renal or liver disease, congestive heart failure, progressive autoimmune
diseases like AIDS, and progressive neurological diseases like Parkinson’s or Alzheimer’s disease.

This holistic approach to health care requires an interdisciplinary team to address the complex and multidimensional needs of patients and their families. Teams typically include nurses, physicians, and social workers, though with increasing frequency it also includes psychologists, chaplains, pharmacists, dietitians, occupational or physical therapists, and volunteers (Haley et al., 2003). Psychologists are becoming more common members of the team due to recent policy changes within the U.S. Veterans Affairs Health Care System recognizing the value of a psychologist in quality care. Psychologists can contribute to end-of-life care through interventions with patients and families during the dying process and the bereavement process. For example, some interventions include helping the patient to say goodbye, helping the family to temporarily set aside conflicts and rifts to ease the dying process for the patient, and help the long-term caregiver create a meaningful life after the passing of a loved one. The psychologist trained in team dynamics can also be an asset to maintaining team functioning in the best interest of the patient when conflicts between team members inevitably arise. This may be related to best course of care from a discipline perspective or from strong personal beliefs. Education about diverse cultural beliefs may be especially beneficial in the latter case.

This movement to improve life’s final passage for patients and their families, which began in the United States with the first U.S. hospice founded in Connecticut in 1974, was strengthened from research documenting major failures in hospital care of the seriously ill. Field and Cassel (1997) discussed the major end-of-life health care quality problems as overuse of care (e.g., unwanted treatments or hospitalizations; diagnostic
tests that will not inform patient care but may cause physical and emotional distress) and *underuse of care* (e.g., failure to assess and treat pain; late referral for hospice care, premature hospital discharge). Cleeland and colleagues (1994) found that 42% of outpatient cancer patients were not appropriately treated. A study of ambulatory AIDS patients identified pain treatment as inadequate in 85% of patients; for example, strong opioids, which are recommended for patients with severe pain, were prescribed in only 8% of such patients (Breitbart et al., 1996). Another study, which found pain reported by 78% of randomly selected patients hospitalized in an academic medical center, discovered that only 49% of those patients had a progress note mentioning pain in their chart (Donovan, Dillon, & McGuire, 1987). Fins et al. (1999) conducted a chart review of 200 adult patients who died in a large urban medical hospital. Charts of 72% of the patients had evidence that they were considered dying but only 46% had comfort care plans. Additionally, these comfort care plans were put in place 15 days after admission, as compared with an overall mean length of stay of 17 days. Furthermore, substantial proportions of patients with comfort care plans continued to receive antibiotics (41%) and blood draws (30%).

In another study, the SUPPORT Principal Investigators (1995) documented shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death. Only 47% of physicians knew when their patients preferred to avoid CPR; 46% of do-not-resuscitate (DNR) orders were written within 2 days of death; 38% of patients who died spent at least 10 days in an intensive care unit (ICU); and for 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time. In contrast, evidence suggests that
when dying individuals and their families are under the care of a hospice team, pain is better managed and families are more satisfied with the care (Connor, Teno, Spense & Smith, 2005; Miceli & Mylod, 2003; Miller, Mor, Wu, Gozalo, & Lapane, 2002; Steele, Mills, Long, & Hagopian, 2002). However, minimal evaluations on outcomes relating to patients’ psychosocial well-being exist (i.e., quality of life, symptoms of depression or anxiety, death related distress) and represent a clear gap in the literature (Candy, Holman, Leurent, Davis, & Jones, 2011).

**Marginalized Populations and End-of-Life Care**

According to the most recent data published by the National Hospice and Palliative Care Organization’s (NHPCO Facts and Figures: Hospice Care in America, 2010), an estimated 1.56 million patients received services from a hospice team in 2009. However, the vast majority (80.5%) were European American. As such, some research efforts have focused on understanding this disparity. These efforts are part of a movement to understand how diversity impacts access to quality health care which is an ever-increasing value among professionals as our American society continues to diversify. Research on attitudes, values, beliefs, issues of discrimination, and issues of access that may prevent minorities from utilizing end-of-life care is described here.

**Racial and Ethnic Minorities.** The National Hospice and Palliative Care Organization estimated that only 8.7% of patients who used hospice care in 2009 identified as African American. Additionally, 8.7% identified as Multiracial or Other, 1.9% identified as Asian, Hawaiian or Other Pacific Islander, and 0.2% identified as Native Indian or Alaskan Native. Individuals of Hispanic or Latino origin, the largest ethnic minority in the United States based on the 2000 U.S. census, only accounted for
5.3% of hospice users in 2009. Kwak and Haley (2005) conducted a review of 33 empirical studies regarding end-of-life issues in which race or ethnicity were topics of investigation and found that non-European American groups reported less knowledge of end-of-life treatment options than European Americans. Additionally, African Americans were more likely than European Americans to opt for life-sustaining medical interventions regardless of the subsequent state of health, a finding that is consistent with the statistics on hospice and palliative care utilization.

Cultural beliefs are central to perceptions of illness and may influence healthcare utilization, particularly at the end of life. Preferences for life-sustaining therapies, spirituality, beliefs about death and dying, and mistrust of the healthcare system have all been suggested as explanations for the decision-making of African Americans at the end of life (Blackhall et al., 1999; Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004; Bullock, 2006; Reese, Ahern, Nair, O’Faire, & Warren, 1999; Waters, 2001). In the Blackhall et al. (1999) study, African Americans stated that doctors could not always be trusted about stopping life support because they may remove life support for economic reasons; this is not surprising, considering the American history of unethical experiments that exploited African Americans (e.g., U.S. Public Health Service Syphilis Study at Tuskegee, 1932-1972). Johnson, Kuchibhatla, and Tulsy (2008) further explored how these factors could explain the relationship between African-American culture and the use of advance directives or attitudes toward hospice care specifically. The researchers surveyed 205 older adults and found that African Americans were less likely than European American participants to have completed an advance directive (35.5% vs. 67.4%) and had less favorable beliefs about hospice care. African Americans were more likely to express
discomfort discussing death, want aggressive care at the end of life, have spiritual beliefs that conflict with the goals of palliative care, and distrust the healthcare system. However, the researchers also found that when all of the variance of these factors was accounted for in a regression analysis, race was no longer a significant predictor of either of the two outcomes. Therefore, it is not race per se that influences decision making at the end of life, but rather the cultural beliefs and values of this group.

The devoutness of religious beliefs among specific ethnic groups may also contribute to end-of-life health care decisions. Kalish and Reynolds (1981) reported that much of the Mexican-American response to death can be understood within the dimension of religion. For many Hispanic Catholics, the “sacrament of the sick,” formerly known as “last rites,” remains a dreaded process. Frequently, Hispanic families delay calling a priest for this sacrament so they do not appear to have given up hope that the individual will recover. This may parallel with Hispanics accessing hospice at relatively lower rates. Accepting hospice services implies that the family member will not be cured, since hospice is a service for individuals who are dying. Often, Hispanic families may refuse to access, or delay accessing, hospice services because they do not want their loved one to know that he or she is dying (Adams, Horn, & Bader, 2006). Fatalistic attitudes may result in Hispanics’ acceptance of death without seeking health and hospice services (Brodie, 2002). Fatalism is the belief that it does no good to plan for the future, because one does not have any control over it. Similarly, some patients may believe that pain should be endured and pain medications avoided because they believe that patiently accepting God’s will, including suffering, is desirable or pleasing to God, or because they believe that they deserve to suffer because of past behavior (Francoeur,
Payne, Raveis, & Shim, 2006). As such, strength of religious faith may be an important factor to consider in understanding hospice and palliative care service use among all populations with a Christian faith background.

Gender differences may also exist within these minority cultures. Duffy, Jackson, Schim, Ronis, and Fowler (2006) conducted focus groups with a follow-up survey to obtain in-depth information on end-of-life preferences across five racial/ethnic groups in Michigan stratified by sex. There were 73 focus group participants, including Arab Muslims, Arab Christians, Hispanics, African Americans, and European Americans aged 50 years and older. They found that Hispanic and African American women were against assisted suicide and in favor of extending life, whereas the men in these groups felt the opposite. Muslim women spoke of cultural barriers when asked about discrimination related to end-of-life care.

Other research suggests that cultural differences may not be the only reason for the disparate rates of hospice and palliative utilization between European Americans and minorities. Extrinsic barriers may also be present, such as financial and general health care access barriers. Inability to pay for care and lack of insurance are major barriers, and ethnic minorities are at least twice as likely to be uninsured as European Americans (Krakauer, Crenner, & Fox, 2002). Among minorities with cancer, uninsured patients are more likely to be treated at late stages, most likely because they are receiving medical care through emergency room visits where the staff is trained to aggressively fix the problem (Ward et al., 2004). Additionally, minority patients deprived of appropriate health care and symptom management earlier during the course of their illness may be less receptive to palliative care when their conditions become more advanced. Gibson
(2001) and Bonham (2001), both in regards to minority palliative care disparities, state that African Americans and Latinos are more likely to be undertreated for pain than are European American patients, and pharmacies in minority neighborhoods are less likely to carry opioids, a major pain management medication. This may be due to stereotypical or real fears of this highly addictive and abused medication being stolen and sold illegally on the streets.

**Lesbian, Gay, Bisexual, and Transgender (LGBT) Population.** The research which has focused on end-of-life care issues for the LGBT community is thin and has primarily centered on the necessity for advanced directives and legal documentation surrounding the dying process because of the many legal rights that are given to married couples but denied to homosexual partners. In the absence of proper documentation, for example, a partner may not even be allowed to visit his or her dying loved one. As one can imagine, this could be terribly devastating. Stein and Bonuck (2001) surveyed 575 LGBT individuals (aged 19 to 83 years-old) in the New York Metropolitan area regarding advance care planning preferences. Nearly two-thirds (61%) described themselves as a gay man and 31% as lesbian. Whereas 90% were knowledgeable about living wills, only 38% had a living will. Similarly, 72% were aware of health care proxies but only 42% had signed one. Not surprisingly, partners were the preferred medical decision makers (43%) but only 21% of the participants reported partners having the legal capacity to be the surrogate decision maker. Additionally, older respondents were more likely to know more about and complete advance directives. In a related study by McFarland and Sanders (2003), the majority of LGBT participants (73%) had made plans for “growing old” including wills, powers of attorney, life insurance, and estate planning.
These documents are not only important for end-of-life care, but for after the loved one’s death to ensure that inheritance of shared property does not simply pass along to the closest living relative—a problem not faced by married couples. The majority of the 1000 LGBT respondents (aged 51 to 60 years-old) in the MetLife, LGAIN, and Zogby (2006) study had begun the process of advance planning. Although 73% reported discussing end-of-life preferences with someone, 26% of participants aged 40 to 49 years-old and 16% of participants aged 50 to 61 years-old reported not having formal documents stating those wishes. Hash and Netting (2007) conducted interviews with 19 gay men and lesbian women (aged 50 to 77 years-old) recently following the cessation of care they provided for a partner. The researchers found that all but four of the cared-for partners had advance directives, but that the majority of the caregivers did not have advance directives for themselves and were concerned about who would take care of them if they were to get sick.

In one of the only studies to examine values surrounding care during the dying process, Powell (2005) conducted interviews with 12 lesbian older adults to assess end-of-life planning and the meaning of a “good death.” Participants characterized a good death as quick, comfortable, and painless, and ideally including the presence of significant others. Participants emphasized taking care of one's business in advance and maintaining a strong social support system in increasing the likelihood of a good death. However, no questions about hospice and palliative care were asked.

In a very recent study, Almack and colleagues (2010) conducted focus groups with gay and lesbian older adults (n = 15) in the United Kingdom on end of life planning and bereavement. Qualitative analysis revealed primarily relational concerns, more about
personal than professional providers. Most notably, participants were concerned about how families of origin would treat families of choice after death; specifically, would their partner’s desires and wishes be recognized and honored. Also, many individuals not having had children wondered who would be around to care for them as their health deteriorated. Their current support system was primarily the families that they had chosen in fellow LGBT persons, but they too were aging. Again, although no questions were asked about hospice and palliative care directly, this study exemplifies the potential complexity of accessing end-of-life health care services for sexual minorities.

Understanding the legal issues surrounding access for partners and non-related family to their dying loved one and the level of preparation in the LGBT community for such an event is an important research area to improve quality and sensitive care. And yet, health care providers need to be sensitive to all factors influencing access to end-of-life care services for this population. The research by Powell (2005) and Almack et al. (2010) suggest there is more to learn. While the literature examining how lesbian women think about utilizing hospice and palliative care and the factors that would be important to them in making such a decision is scarce, a growing body of literature exists regarding lesbian women’s experiences and expectations for treatment within the traditional health care system. These factors influencing utilization of traditional health care services may also be important for influencing use of hospice and palliative care services.

**Lesbian Women Accessing Health Care Services**

According to a study by Apuzzo (2001) based on the Lesbian Health Study conducted by the National Institute of Health and the Center for Disease Control, more research is needed because “we know virtually nothing about lesbian health issues . . . Of
course, we know even less about older lesbian health issues” (pp. 3-4). This may be because lesbian women largely remain invisible within the health care system and have fewer contacts with health providers than their heterosexual counterparts (Peterson & Bricker-Jenkins, 1996). The literature documents a variety of barriers to lesbian women seeking health care. Most notably, these include discrimination (homophobia and heterosexism), unequal treatment, feelings of exclusion, and lack of resources (Addis, Davies, Greene, MacBride-Stewart, & Sheperd, 2009; Bergeron & Senn, 2003; Dennenberg, 1992; Mathieson, 2007; Powers, Bowen, & White, 2001; Stevens, 1992; Trippet & Bain, 1992).

Because of feared and experienced poor quality care, many lesbian women dislike disclosing their sexual orientation to health care providers (Claes & Moore, 2001; Eliason, 1996; Ponticelli, 1998; Solarz, 1999), forcing them to create an atmosphere of miscommunication about lifestyle behaviors which can place them at increased risk for health problems (van Dam, Koh, & Dibble, 2001). Lesbian patients have reported a myriad of negative reactions from healthcare providers which include embarrassment, anxiety, rejection or hostility, curiosity, pity, condescension, ostracism, withholding treatment, detachment, avoidance of physical contact and breach of confidentiality (Brotman, Ryan, & Cormier, 2003). Stevens’ (1992) review of lesbian health care research from 1970 to 1990 reported that in a number of studies, lesbian women “only felt safe when accompanied by a partner or friend who could act as a witness or advocate” (p. 111). And, if sexual orientation is discussed with a physician, many are explicit about not wanting it included in their charts (Lucas, 1992).
Lesbian women may also feel excluded by sexual health messages that presume heterosexuality, a finding linked to lower levels of Papanicolaou (Pap) testing and later detection of cervical cancer (Diamant, Schuster, & Lever 2000; McIntyre, Szewchuk, & Munro, 2010). Dilley, Wynkoop-Simmons, Boysun, Pizacani, and Stark (2010) similarly found lower rates of receiving routine Pap tests but also routine mammograms among lesbian women compared to heterosexual women. Research suggests that one in five women who have never had heterosexual intercourse have human papilloma virus (HPV), and, although uncommon, female-to-female transmission of HIV is reported (Hughes & Evans, 2003), documenting clear need for preventative screening. Yet, a study by Bauer and Welles (2001) suggests that self-identifying lesbian women are only 27% as likely as bisexual or heterosexual women to obtain regular sexually transmitted disease (STD) testing. An atmosphere of miscommunication created by patients and tendency for service providers to assume that patients are heterosexual will only exacerbate these risks (MacBride-Stewart, 2004a,b).

The cost of health care is also a documented concern (Dilley et al., 2010; Valanis et al., 2000). Because most public and private health insurance programs neither recognize same sex partners nor offers domestic partner benefits to same sex couples, some lesbian women may not have access to health insurance granted to their heterosexual peers. An older woman may not experience cost as a current barrier because of national Medicare health care coverage but it may have meant seeking care at later stages of an illness with treatment being more invasive as a young woman, and now, an unwillingness to regularly engage with a system that was unavailable to her before.
Recent research efforts indicate that many lesbian women, unsatisfied with the traditional medical system, choose to focus on complementary and alternative medicine (CAM) for treatment. CAM modalities include a wide variety of methods, often comprising of behavioral (e.g., relaxation), manual manipulation (e.g., types of massages, acupuncture, chiropractics), and food supplement and botanical modalities (e.g., vitamins, herbs). Trippet and Bain (1992) conducted a study of 503 women (78% who identified themselves as lesbian) and found that 38% of the lesbian women used natural modalities, including herbs and natural remedies. Buenting (1992) compared health lifestyles of lesbian and heterosexual women, finding that lesbian women had significantly higher mean scores on alternative diet and meditation/relaxation techniques. Mathews, Hughes, Osterman, and Kodl (2005) also collected information on CAM modalities use as part of a survey of lesbian and heterosexual women’s health (aged 20 to 86 years; \(M = 43\)). Eighty-two percent of the entire sample reported CAM use and predictors of CAM use included a lesbian sexual orientation, less health-related worry, and perceived discrimination in health care settings. Bowen, Anderson, White, Powers, and Greenlee (2002) surveyed 150 community-dwelling sexual minority women (aged 24 to 69 years) and found that 68% of the women wanted access to an alternative provider and reported equal and high levels of trust in both traditional and alternative providers. Therefore, it may be that with equal trust in both sciences, lesbian women may seek alternative medicine because they feel more supported by these providers than by their physicians. However, evidence for the efficacy of CAMs seems to support its use with chronic illnesses rather than acute self-limiting illnesses (Robinson, 2010).
Differences between Lesbian Identity Cohorts

Lesbian women’s experiences and expectations for treatment within the traditional health care system may also be influenced by the generation in which they grew up and the zeitgeist of the times regarding sexual orientation. The older lesbian and gay population in the United States is estimated at 1.75 to 3.5 million (National Gay and Lesbian Task Force Policy Institute, 2010). Unfortunately, many older LGBT persons today have hidden their sexual orientation out of a very real fear of discrimination and persecution. In the United States, the political movement for gay liberation emerged in the late-1960s beginning with the Stonewall riots on June 28th, 1969 (Engel, 2001). For many older persons today (60 years and older), this liberation movement occurred when they were already young adults, after years of hearing hostile messages of the immorality of their feelings, feeling alone, and worrying what would happen if others found out. Prior to Stonewall, those who did try to meet endured police harassment, entrapment, arrest, and public outing in the newspapers (Heaphy, Yip, & Thompson, 2003), whereas currently middle-aged LGBT persons grew up in era after Stonewall when “I” became “We.” After Stonewall there was a greater sense of LGBT community for those “coming out,” increased education and activism for equal and fair treatment, and greater awareness and sensitivity in society which has progressively gotten better with time. Andersen and Fetner (2008) explored how birth cohort, time, and country (US and Canada) interact in their effects on attitudes toward homosexuality over a 20-year period and found that by 2000, public acceptance for homosexuality had increased significantly in both countries and within all cohorts. This is not to say that individuals who have grown up post-Stonewall have not experienced discrimination and stigmatization; however, most LGBT
researchers and scholars recognize Stonewall as an event separating very private LGBT persons from less private LGBT persons.

Older lesbian women have been under investigation as a unique group (within society at large and the gay community) since at least 1978 (Minnigerode & Adelman, 1978). *Lesbian women Over 60 Speak for Themselves* (Kehoe, 1989) is the most extensive investigation of older lesbian women to date, and was based on 100 questionnaires from women 60 years old and older in 1984. More recent investigations have relied on interviews to gather information about these generations’ experiences in more domains of their lives. In *Whistling Women*, Claassen (2005) conducted interviews with 44 lesbian women in two age cohorts: birth years 1917-1929 and birth years 1930-1938, and Clunis, Fredriksen-Goldsen, Freeman, and Nystrom (2005) interviewed 62 lesbian women in *Lives of Lesbian Elders*. Both provided captivating, first-person accounts of their memories, feelings, thoughts and life choices within the contexts of culture, politics, and social mores during the eras in which they lived. For the purposes of this study, both cohorts of lesbian woman were included to understand potential differences in the way they view end-of-life health care.

**Willingness to Seek Help**

In addition to considering distrust in the health care system as a potential barrier to accessing hospice and palliative care services, it was also important to consider that distrust may not be limited to the health care system; individuals of minority groups may have a general unwillingness to seek professional help outside of their immediate social network because of experiences with discrimination. This may be especially true for the older lesbian cohort who grew up hearing hostile messages about how they felt. Several
models and measures of help-seeking behavior have been developed over the years for use in understanding service utilization (Aday, Fleming, & Andersen, 1984; Fisher, Nadler, & Whitcher-Alagna, 1982; Fischer & Turner, 1970; Kelley, 1967; Walster, Walster, & Berscheid, 1978). The Keith-Lucas model (1972; rev. ed., 1994) indicates that in order for a person to seek help, four conditions must be met: the individual must admit a problem that he or she cannot solve with his or her resources alone, the individual must be prepared for self-disclosure, the individual must be prepared to allow another person some measure of control over his or her life, and the individual must be willing to change. This theory was the basis for the Willingness to Seek Help Questionnaire (WSHQ) developed by Cohen (1999) which has been used to understand service utilization in the medical and mental health fields (e.g., Segal, Coolidge, Mincic, & O'Riley, 2005). The WSHQ will be included in this study to understand how general unwillingness to seek professional help outside of one’s immediate social network relates to hospice and palliative care beliefs among sexually diverse women.

Taken together, this literature review suggests several important themes. It is evident that enrollment in hospice and palliative care can improve the quality of the dying process, avoiding painful tests and prolonged hospitalizations. However, diverse populations differ about how they think about death and the factors that may influence accepting this type of care. Whereas there is a solid foundation of literature for racial and ethnic minorities, a dearth of research exists for sexual minorities on the decision to utilize hospice and palliative care services and the factors that would influence this decision. The purpose of the present study was to explore attitudes and beliefs about pain management, hospice, and other factors that may influence a decision to utilize end-of-
life care for sexually diverse women. The first specific aim of the study was to explore whether end-of-life health care attitudes are different among lesbian and heterosexual women, a second aim was to explore whether end-of-life health care attitudes are different among middle-aged women and older adult women, a third aim was to understand how healthcare system distrust, willingness to seek help, religiosity/spirituality, and beliefs about alternative medicines are related to one’s beliefs about hospice and palliative care, and a fourth aim was to further elucidate quantitative survey data with qualitative key themes from interviews with lesbian older adults about perceived barriers of using hospice and palliative care and to identify areas of future study in this area.

Hypotheses

1. It was hypothesized, based on the literature citing real and feared discrimination within the health care system by lesbian women that they would endorse less favorable beliefs about hospice, less comfort discussing pain management, an overall lower willingness to seek help, greater preference for life-sustaining care, greater distrust in the healthcare system, and more positive views about CAM compared to heterosexual women.

2. It was predicted that older women would endorse more favorable beliefs about hospice, more comfort discussing pain management and lower preference for life-sustaining care compared to middle-aged women because of more exposure to loved ones dying and greater openness to options for the dying process.

3. It was hypothesized, because of differences between the identity cohorts of lesbian women, there would be a significant interaction for age X orientation on health care
system distrust, such that older lesbian would endorse more distrust than older heterosexual women compared to the difference between the middle-aged groups.

4. For each of the four groups (older lesbian women, older heterosexual women, middle-aged lesbian women, and middle-aged heterosexual women), hospice beliefs and comfort discussing pain management were hypothesized to be significantly predicted by and negatively correlated with scores on health care system distrust, and strength of religious faith, and CAM, but positively correlated with overall willingness to seek help. Also, it is hypothesized that the relationship for health care system distrust would be stronger for the lesbian women than for the heterosexual women (as evidenced by significantly larger correlation coefficients), indicating it as a stronger barrier to accessing services.

5. Among the interviews with lesbian older women, it was predicted that when discussing their experiences of the traditional health care system, their perceptions of end-of-life health care, and any other factors influencing utilizing this type care, qualitative content analysis will reveal major themes of distrust, of concerns about the exclusion of a partner, and of a desire for inclusiveness.
CHAPTER 2

Method

Participants

Self-identified middle and older adult heterosexual and lesbian women were recruited for this study. Participants were recruited through undergraduate students at the University of Colorado at Colorado Springs (UCCS) who received extra credit for their recruitment of older adult family members or friends, through the UCCS Gerontology Center Participant Registry, through UCCS staff members, and through Colorado Springs, Pueblo, Boulder, and Denver Pride Centers’ newsletters and events.

Lesbian older adult women (n = 30; 90% White) ranged in age from 60 to 81 years old (M age = 66 years, SD = 5.5 years) with a mean level of 18 years of education (SD = 2.5 years). Forty five percent identified living alone. Their level of religiosity/spirituality was reported as follows: 20% very religious/spiritual, 60% somewhat, 13% not very and 7% not at all. Thirteen percent rated their current health status as excellent, while 40% said very good, 40% said good, and 7% said fair. Eighty percent identified having a Living Will and 83% have a Durable Power of Attorney for health care.

Heterosexual older adult women (n = 31; 87% White) ranged in age from 60 to 77 years old (M age = 64.8 years, SD = 4.6 years) with a mean level of 16.8 years of education (SD = 2.4 years). Thirty nine percent identified living alone. Their level of religiosity/spirituality was reported as follows: 26% very religious/spiritual, 61%
somewhat, 10% not very and 3% not at all. Seven percent rated their current health status as excellent, while 55% said very good, 36% said good, and 3% said fair. Seventy four percent identified having a Living Will and 67% have a Durable Power of Attorney for health care.

Lesbian middle-aged adult women (n = 35; 97% White) ranged in age from 35 to 59 years old (M age = 50 years, SD = 7.3 years), with a mean level of 16.5 years of education (SD = 2.7 years). Forty three percent identified living alone. Their level of religiosity/spirituality was reported as follows: 27% very religious/spiritual, 47% somewhat, 9% not very and 18% not at all. Fourteen percent rated their current health status as excellent, while 46% said very good, 26% said good, 9% said fair, and 6% said poor. Fifty one percent identified having a Living Will and 54% have a Durable Power of Attorney for health care.

Heterosexual middle-aged adult women (n = 49; 88% White) ranged in age from 35 to 59 years old (M age = 50.5 years, SD = 5.5 years) with a mean level of 16 years of education (SD = 2.5 years). Fifteen percent identified living alone. Their level of religiosity/spirituality was reported as follows: 22% very religious/spiritual, 45% somewhat, 18% not very and 14% not at all. Twenty five percent rated their current health status as excellent, while 31% said very good, 39% said good, and 6% said fair. Fifty one percent identified having a Living Will and 41% have a Durable Power of Attorney for health care.

Thirty lesbian older adults indicated initial interest in the follow-up interview. The analysis presented is based upon the six women with whom an interview could be conducted (age range = 62 to 71 years; 100% European American; M level of education =
18 years). Attrition was based on failure to establish initial contact with the participant, participants’ desire not to be audio taped, and participant changing her mind about the interview for various reasons. To protect confidentiality of the participants, pseudonyms were used to indicate the source of quotes.

**Procedure**

Participants were asked to complete a self-report questionnaire in person or online exploring beliefs that may affect decision-making at the end of life. Each of the measures is described below. Several questions within the measures were modified to be inclusive of both sexual orientations. For example, questions about marriage were changed to marriage/partnership and questions about children were changed to loved ones. Several questions were also added to one of the measures to ask more specific questions about end-of-life care. Participants were classified in age and sexual orientation groups based upon self-reported identity classification.

Additionally, at the end of the questionnaire, the subsample of lesbian participants aged 60 years and above were invited to participate in a brief phone interview and asked to provide contact information if interested. Follow-up calls were made by the Principal Investigator within 3 weeks of the participant completing the survey. The following questions were asked of each interviewee:

1. What factors might influence your willingness to utilize hospice and palliative care?
2. Where would you like to be cared for at the end of your life? By whom?
3. What are some concerns you have about receiving hospice and palliative care services?
4. What would deciding to receive hospice and palliative services mean to you?
5. How might you go about looking for a hospice or palliative provider and what would be important to you?

6. In what ways might your decision process to receive hospice and palliative services as a lesbian be different than a heterosexual woman?

Interviews were semi-structured to generate dialogue about experiences or beliefs that may have been overlooked or underexplored in the survey. All interviews were audio-recorded and transcribed; transcripts were then compared to audio-recordings for accuracy. Based on the review of the data, it was concluded that sufficient saturation had been reached with the six interviews to comment on factors that are important for these women when considering end-of-life health care and their broader experiences within the traditional healthcare system.

Conventional qualitative content analysis (Hsieh & Shannon, 2005) was used to code and interpret the interviews using NVivo 9 (QSR International, 2010). While it is one of numerous research methods used to analyze text data, this type of design was chosen because it utilizes subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns and is appropriate when existing theory or research literature on a phenomenon is limited (Hsieh & Shannon 2005). Researchers utilizing this design avoid using preconceived categories (Kondracki & Wellman, 2002), instead allowing the categories and names for categories to flow from the data. Researchers immerse themselves in the data to allow new insights to emerge (Kondracki & Wellman, 2002), a method that has also been described as inductive category development (Mayring, 2000). Furthermore, content analysis has been a popular analytic method in studies related to end-of-life care (Hsieh & Shannon 2005).
Measures

*End-of-Life Care Questionnaire* (Johnson, Kuchibhatla, & Tulsky, 2008) is a self-report questionnaire developed at Duke University to assess beliefs that may affect decision-making at the end of life. The original measure consisted of six sections and included questions taken or modified from previously developed measures. A 5-point Likert scale (*strongly agree, agree, neither agree nor disagree, disagree, strongly disagree*) is used to respond to statements from each of the scales. Sections of the questionnaire relevant to this study are described here. The *Preferences for End-of-Life Care* scale includes 8 statements exploring beliefs about the desire to live as long as possible with a terminal illness. Johnson and colleagues developed statements based on a review of the literature or with minor modification from the AARP North Carolina End-of-Life Care Survey, which was based on the Missoula Demonstrations Project’s Community Survey (Straw & Cummins, 2003). Higher scores indicate a greater preference for life-sustaining therapies in the event of a terminal illness. Cronbach’s alpha for the scale was .71 in the original study. For this sample, Cronbach’s alpha was calculated to be .66, indicating adequate reliability. Calculated separately by sexual orientation, for lesbian women it was .63, and for heterosexual women it was .68. The *Beliefs about Pain Management* scale includes 8 statements exploring beliefs about using pain medications. These questions were taken or modified from the AARP North Carolina End-of-Life Care Survey and Reese’s Hospice Barriers Scale (Reese et al., 1999). Higher scores indicate greater comfort with discussing pain and pain medication. For this sample, Cronbach’s alpha was calculated to be .68, indicating adequate reliability. Calculated separately by sexual orientation, for lesbian women it was .63, and
for heterosexuals it was .71. The *Hospice Beliefs and Attitudes* scale includes eight statements examining attitudes toward hospice care, including desire for hospice care and beliefs about the type of care hospice provides. These items included some developed by Johnson and colleagues and others from the Hospice Barriers and Hospice Values Scales (Reese, et al., 1999). Higher scores indicate more favorable beliefs about hospice. Cronbach’s alpha for the scale was .74 in the original study. For this sample, Cronbach’s alpha was calculated to be .73, indicating adequate reliability. Calculated separately by sexual orientation, for lesbian women it was .69, and for heterosexual women it was .72.

*Health Care System Distrust Scale* (Rose, Peters, Shea, & Armstrong, 2004) is a 10-item self-report scale with 4 items measuring honesty, 2 items measuring confidentiality, 2 items measuring competence, and 2 items measuring fidelity. Respondents answer using a 5-point Likert scale ranging from *strongly agree* (5) to *strongly disagree* (1). Higher scores indicate greater distrust in the healthcare system. In the initial validation study, Cronbach’s alpha was .75 and item-total correlations ranged from .27 to .57. For this sample, Cronbach’s alpha was calculated to be .83, indicating good reliability. Calculated separately by sexual orientation, for lesbian women it was .83, and for heterosexual women it was .83.

*Willingness to Seek Help Questionnaire* (*WSHQ*; Cohen, 1999) is a 25-item self-report questionnaire that evaluates one’s openness to seeking help. Items are rated on a 4-point Likert scale ranging from *do not identify with the statement at all* (0) to *strong identification* (3). The measure yields a total score only; higher scores indicate a greater willingness to seek help. The measure is based on a theoretical view of help-seeking – specifically, that the willingness of a person to seek help is dependent on three elements:
recognition of the need for outside assistance, readiness for self-disclosure, and willingness to relinquish at least some degree of control to an expert helper. The scale has good internal reliability (Cronbach’s alpha = .85) and evidence of content validity (Cohen, 1999). For this sample, Cronbach’s alpha was calculated to be .88, indicating good reliability. Calculated separately by sexual orientation, for lesbian women it was .88, and for heterosexual women it was .87.

Holistic Complementary and Alternative Medicine Questionnaire (HCAMQ; Hyland, Lewith, & Westoby, 2003) is an 11-item self report questionnaire consisting of six items about attitude toward complementary and alternative medicine (CAM items) and six items about holistic health (HH items). Items were selected to cover a wide range of content in each of these areas. Responses to each item are made using a 6-point Likert response format ranging from strongly agree to strongly disagree. A total score can be obtained as well as individual scores for CAM and HH. As the scale is designed, lower scores on the HCAMQ indicate more positive attitudes towards CAM and HH; however, to simplify the analyses for this study, higher scores will indicate more positive attitudes toward CAM. The HCAMQ has good test-retest reliability ($r = .86, .82$ and $.77$ for the total, CAM subscale and HH subscale, respectively) and good convergent and divergent validity (Hyland et al., 2003). For the current study, using the same response format, three questions designed specifically to understand how participants think about complementary and alternative treatment for hospice care and pain management were added to the end of the original measure. These included:

1. If I were experiencing pain, I would seek out alternative medicine for treatment before going to a physician.
2. I would want my palliative and hospice care to incorporate complementary and alternative medicines.

3. If I were dying, I would rather utilize complementary and alternative medicines than traditional medical care.

Therefore, a total of 14 items were included under the HCAMQ section of the questionnaire packet for this study. For this sample, with the additional questions added, Cronbach’s alpha was calculated to be .81, indicating good reliability. Calculated separately by sexual orientation, for lesbian women it was .82, and for heterosexual women it was .80.

Santa Clara Strength of Religious Faith Questionnaire (SCSRF; Plante & Boccaccini, 1997) is a 10-item self report measure designed to assess the strength of an individual’s religious/spiritual faith regardless of affiliation or denomination. As designed, items are rated on a 4-point Likert scale ranging from strongly disagree (1) to strongly agree (4); however, to identify more subtle differences, the scale was modified for this study to a 6-point Likert scale ranging from strongly disagree (1) to strongly agree (6), adding mildly disagree (2) and mildly agree (5). Higher scores indicate greater religious/spiritual faith. The SCSORF was found to have high internal reliability. Cronbach alpha’s in the initial validation study were .94 for a university student sample, .97 for a civic group sample, and .96 for a high school sample. The SCSORF also correlated highly with other measures of religiosity (r’s ranged from .64 to .90). For this sample, Cronbach’s alpha was calculated to be .98, indicating good reliability. Calculated separately by sexual orientation, for lesbian women it was .98, and for heterosexual women it was .98.
Power Analysis

To test the identified hypotheses, a series of analysis of variance (ANOVA) and multiple regression analyses needed to be conducted. Cohen (1992) indicates that the necessary $N$ for a power of .80 for any given statistical test depends upon the expected population effect size, desired alpha level, and number of factors analyzed (i.e., number of groups, independent variables, degrees of freedom). In this study, alpha will be set at .05. Given that this is the first study to examine hospice beliefs and comfort discussing pain management among these populations, previous literature cannot provide a guide for expected effect size. Therefore, a medium to large effect size was identified as a meaningful effect and established as a guide for determining sample size.

For an ANOVA with the expected 4 groups, assuming a medium effect at the .05 alpha level, Cohen recommends a sample size of 48 in each group. Assuming a large effect the recommended sample size decreases to 18 in each group. For a multiple regression analysis with the expected 4 independent variables, assuming a medium effect at the .05 alpha level, Cohen recommends a sample size of 84 participants. Assuming a large effect, the sample size needed decreases to 38 participants. Inclusion of additional variables to the analysis would increase the necessary sample size and power to detect medium and large effects.

Based on the sample recruited for this study, adequate power was obtained to detect medium to large effects in mean differences for age and sexual orientation. For the multiple regressions, the number of participants recruited was close to that needed for detecting large effects. Limitations of this potential low level of power are addressed in the discussion.
CHAPTER 3

Results

Quantitative Analyses

Equivalency of Groups. Demographic variables for the heterosexual women and lesbian women were compared to assess the equivalency of the two sexual orientations at each age group. Among the older adults, orientations were not significantly different on level of education, \( t(59) = 1.37, p > .05 \). Additionally, chi squared analyses revealed no significant differences on ethnicity, currently living alone, level of religiosity/spirituality, current health rating, having a Living Will, and having a Durable Power of Attorney (POA) for health care. Among the middle-aged adults, orientations were not significantly different on level of education, \( t(82) = 0.85, p > .05 \). Chi square analyses also revealed no significant differences on ethnicity, level of religiosity/spirituality, current health rating, having a Living Will, and having a Durable POA. The percentage of lesbian women and heterosexual women who currently live alone did significantly differ, \( \chi^2 (1) = 8.31, p < .05 \), with more lesbian women living alone. However, living alone did not significantly correlate with any of the measures.

Demographic variables were also compared for the middle-aged and older women to assess the equivalency of the two age groups for each sexual orientation. Among the lesbian women, age groups were not significantly different on level of education, \( t(63) = 1.72, p > .05 \). Additionally, chi squared analyses revealed no significant differences on ethnicity, currently living alone, level of religiosity/spirituality, and current health rating.
However, the percentage of middle-aged and older lesbian women significantly differed on having a Living Will, $\chi^2 (1) = 5.77, p < .05$ and having a Durable POA, $\chi^2 (1) = 5.83, p < .05$. Older lesbian women had completed significantly more Living Wills and Durable POAs. Additionally, having a Living Will significantly correlated with the Beliefs about Pain Management total ($r = -.25, p < .05$) and Hospice Beliefs and Attitudes total ($r = -.28, p < .05$), and having a Durable POA significantly correlated with Hospice Beliefs and Attitudes total ($r = -.28, p < .05$). Consequently, these demographic variables were statistically controlled for in the following analyses to avoid potential confounds. Among the heterosexual women, age groups were not significantly different on level of education, $t(78) = 1.32, p > .05$. Chi squared analyses also revealed no differences on ethnicity, level of religiosity/spirituality, and current health rating. However, the percentage of middle-aged and older heterosexual women significantly differed on currently living alone, $\chi^2 (1) = 8.31, p < .05$, having a Living Will, $\chi^2 (1) = 4.25, p < .05$, and having a Durable POA, $\chi^2 (1) = 5.51, p < .05$. A greater number of older heterosexual women reported living alone, having a Living Will, and having a Durable POA. However, correlations revealed no significant relationship between these variables and the measures used.

Finally, the type of survey participants completed (paper copy vs. on-line) significantly correlated with religious/spiritual faith total ($r = .20, p < .05$) and complementary and alternative medicine total ($r = -.17, p < .05$). Those who completed a paper copy endorsed more spiritual/religious faith and less positive beliefs about complementary and alternative medicine than those who completed the survey on-line.
As such, the type of survey was included as a covariate in the relevant analyses to control for any overlapping variance.

**Age and Sexual Orientation Effects.** It was hypothesized that lesbian would score lower on the Hospice Beliefs and Attitudes scale, the Beliefs about Pain Management scale, and the Willingness to Seek Help Questionnaire, and score higher on the Preferences for Care scale, the Health Care System Distrust scale, and the Holistic Complementary and Alternative Medicine scale compared to heterosexual women. It was also predicted that older women would score higher on the Hospice Beliefs and Attitudes scale, higher on the Beliefs about Pain Management scale, and lower on the Preferences for Care scale compared to middle-aged women. A significant interaction for age by orientation on the Health Care System Distrust scale would also exist, such that older lesbian would score significantly higher than older heterosexual women compared to the difference between the middle-aged groups. To test these hypotheses, a series of two-way ANCOVAs was conducted to examine the effects of sexual orientation and age group on each of the measures covarying having a Living Will and Durable POA. Results are presented by measure. Adjusted means are provided in Table 1.

**Beliefs about Pain Management.** The ANCOVA revealed a significant main effect for age, $F(1, 138) = 12.37, p < .01$, with a moderate effect size ($\eta^2 = .08$). Older adult women reported more comfort discussing pain management than middle-aged women. The main effect for sexual orientation was not significant, $F(1, 138) = 1.39, p = .24, \eta^2 = .01$, and the interaction of sexual orientation by age was not significant, $F(1, 138) = 0.53, p = .47, \eta^2 < .01$. These results provided partial support for the hypotheses.
Table 1

*Adjusted Means for each Measure across Orientation and Age*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Sexual Orientation</th>
<th>Middle-aged Women $M (SD)$</th>
<th>Older Women $M (SD)$</th>
<th>Total $M (SD)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beliefs about Pain</td>
<td>Heterosexual</td>
<td>3.29 (.08)</td>
<td>3.57 (.10)</td>
<td>3.43 (.07)</td>
</tr>
<tr>
<td></td>
<td>Lesbian</td>
<td>3.33 (.10)</td>
<td>3.75 (.10)</td>
<td>3.54 (.07)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>3.31 (.06)</td>
<td>3.67 (.04)</td>
<td>3.49 (.05)</td>
</tr>
<tr>
<td>Hospice Beliefs</td>
<td>Heterosexual</td>
<td>3.74 (.08)</td>
<td>3.93 (.10)</td>
<td>3.41 (.06)</td>
</tr>
<tr>
<td></td>
<td>Lesbian</td>
<td>3.94 (.09)</td>
<td>4.20 (.10)</td>
<td>4.07 (.07)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>3.84 (.06)</td>
<td>4.06 (.07)</td>
<td>3.95 (.05)</td>
</tr>
<tr>
<td>Preferences for Care</td>
<td>Heterosexual</td>
<td>1.81 (.07)</td>
<td>1.76 (.09)</td>
<td>1.78 (.06)</td>
</tr>
<tr>
<td></td>
<td>Lesbian</td>
<td>1.68 (.08)</td>
<td>1.55 (.09)</td>
<td>1.62 (.06)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1.74 (.05)</td>
<td>1.65 (.06)</td>
<td>1.70 (.04)</td>
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<tr>
<td>Health Care Distrust</td>
<td>Heterosexual</td>
<td>2.94 (.10)</td>
<td>2.91 (.12)</td>
<td>2.92 (.08)</td>
</tr>
<tr>
<td></td>
<td>Lesbian</td>
<td>3.00 (.11)</td>
<td>2.76 (.13)</td>
<td>2.88 (.09)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>2.97 (.08)</td>
<td>2.83 (.09)</td>
<td>2.90 (.06)</td>
</tr>
<tr>
<td>Alternative Medicine</td>
<td>Heterosexual</td>
<td>4.32 (.09)</td>
<td>4.29 (.11)</td>
<td>4.30 (.07)</td>
</tr>
<tr>
<td></td>
<td>Lesbian</td>
<td>4.53 (.10)</td>
<td>4.52 (.11)</td>
<td>4.53 (.07)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>4.43 (.07)</td>
<td>4.40 (.08)</td>
<td>4.14 (.05)</td>
</tr>
<tr>
<td>Willingness to Seek Help</td>
<td>Heterosexual</td>
<td>2.95 (.05)</td>
<td>3.11 (.06)</td>
<td>3.03 (.04)</td>
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<tr>
<td></td>
<td>Lesbian</td>
<td>3.10 (.06)</td>
<td>3.11 (.07)</td>
<td>3.11 (.05)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>3.03 (.04)</td>
<td>3.11 (.05)</td>
<td>3.07 (.03)</td>
</tr>
<tr>
<td>Religious/Spiritual Faith</td>
<td>Heterosexual</td>
<td>4.33 (.23)</td>
<td>4.18 (.29)</td>
<td>4.25 (.18)</td>
</tr>
<tr>
<td></td>
<td>Lesbian</td>
<td>3.90 (.26)</td>
<td>3.37 (.29)</td>
<td>3.63 (.20)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>4.11 (.18)</td>
<td>3.77 (.21)</td>
<td>3.94 (.13)</td>
</tr>
</tbody>
</table>
Hospice Beliefs and Attitudes. Significant main effects were found for age, $F(1, 138) = 5.43, p = .02$, and for sexual orientation, $F(1, 138) = 6.06, p = .02$, with moderate effect sizes for both ($\eta^2 = .04$). Results showed that older adult women held more positive beliefs about hospice care than middle-aged women and lesbian women held more positive beliefs than heterosexual women. The interaction was not significant, $F(1, 138) = 0.11, p = .74, \eta^2 < .01$. These findings provided mixed support for the hypotheses.

Preferences for Care. The ANCOVA revealed a significant main effect for sexual orientation $F(1, 138) = 4.04, p = .05$, with a relatively small effect size ($\eta^2 = .03$). Heterosexual women reported a greater desire for life-sustaining treatments than lesbian women in the event of an incurable disease and severe life-limiting conditions (e.g., feeding tube, life support, no brain response). This result was not in the expected direction. The main effect for age was not significant, $F(1, 138) = 1.12, p = .29, \eta^2 < .01$, and the interaction of sexual orientation by age was not significant, $F(1, 138) = 0.27, p = .60, \eta^2 < .01$.

Health Care System Distrust. The ANCOVA revealed no significant differences for sexual orientation, $F(1, 138) = 0.14, p = .71 \eta^2 < .01$, or age, $F(1, 138) = 1.29, p = .26, \eta^2 < .01$. Additionally, the interaction was not significant, $F(1, 138) = 0.80, p = .37, \eta^2 < .01$. These findings did not support the hypotheses.

Holistic Complementary and Alternative Medicine. For this ANCOVA, in addition to covarying having a Living Will and Durable POA, type of survey was also included. A significant main effect was found for sexual orientation, $F(1, 138) = 4.37, p = .04$, with a relatively small effect size ($\eta^2 = .03$). Lesbian women reported more
positive beliefs about the role of alternative medicines in health care compared to heterosexual women. This result was consistent with the hypothesis. The main effect for age was not significant, \( F(1, 138) = 0.04, p = .85, \eta^2 < .01 \), and the interaction of sexual orientation and age was not significant, \( F(1, 138) = 0.01, p = .92, \eta^2 < .01 \).

**Willingness to Seek Help.** The ANCOVA revealed no significant differences for sexual orientation, \( F(1, 138) = 1.64, p = .20, \eta^2 = .01 \), or age, \( F(1, 138) = 1.76, p = .19, \eta^2 = .01 \). These results did not support the hypotheses. Additionally, the interaction was not significant, \( F(1, 138) = 1.69, p = .20, \eta^2 = .01 \).

**Religious/Spiritual Faith.** As an exploratory analysis, age and sexual orientation effects were also examined on strength of religious/spiritual faith. For this ANCOVA, type of survey was also included as a covariate. A significant main effect was found for sexual orientation, \( F(1, 138) = 5.33, p = .02 \), with a moderate effect size (\( \eta^2 = .04 \)). Lesbian women endorsed an average level of religious/spiritual faith and heterosexual women reported a stronger sense of faith. The main effect for age was not significant, \( F(1, 138) = 1.47, p = .23, \eta^2 = .01 \), and the interaction of sexual orientation and age was not significant, \( F(1, 138) = 0.53, p = .47, \eta^2 < .01 \).

**Predictors of End-of-life Health Care Attitudes.** To better understand how scores on the Hospice Beliefs and Attitudes scale and the Beliefs about Pain Management scale may be predicted by willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith (Hypothesis 4), sequential regressions were performed for each group (i.e., old lesbian women, old heterosexual women, middle-aged lesbian women, and middle-aged heterosexual women). For each of these analyses having a Living Will, having a Durable
POA for health care, and the type of survey they completed were placed into the first block to control for group differences. Willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith were placed in the second block. The results of these analyses are described here by group.

**Lesbian older women.** Predicting hospice beliefs and attitudes, in the first block of the analysis type of survey, having a Living Will, and having a Durable POA for Health Care did not account for a significant amount a variance in Hospice Beliefs and Attitudes total, $R^2 = .23$, $F(3, 25) = 2.50$, $p = .08$. Table 2 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith significantly predicted Hospice Beliefs and Attitudes total scores, $\Delta R^2 = .39$, $\Delta F (4, 21) = 5.42$, $p < .01$. Examining the factors separately, willingness to seek help ($\beta = .41$, $p = .02$) and beliefs about complementary and alternative medicine ($\beta = .46$, $p < .01$) significantly contributed to the proportion of variance accounted for by the model.

For beliefs about pain management, the first block did not significantly predict Beliefs about Pain Management total scores, $R^2 = .05$, $F(3, 25) = 0.45$, $p = .72$. Table 3 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith significantly predicted Beliefs about Pain Management total scores, $\Delta R^2 = .37$, $\Delta F (4, 21) = 3.35$, $p = .03$. Examining the factors separately, only distrust, ($\beta = -.43$, $p = .03$), significantly
Table 2

Summary of Older Lesbian Women Sequential Regression Analysis for Variables Predicting Hospice Beliefs and Attitudes Total

<table>
<thead>
<tr>
<th>Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>b</td>
<td>SE b</td>
<td>β</td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of Survey</td>
<td>.69</td>
<td>.30</td>
<td>.49</td>
</tr>
<tr>
<td>Living Will</td>
<td>-.44</td>
<td>.50</td>
<td>-.41</td>
</tr>
<tr>
<td>POA</td>
<td>.22</td>
<td>.54</td>
<td>.19</td>
</tr>
</tbody>
</table>

|                               | b  | SE b | β  |     |
| Step 2                        |    |      |    |     |
| Type of Survey                | .45 | .24  | .32 | 1.86|
| Living Will                   | -.73| .40  | -.68| -1.84|
| POA                           | .48 | .43  | .42 | 1.12|
| Willingness to Seek Help      | .59 | .22  | .41 | 2.62*|
| Health Care System Distrust   | .04 | .10  | .06 | .37 |
| Complimentary & Alternative Med | .30 | .10  | .46 | 3.17*|
| Religious/Spiritual Faith     | .01 | .04  | .04 | .30 |

Note. $R^2 = .23$ ($p = .08$) for Step 1; $\Delta R^2 = .39$ ($p < .05$) for Step 2.

*p < .05.
Table 3

Summary of Older Lesbian Women Sequential Regression Analysis for Variables Predicting Beliefs about Pain Management Total

<table>
<thead>
<tr>
<th>Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>b</td>
<td>SE</td>
</tr>
<tr>
<td>Step 1</td>
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<td></td>
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<tr>
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<tr>
<td>Living Will</td>
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<td>.48</td>
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<tr>
<td>POA</td>
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<td>.51</td>
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<td>Step 2</td>
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<td></td>
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<td>Type of Survey</td>
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<tr>
<td>Living Will</td>
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<td>.42</td>
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<tr>
<td>POA</td>
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<td>.45</td>
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<td>Willingness to Seek Help</td>
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<td>.24</td>
</tr>
<tr>
<td>Health Care System Distrust</td>
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<td>.10</td>
</tr>
<tr>
<td>Complimentary &amp; Alternative Med</td>
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<td>.10</td>
</tr>
<tr>
<td>Religious/Spiritual Faith</td>
<td>.04</td>
<td>.04</td>
</tr>
</tbody>
</table>

Note. $R^2 = .05\ (p = .72)$ for Step 1; $\Delta R^2 = .37\ (p < .05)$ for Step 2.

*p < .05.
contributed to the proportion of variance accounted for by the model, demonstrating the importance of level of distrust in the health care system as a potential barrier to discussing pain management for this group.

Heterosexual older women. Predicting hospice beliefs and attitudes, the first block did not account for a significant amount a variance in Hospice Beliefs and Attitudes total, \( R^2 = .05, F(3, 27) = 0.48, p = .70 \). Table 4 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith also did not significantly predict Hospice Beliefs and Attitudes total scores as a model, \( \Delta R^2 = .29, \Delta F(4, 23) = 2.47, p = .07 \). However, willingness to seek help, \( (\beta = .68, p < .01) \), was a significant individual predictor of hospice scores.

For beliefs about pain management, the first block did not significantly predict Beliefs about Pain Management total scores, \( R^2 = .10, F(3, 27) = 1.01, p = .41 \). Table 5 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith also did not significantly predict Beliefs about Pain Management total scores, \( \Delta R^2 = .29, \Delta F(4, 23) = 2.77, p = .05 \). However, distrust, \( (\beta = -.43, p = .04) \), was a significant individual predictor, demonstrating the importance of level of distrust in the health care system as a potential barrier to discussing pain management for this group.
Table 4

*Summary of Older Heterosexual Women Sequential Regression Analysis for Variables Predicting Hospice Beliefs and Attitudes Total*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
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<td>$SE_{b}$</td>
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<td></td>
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<tr>
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<td>.24</td>
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<tr>
<td>Living Will</td>
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<td>.48</td>
</tr>
<tr>
<td>POA</td>
<td>.24</td>
<td>.45</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of Survey</td>
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<td>.26</td>
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<tr>
<td>Living Will</td>
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<tr>
<td>POA</td>
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<td>.51</td>
</tr>
<tr>
<td>Willingness to Seek Help</td>
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<td>.44</td>
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<tr>
<td>Health Care System Distrust</td>
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<td>.19</td>
</tr>
<tr>
<td>Complimentary &amp; Alternative Med</td>
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<td>.18</td>
</tr>
<tr>
<td>Religious/Spiritual Faith</td>
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<td>.08</td>
</tr>
</tbody>
</table>

*Note.* $R^2 = .05 \ (p = .70)$ for Step 1; $\Delta R^2 = .29 \ (p = .07)$ for Step 2.

*p < .05.
Table 5

Summary of Older Heterosexual Women Sequential Regression Analysis for Variables Predicting Beliefs about Pain Management Total

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Variables</th>
<th>Unstandardized Coefficients $b$</th>
<th>$SE$</th>
<th>Standardized Coefficients $\beta$</th>
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<td>-.05</td>
<td>-.15</td>
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</tr>
<tr>
<td>POA</td>
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<td>.36</td>
<td>.02</td>
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</table>

<table>
<thead>
<tr>
<th>Step 2</th>
<th>Variables</th>
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<th>$SE$</th>
<th>Standardized Coefficients $\beta$</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Survey</td>
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<td>.21</td>
<td>-.40</td>
<td>-2.05</td>
<td></td>
</tr>
<tr>
<td>Living Will</td>
<td>-.24</td>
<td>.44</td>
<td>-.22</td>
<td>-.54</td>
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</tr>
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<td>POA</td>
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<td>.11</td>
<td>.27</td>
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<tr>
<td>Willingness to Seek Help</td>
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<td>.35</td>
<td>.07</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>Health Care System Distrust</td>
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<td>.15</td>
<td>-.43</td>
<td>-2.14*</td>
<td></td>
</tr>
<tr>
<td>Complimentary &amp; Alternative Med</td>
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<td>.14</td>
<td>-.05</td>
<td>-.28</td>
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</tr>
<tr>
<td>Religious/Spiritual Faith</td>
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<td>-.23</td>
<td>-1.19</td>
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</tr>
</tbody>
</table>

Note. $R^2 = .10$ ($p = .41$) for Step 1; $\Delta R^2 = .29$ ($p = .05$) for Step 2.

*p < .05.
Lesbian middle-aged women. Predicting hospice beliefs and attitudes, the first block did not account for a significant amount of variance in Hospice Beliefs and Attitudes total, $R^2 = .21$, $F(3, 31) = 2.73, p = .06$. Table 6 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith significantly predicted Hospice Beliefs and Attitudes total scores, $\Delta R^2 = .28$, $\Delta F (4, 27) = 3.87, p = .01$. Examining the factors separately, only distrust, ($\beta = -.36, p = .03$), significantly contributed to the proportion of variance accounted for by the model, demonstrating the importance of level of distrust in the health care system as a potential barrier to hospice services for this group.

For beliefs about pain management, the first block did not significantly predict Beliefs about Pain Management total scores, $R^2 = .02$, $F(3, 31) = 0.16, p = .92$. Table 7 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith significantly predicted Beliefs about Pain Management total scores, $\Delta R^2 = .54$, $\Delta F (4, 27) = 8.20, p < .01$. Examining the factors separately, distrust ($\beta = -.51, p < .01$) and religious/spiritual faith ($\beta = -.34, p = .02$) significantly contributed to the proportion of variance accounted for by the model, demonstrating the importance of these variables in this group’s comfort discussing pain management.
<table>
<thead>
<tr>
<th>Step 1</th>
<th>Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>$SE$</td>
<td>$b$</td>
<td>$\beta$</td>
</tr>
<tr>
<td></td>
<td>Type of Survey</td>
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<td>.30</td>
<td>-.03</td>
<td>-.18</td>
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<tr>
<td></td>
<td>Living Will</td>
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<td>POA</td>
<td>.37</td>
<td>.30</td>
<td>.34</td>
<td>1.20</td>
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<td>Step 2</td>
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<td></td>
</tr>
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<td>Type of Survey</td>
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<td>.07</td>
<td>.44</td>
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<td>-.01</td>
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<td>.27</td>
<td>1.68</td>
</tr>
<tr>
<td></td>
<td>Health Care System Distrust</td>
<td>-.31</td>
<td>.13</td>
<td>-.36</td>
<td>-2.37*</td>
</tr>
<tr>
<td></td>
<td>Complimentary &amp; Alternative Med</td>
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<td>.13</td>
<td>.10</td>
<td>.66</td>
</tr>
<tr>
<td></td>
<td>Religious/Spiritual Faith</td>
<td>.01</td>
<td>.05</td>
<td>.04</td>
<td>.27</td>
</tr>
</tbody>
</table>

*Note. $R^2 = .21$ ($p = .06$) for Step 1; $\Delta R^2 = .28$ ($p < .05$) for Step 2. 

*p < .05.
### Table 7

*Summary of Middle-Aged Lesbian Women Sequential Regression Analysis for Variables Predicting Beliefs about Pain Management Total*

<table>
<thead>
<tr>
<th>Step 1 Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
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<tbody>
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<tr>
<td>Living Will</td>
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<td>.39</td>
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<tr>
<td>POA</td>
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<td>.39</td>
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</table>

<table>
<thead>
<tr>
<th>Step 2 Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
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</tr>
<tr>
<td>Type of Survey</td>
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<td>.31</td>
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<tr>
<td>Living Will</td>
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<td>.29</td>
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<tr>
<td>POA</td>
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</tr>
<tr>
<td>Willingness to Seek Help</td>
<td>.47</td>
<td>.24</td>
</tr>
<tr>
<td>Health Care System Distrust</td>
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<td>.14</td>
</tr>
<tr>
<td>Complimentary &amp; Alternative Med</td>
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<td>.14</td>
</tr>
<tr>
<td>Religious/Spiritual Faith</td>
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<td>.05</td>
</tr>
</tbody>
</table>

*Note. $R^2 = .02$ ($p = .92$) for Step 1; $\Delta R^2 = .54$ ($p < .05$) for Step 2.*

*p < .05.
Heterosexual middle-aged women. Predicting hospice beliefs and attitudes, the first block did not account for a significant amount a variance in Hospice Beliefs and Attitudes total, $R^2 = .02, F(2, 46) = 0.51, p = .61$. Table 8 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith significantly predicted Hospice Beliefs and Attitudes total scores, $\Delta R^2 = .20, \Delta F (4, 42) = 2.69, p = .04$. Examining the factors separately, only distrust, ($\beta = -.54, p < .01$), significantly contributed to the proportion of variance accounted for by the model, demonstrating the importance of level of distrust in the health care system as a potential barrier to hospice services for this group.

For beliefs about pain management, the first block did not significantly predict Beliefs about Pain Management total scores, $R^2 = .03, F(2, 46) = 0.65, p = .53$. Table 9 provides the regression coefficients. Together in the second block of the analysis, results revealed that willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith significantly predicted Beliefs about Pain Management total scores, $\Delta R^2 = .26, \Delta F (4, 42) = 3.87, p < .01$. Examining the factors separately, only distrust, ($\beta = -.39, p = .02$), significantly contributed to the proportion of variance accounted for by the model, demonstrating the importance of level of distrust in the health care system as a potential barrier to discussing pain management for this group.
Table 8

Summary of Middle-Aged Heterosexual Women Sequential Regression Analysis for Variables Predicting Hospice Beliefs and Attitudes Total

<table>
<thead>
<tr>
<th>Variables</th>
<th>Step 1</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
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<tr>
<td>Living Will</td>
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<td>.28</td>
</tr>
<tr>
<td>POA</td>
<td></td>
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<td>.29</td>
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<table>
<thead>
<tr>
<th>Variables</th>
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<th>Standardized Coefficients</th>
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<tr>
<td>Religious/Spiritual Faith</td>
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<td>.05</td>
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</table>

Note. Type of survey was omitted because all participants completed the survey on-line.

Note. $R^2 = .02$ ($p = .61$) for Step 1; $\Delta R^2 = .20$ ($p < .05$) for Step 2.

*p < .05.
Table 9

**Summary of Middle-Aged Heterosexual Women Sequential Regression Analysis for Variables Predicting Beliefs about Pain Management Total**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
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</thead>
<tbody>
<tr>
<td></td>
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<td><strong>Step 2</strong></td>
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<td></td>
</tr>
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<td>Complimentary &amp; Alternative Med</td>
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<td>.17</td>
</tr>
<tr>
<td>Religious/Spiritual Faith</td>
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<td>.06</td>
</tr>
</tbody>
</table>

*Note.* Type of survey was omitted because all participants completed the survey on-line.

*Note.* \( R^2 = .03 \) (\( p = .53 \)) for Step 1; \( \Delta R^2 = .26 \) (\( p < .05 \)) for Step 2.

*\( p < .05 \).*
Strength of Significant Predictors Relative to the Other Groups. It was also hypothesized that the relationship for health care system distrust would be stronger for the lesbian women than for the heterosexual women, indicating it as a stronger barrier to accessing services. To understand the relative strength of the significant relationships between the dependent variables and all common individually significant predictor variables, confidence intervals for the difference between regression coefficients were calculated (Cohen, Cohen, West, Aiken, 2003). Table 10 provides a summary table of the individually significant predictors for each group. Despite some noticeable differences in the regression coefficients for distrust and willingness to seek help by orientation and age group, calculations revealed all confidence intervals overlapping zero, indicating no significantly differences. This suggests that considering level of distrust is equally important in comfort discussing pain medication among all groups. Willingness to seek help is an equally important factor to consider in beliefs about hospice care among older lesbian and heterosexual women. Additionally, considering level of distrust is equally important for beliefs about hospice care and comfort discussing pain medication among middle-aged lesbian and heterosexual women. These findings, therefore, did not support the hypothesis.

Qualitative Analysis

Conventional qualitative content analysis (Hsieh & Shannon, 2005) was used to code and interpret the interview data using NVivo 9 (QSR International, 2010). While the identified hypotheses were limited due to the data-driven approach of this method, several major themes were offered. It was predicted that when discussing their experiences of the traditional health care system, their perceptions of end-of-life health
Table 10

Summary of Individually Significant Predictors from Sequential Regression Analyses

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>Standardized Coefficients $\beta$</th>
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</thead>
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<td>Lesbian Hospice Willingness to Seek Help</td>
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</tr>
<tr>
<td></td>
<td>Complementary &amp; Alternative Med Pain</td>
<td>.46</td>
</tr>
<tr>
<td></td>
<td>Management Health Care System Distrust</td>
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</tr>
<tr>
<td>Heterosexual</td>
<td>Hospice Willingness to Seek Help</td>
<td>.68</td>
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<tr>
<td></td>
<td>Pain Health Care System Distrust</td>
<td>-.43</td>
</tr>
<tr>
<td>Middle-Aged Women</td>
<td>Lesbian Hospice Health Care System Distrust</td>
<td>-.36</td>
</tr>
<tr>
<td></td>
<td>Pain Religious/Spiritual Faith Distrust</td>
<td>-.51</td>
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<tr>
<td></td>
<td>Management Health Care System Distrust</td>
<td>-.34</td>
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<td>Heterosexual</td>
<td>Hospice Health Care System Distrust</td>
<td>-.54</td>
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<tr>
<td></td>
<td>Pain Health Care System Distrust</td>
<td>-.39</td>
</tr>
</tbody>
</table>
care, and any other factors influencing utilizing this type care, qualitative content analysis will reveal major themes of distrust, of concerns about the exclusion of a partner, and of a desire for inclusiveness. The following results showed mixed support for the hypothesized themes and several unexpected themes.

The older lesbian women interviewed in this study (n = 6) identified caregiver burden, level of pain, the diagnosis, and prior experience with end-of-life health care services as several factors important in their willingness to engage with hospice and palliative care services. The women held generally positive views of hospice and palliative services and a willingness to be open with service providers to obtain the quality of services they desired. Crucial to this for many of the participants is the inclusiveness of a partner. Other desires and concerns voiced by these women were more about the competency of care rather than the sensitivity of care. Many of the women were open about their sexuality with their current health provider and had positive experiences within the health care system. They also reflected upon aging as an experience of liberation associated with increased confidence to discuss their needs and upon the increased availability of a large social network with age to find sensitive providers. Finally, messages of inclusiveness were very important to these women in establishing a positive relationship with hospice and palliative care services.

**Willingness to receive services.** Participants identified level of pain, the diagnosis, and caregiver burden as important factors influencing their willingness to receive hospice and palliative care services:

Pain that was unbearable. Unbearable pain. That need, you know, a massive amount of drugs in order to stay comfortable, for one reason. (Sam, age 71)
I mean there are certain diagnoses if I received I would call hospice first. [T]hings like pancreatic cancer, where I know what the prognosis is. I know the alternatives and not probably willing to go through most of those alternatives. So, the diagnosis itself would help me determine. Um, I have a real sense of wanting to spend time with family and friends that if my life comes to an end, not having them have to be my caregivers, actually having the time together. So, as I saw that I was diminishing in capacity, I would, I would seek hospice in order to take the caregiving stress off of them . . . I know [my partner] would be there all the way. But I’d want her to be there, you know, without the caregiving stress, as things got towards, progressively towards the end. (Terri, age 63)

Those who had prior experience with hospice through family, friends, or volunteering also spoke with resolve that hospice and palliative services would be involved during their death:

You know, my, I was talking about my partner’s mother, you know, and we had to put her in hospice and she knew exactly what that meant and she had to, and her’s was such that it couldn’t be cared for at home, and, um, and she lived much longer than anybody expected her to and it was only about three weeks from the time that she went in but her first comment when she got there was, “who would have thought that in the last few days of my life I would have such a lovely place and surrounded by all the people I wanna be surrounded by and this beautiful view and, and the birds singing outside my window.” I mean, that would be the way to go. (Nancy, age 62)

I have dealt with them frequently and I have nothing but the greatest admiration and if I felt I needed hospice or palliative care I would have absolutely no problem seeking it. (Sam, age 71)

Previous experience as an end user with family members is certainly part of that [decision for me]. I have been a hospice volunteer in the past so I know what the program, the philosophy is about and the approaches of that. I would probably look for [a company] that was a little smaller and more intimate . . . I would probably be pretty quick to call hospice relative to most of the population. (Terri, 63)

Though some of the women had no prior personal experience with hospice, all of the women held generally positive views of hospice services and endorsed similar goals for end-of-life care to NHPCO’s *Standards of Practice for Hospice Programs* (2000):
**Views of hospice and palliative care services.** When asked what it would mean to them to receive hospice and palliative services they said:

Um, it would mean that the end was fairly near and there are ways to do that more comfortably. (Brenda, age 66)

My understanding of hospice is providing terminal life assistance and I don’t think that they are called in because people are giving up, they are called in because they are sick and their condition requires . . . it is not hospice that is making the condition terminal, it is the disease that is making it terminal. I believe that hospice is for making the patient as comfortable as possible until that final day. (Martha, age 71)

I see hospice as about living and a quality of life. I do not see it about, as about being about dying. Um, I, so for me it’s more of a quality of life thing. I’ve had the experience with people who think it’s a warehousing system, and that we’ve given up and, you know, I don’t feel that way. I just feel it’s a loving environment full of dignity and respect. And I’ve never met a hospice worker I don’t like. So, um, they’re nice people to have with you on that journey. (Terri, age 63)

This is not to say that the women did not have desires or concerns about the quality of sensitive care and about letting strangers into their lives during such a vulnerable time.

**Desires and Concerns.** A desire for hospice and palliative care to be inclusive and respectful of partners was clearly voiced by all participants. Even those who identified as currently single mentioned it as an added component that lesbian women must consider compared to their heterosexual counterparts.

I mean I do think that it is real important that we be open when we go into a real life and death situation. We make it perfectly clear to the attending physician and the nursing staff that we have a partner. To make sure that she has partnership rights and visitation and decision making. (Martha, age 71)

I do have rules set up and powers of attorney so that [my partner] has my medical power of attorney . . . I would certainly tell whoever, if I had to go into a facility or work with an agency, I would make sure that they were comfortable, you know involving her in my care and the decision-making processes, and if the time comes where I can’t make decisions that they would be comfortable and they would respect my wishes for her to be the primary decision maker or the final
authority and decision maker. So yeah, I mean I would definitely seek out an agency like that. . . it would be a requirement. (Nancy, age 62)

One thing that would be important to me, and I really don’t worry about this with hospice very much anymore, is that my partner and I, as lesbians, would want a supportive environment, an absolute acknowledgment of what our partnership really is and what the level of grief will be as we, you know, say goodbye. (Terri, age 63)

Other concerns were more about the competency of care and letting strangers into their lives during such a vulnerable time:

Not pushing drugs unless, you know, I mean obviously it’s a pain relief but I’m not much of a drug taker and don’t want a bunch of things like that pushed on me . . . Yeah, respect for how I want it to happen. (Brenda, age 66)

I mean I have heard stories of clothes being taken, eyeglasses being taken, jewelry being taken [from someone’s home]. That is not something a terminally ill person should have to deal with. (Martha, age 71)

Jane (age 62) voiced concerns about medications being delivered as the physician prescribed, rooted in on a personal experience of miscommunication between providers in the past. And Nancy (age 62) spoke about the importance of providers maintaining a professional relationship with clients and families. Despite these concerns about end-of-life health care services, most of the women were open about their orientation with their health care providers and spoke about positive experiences.

**Experiences within the health care system.** Five of the six women were open about their orientation with their current primary health provider and all had been open with a provider in the past. Many spoke of positive experiences within the healthcare system with those they had told:

Yes I guess it would be an issue that [my sexual orientation] would be accepted and not looked down upon. It’s not something that comes to mind very often because I’ve just never experienced much of that. (Brenda, 66)
Oh, different [treatment by end-of-life healthcare providers]? I wouldn’t think so. I haven’t had any problems in the past. You know. No, I don’t feel it would be different. I know in our situation, [this specific hospital system] been wonderful. Actually, the people that we deal with, mental health and primary care and all that is great. (Jane, 62)

[The oncologist] was very accepting and she, she made a concerted effort to involve my partner in everything and that partner went with me to all decision meetings, to all appointments, and she went with me to two surgeries and she was the one who was permitted, and I told [the oncologist] she was gonna be the one who’s waiting for me in, you know, when I get outta recovery. And [the oncologist] was great. She, she was perfect. Absolutely wonderful. (Nancy, age 62)

However, it should be noted that when these women were describing positive experiences, they tended to use the pronoun “she” for the physician, suggesting there may be gender differences in disclosure comfort and outcome. The level of openness described by these women and the positive experiences they have had may also be influenced by age.

**Influence of Age.** The participants reflected upon the influence of age in how they interacted with the health care system. They saw aging as an experience of liberation associated with increased confidence to discuss and meet their needs:

I am me first and a lesbian second. You know. And I’m just gonna do what’s in my best interest and greatest good. And everybody else can kind of be damned. [A physician] might have been what I wanted but I’ll find a different one. You know and I’ll keep looking until I can find one who is gonna be as accepting of me and my, my being out and my relationship, and, and be accepting of my partner. (Nancy, age 62)

I’ve been a lesbian since before it was cool to be a lesbian, you know? And I’ve dealt with prejudice all my life. But since I’ve moved here to [city], I’m a retired veterinarian. Since I am not practicing, I do not need to depend on other people’s opinions and so I am more open than I have ever been in my life and it really is quite freeing because it really does free you up to be who you are, totally. (Martha, age 71)
The participants also spoke to the large social networks they had built with age within the LGBT community and within the larger local community to find sensitive providers:

Fortunately, in our area here, we have a very big LGBT organization and, um, and deal with the health care people and a lot of them are in the gay community so I’m in a way fortunate to know that that availability is there for me. (Sam, age 71)

I also have, because of my age, quite a network of friends who have been social workers, hospice workers, um, chaplains, and I would call them. I mean that’s another source I would use. You know, what do you know about? Who would you suggest? Who might I contact in a particular hospice, um, to talk to originally? So that word of mouth communication when you are connected to the LGBT community is another very important aspect. (Terri, age 63)

I’ve lived in this community for 15 years and, and even though we plan to travel, this will continue to be home base. And I know a lot of people who have had occasion to utilize hospice services for family members in the past and I would certainly do what I always do and that is talk to people. (Nancy, age 62)

**Importance of inclusive messages.** These women also spoke about the importance of messages of inclusiveness for services and how certain environmental cues can make them more concerned:

I mean she is so religious that she has religious music playing in her office and waiting room and she has little bible verses that are part of the wallpaper and you know, that’s over the top. And I’ve got nothing against religious people but my, uh, the question in my mind, I thought, “She might, you know, be very judgmental, and, and biased, you know, against lesbian couples. (Nancy, age 62)

Every new doctor I went to asked about a spouse and a lot of the patient questionnaires now say partner and those places I really appreciate. I really do. Even if a hospice/palliative service had that on their form, that would be a great beginning right there. (Martha, age 71)

Any materials that are out there, if I could tell by a same-sex couple picture on the marketing materials, or a pink triangle safe-zone sign, or if their sexual orientation and gender identification is a part of their mission statement, I think those would be good indicators to me. Um, if I saw something that looked heavily, you know like I said, I’m not aware of this having been an issue but if I saw, uh, a lot of
Christian emblems, um, I, I would be wary. There’s just enough tension there that I wouldn’t wanna do that to either party. (Terri, age 63)
Hypotheses

The aims of the present study were to explore similarities and differences of end-of-life health care attitudes among lesbian and heterosexual women and among middle-aged women and older adult women, to understand how healthcare system distrust, willingness to seek help, religiosity/spirituality, and beliefs about alternative medicines are related to one’s beliefs about hospice and palliative care, and to further elucidate quantitative survey data with qualitative data from interviews with lesbian older adults about perceived barriers of using hospice and palliative care.

The results of the ANCOVAs did not support the hypotheses that lesbian women would endorse less favorable beliefs about hospice, less comfort discussing pain management, an overall lower willingness to seek help, greater preference for life-sustaining care, greater distrust in the healthcare system, and more positive views about CAM compared to heterosexual women. No differences were found for sexual orientation on comfort discussing pain management. Although there were differences on hospice beliefs and attitudes, it was not in the predicted direction. Results indicated that lesbian women held more positive beliefs than heterosexual women. And again, although there were differences on preferences for life-sustaining care, it was not in the expected direction. In this study, heterosexual women reported a greater desire for life-sustaining treatments than lesbian women in the event of an incurable disease and severe life-
limiting conditions (e.g., feeding tube, life support, no brain response). No significant differences were found on level of health care system distrust or willingness to seek help. Both groups endorsed average levels of each.

These findings were surprising, particularly for level of health care system distrust given there is considerable literature documenting the experienced discrimination and real fear by lesbian persons in health care (Addis, Davies, Greene, MacBride-Stewart, & Sheperd, 2009; Bergeron & Senn, 2003; Dennenberg, 1992; Mathieson, 2007; Powers, Bowen, & White, 2001; Stevens, 1992; Trippet & Bain, 1992). And, the interaction of age by sexual orientation was not significant, ruling it out as an explanation for the non-significant main effect for sexual orientation. One possible explanation for these findings involves how level of distrust was measured. Here, most of the questions on the measure involved statements of health care competence rather than sensitivity (e.g., If a mistake were made in my health care, the health care system would try to hide it from me; People die every day because of mistakes by the health care system). Competence distrust and sensitivity distrust may be two different constructs in considering how individuals seek out services in this population, even though racial and ethnic minority differences have been found using this scale (Johnson, et al., 2008). The study by Bowen et al. (2002) may lend additional support for this possible explanation; they found that 68% of the 150 community-dwelling sexual minority women they surveyed wanted access to an alternative provider but reported equal and high levels of trust in both traditional and alternative providers.

The results did, however, support the hypothesis about the Holistic Complementary and Alternative Medicine scale. Lesbian women reported more positive
beliefs about the role of alternative medicines in health care compared to heterosexual women. This finding echoes the current literature on sexual orientation differences in complementary and alternative medicine (CAM) use (Buenting, 1992; Mathews, et al., 2005) suggesting the greater importance of incorporating CAM use in health care among the lesbian population.

The hypotheses that older women would endorse more favorable beliefs about hospice, more comfort discussing pain management and lower preference for life-sustaining care compared to middle-aged women had partial support. Results showed that that older women held more positive beliefs about hospice care and reported more comfort discussing pain management than middle-aged women. However, no differences were found by age for preferences for care. This may be because both age groups reported a low desire for maintaining life at any cost.

As stated above, the ANCOVAs revealed no significant age by sexual orientation interactions indicating that the relationships between sexual orientation and these variables do not vary by age. In other words, no cohort effects were found for either sexual orientation. These results, therefore, did not support the hypothesis that because of zeitgeist differences between the identity cohorts of lesbian women, there would be a significant interaction on the Health Care System Distrust scale, such that older lesbian would score significantly higher than older heterosexual women compared to the difference between the middle-aged orientation groups. Again, this result was surprising. This finding may also rule out the possible explanation that previous researchers who found higher levels of health care system distrust (when this study did not), did so with older cohorts of lesbian women who have faced higher levels of discrimination.
The results of the sequential regression analyses for hospice beliefs and pain management for each group (older lesbian women, older heterosexual women, middle-aged lesbian women, and middle-aged heterosexual women) similarly revealed mixed support for the hypotheses. It was predicted that for each of the four groups, hospice beliefs and comfort discussing pain management would be significantly predicted by and negatively correlated with scores on health care system distrust, and strength of religious faith, and CAM, but positively correlated with overall willingness to seek help. The demographic variables placed in the first block of the analyses to control for group differences never significantly accounted for the variance in hospice beliefs and attitudes or comfort discussing pain management. The second block of the analyses for older lesbian women, middle-aged lesbian women, and middle-aged heterosexual women supported the hypothesis that taken together, willingness to seek help, health care system distrust, holistic complementary and alternative medicine beliefs, and strength of religious/spiritual faith would significantly predict hospice scores and pain management scores.

However, for the older heterosexual women, the second block of the analyses did not predict hospice scores or pain management scores. One possible explanation for these findings has to do with the level of power. It is possible, with the unexpected addition of variables, that the sample size was not large enough to reject the null hypotheses. The effect sizes were very large for those expected in the social sciences ($\Delta R^2 = .29$ for both), and the probability levels ($p = .07; p = .05$) were very close to the criteria for rejecting the null hypothesis, lending support to the explanation of a probable Type II error (i.e., false negative). Another possible explanation is that there is another important variable in
explaining hospice and pain management beliefs among this population that this study failed to capture.

The hypothesized level of importance of each variable in contributing to the proportion of variance accounted for by the overall model and the hypothesized direction of the correlations were also not supported by the results. At most, two of the variables were significant individual predictors of the dependent variables and while the relationship was in the predicted direction for some, it was the opposite for others. Health care system distrust was a significant individual predictor in many of the regressions and was, as predicted, always negatively related to hospice and pain management beliefs and attitudes. In this study, lower distrust in the health care system was related to more comfort discussing pain management among all groups and lower distrust in the health care system was related to more positive hospice beliefs among middle-aged lesbian and heterosexual women. As predicted, higher levels of willingness to seek help were related to more positive hospice beliefs among older lesbian and heterosexual women. Additionally, as predicted, lower levels of religious/spiritual faith were significantly related to more comfort discussing pain management, a result congruent with the literature (Francoeur et al., 2006), but only among middle-aged lesbian women. Religious/spiritual faith was not significantly related to comfort discussing pain management in any other group. In the opposite direction than was predicted, more positive beliefs in CAM were related to more positive hospice beliefs among lesbian older women. Consequently, although some predictors were similar across groups, others were more specific to one group, highlighting a differential relationship for that group.
The result that lower religious/spiritual faith was significantly related to increased comfort discussing pain management among lesbian middle-aged women but not any other group was surprising and is difficult to explain. The literature suggests that among some Christian faiths, patients may believe that pain should be endured and pain medications avoided because they believe that patiently accepting God’s will, including suffering, is desirable or pleasing to God (Francoeur et al., 2006). However, the lesbian middle-aged group did not report a higher Christian religious preference compared to the other groups. Additionally, lesbian women in both groups reported a lower overall level of religious/spiritual faith than the heterosexual women. The overall range and distribution of religious/spiritual scores were not different for the lesbian middle-aged women compared to the other groups, with no outliers skewing these similarities. Another possible explanation comes from examining the sequential regression analysis for heterosexual middle-aged women. Religious/spiritual faith predicted comfort discussing pain management at the $p = .07$ alpha level ($\beta = -.34$). Perhaps this was a Type II error and age is moderating this differential relationship. The finding could also be a Type I error (i.e., false positive); with the number of statistical testes conducted it is possible to obtain an incorrect rejection of the null hypothesis.

The positive relationship between CAM beliefs and hospice beliefs and attitudes among lesbian older women was also unexpected and very interesting. Perhaps rather than viewing hospice and palliative care services as part of the traditional medical system, the older lesbian women viewed its emphasis on comfort over cure as more similar to CAM. In this case, hospice and palliative care services might be considered, like CAM, more counter-culture and therefore, a more respectful, sensitive service.
Furthermore, this possible explanation seems to be supported by some information from
the interviews with older lesbian women.

It was also predicted that the relationship between the dependent variables and
health care system distrust would be stronger for the lesbian women than for the
heterosexual women (as evidenced by significantly larger correlation coefficients),
indicating it as a stronger barrier to accessing services. This hypothesis was not
supported; the strength of the relationship was not significantly different suggesting that
distrust in the healthcare system can be an equally important barrier for both sexual
orientations in positive beliefs about hospice and comfort discussing pain management.
In fact, the amount of variance accounted for by the other common significant predictor
variable of willingness to seek help was not significantly different either. Consequently,
while the common individually significant predicting factors are important to consider,
they appear to be no more important in acting as a potential barrier in one population than
the other.

The qualitative interviews with lesbian older women revealed several major
themes when discussing their experiences of the traditional health care system, their
perceptions of end-of-life health care, and any other factors influencing utilizing this type
of care. Participants identified several important factors for their willingness to initially
engage with hospice and palliative care services. Additionally, once the decision was
made to involve these services, the women had clear desires and concerns for the type of
hospice and palliative care provider agency utilized. Age emerged as a contributing factor
to increased confidence to discuss their needs and as a contributing factor to a larger
social network to find sensitive providers. Finally, messages of inclusiveness were very
important to these women in establishing a positive relationship with hospice and palliative care services.

Participants identified caregiver burden, level of pain, the diagnosis, and prior experience with end-of-life health care services as several factors important in their willingness to engage with hospice and palliative care services. Many of the women voiced concerns about becoming a burden upon family members and a desire for loved ones to be *with* them rather than *caring for* them during the dying process. This included family-of-origin, friends, partners, and even adult children. If direct care needs became too great, they would enlist professional help. Interviewees acknowledged that the intensity of pain would necessitate a hospice referral to help manage the dying process more comfortably. Others spoke about known diagnoses where treatment options are limited and/or terribly invasive and how they would forgo such treatment in favor of living and dying comfortably. Those who had prior experience with hospice and palliative care services also spoke very highly of the care and were quicker in our conversation to discuss how they would incorporate hospice and palliative services into their end-of-life care. Overall, however, all of these older lesbian women held generally positive views of hospice services and endorsed similar goals for end-of-life care to NHPCO’s (2000) *Standards of Practice for Hospice Programs* (i.e., comfort rather than cure; quality to end-of-life rather than hastening of death).

In the event that the above conditions were met, the women had clear desires and concerns for the type of hospice and palliative care provider agency they would involve. Many of the women in this sample were open about their sexuality and had positive experiences with their primary physician. As such, there was a clear desire for hospice
and palliative care providers to be equally sensitive. This meant a desire for hospice and palliative care to be inclusive and respectful of partners. Even those who identified as currently single mentioned it as an added component that lesbian women must consider when seeking services compared to their heterosexual counterparts. Analogous to other research, these findings highlight the greater concern of partnership inclusion in the LGBT community (Dean et al., 2000; de Vries, Mason, Quam, & Acquavia, 2009; Hughes, 2007). Other concerns were more about the competency of care and letting strangers into their lives during such a vulnerable time: respect for their care wishes, personnel stealing from their home, personnel lacking professional boundaries, and prescription miscommunication. Overall, however, these women believed in end-of-life services and if needed, they would find an agency that was competent and sensitive to their sexuality. As Brenda put it, “And if they don’t want me there under those circumstances I don’t wanna be there.”

Furthermore, instead of remaining hidden out of continued fear of discrimination, old age seemed to empower these women to advocate for their needs. Again, feeling entitled to the same services as everyone else, they would seek out what they needed (e.g., hospice care) and then find an agency that was sensitive to their needs. And the large social networks these women had built over their lives would help them to accomplish it. As Terri put it, “I’m not looking for an all LGBT organization but I would be looking for signs that they truly walked the walk . . . not just stating [LGBT competence] but living it.”

The participants also spoke about the importance of messages of inclusiveness in establishing a positive relationship with any health care provider. Those providers who
included “partner” or “partnered” on their intake form, rather than only “spouse” or “married,” and those who had a same-sex couple picture on the marketing materials or a pink triangle safe-zone sign or sexual orientation and gender identification as part of their mission statement felt more welcoming. In contrast, those agencies with a heavy emphasis on Christian values made these women feel more on guard and may be a reason for some individuals to walk away immediately. The importance of health care inclusiveness beginning in the waiting room has been documented by other researchers as well (Johnson, Mimiagab, & Bradford, 2008; Seaver, Freund, Wright, Tjia, & Frayne, 2008).

Finally, in conversations with these women it seemed that they considered hospice and palliative care providers to be different than other traditional health care providers. There seemed to be a perception that hospice and palliative care providers were better trained in sensitivity or inertly more compassionate, perhaps given the nature of the profession. Or it may be more closely tied to the AIDS epidemic. One woman interviewed mentioned that her first experience with hospice was volunteering at the beginning of the AIDS epidemic because “nobody wanted to touch those folks.” Given the higher levels of HIV among the homosexual community, perhaps they began to see hospice as a place where our folks could be treated with dignity and respect. This may lend further support to the possible explanation for why there was a significant positive relationship between CAM beliefs and hospice beliefs and attitudes among lesbian older women. Perhaps rather than viewing hospice and palliative care services as part of the traditional medical system, the older lesbian women in this study viewed its emphasis on comfort over cure as more similar to CAM.
Taken together, the findings of this study suggest that there may be differing levels of distrust of the health care system among lesbian women, which may also vary by system (e.g., oncology, gynecology, primary care). In this study, lesbian women did not endorse a different level of distrust than heterosexual women but other empirical research studies have found higher levels of discrimination, fear, and distrust. Lesbian women were also as willing to seek professional help as heterosexual women. Any fear or distrust for interacting with the larger health care system among these women did not seem to translate into strong distrust or fear about hospice and palliative care services. In fact, lesbian women held more positive beliefs about hospice and palliative care services than heterosexual women, a finding that may be related to a perception that hospice is more counter-culture health care with its emphasis on comfort over cure, and therefore more sensitive. However, health care system distrust was significantly related to comfort discussing pain management among all populations and was significantly related to hospice beliefs among all middle-aged women, suggesting the potential for this to be a strong barrier to end-of-life health care services. Age emerged as an important factor in understanding beliefs about hospice, pain management, and preferences for life-sustaining treatments. It was also important for the older lesbian interviewees as old age seemed to empower these women to advocate for their desire for competent and sensitive care. And, the large social networks these women had built over their lives would help them to accomplish it. Recognition of partnerships and messages of inclusiveness were important to these women in a hospice and palliative care service provider.
Strengths, Limitations, and Directions for Future Research

The present study had several strengths. Most notably, it was the first to specifically examine hospice and palliative care beliefs among lesbian women. This study can serve as a foundation for further inquiry into this important area. Another strength of the present study was that it employed mixed methods to understand concerns and possible barriers to utilizing hospice and palliative care services rather than relying on quantitative or qualitative methods alone. Use of the anonymous, on-line survey also allowed for statewide recruitment of lesbian women and likely captured individuals who may not otherwise participate in on-campus research. Finally, unlike many studies of lesbian women, this study successfully recruited women of a large age range (35 to 81 years old) to better understand how age may interact with sexual orientation in producing hospice and palliative care beliefs.

Despite these strengths, several limitations are also evident. The participants in the present study were all relatively high functioning, White adults who lived in an urban area. Given that lower levels of formal education and health literacy are related to lower rates of health care utilization, lower rates of completion of some form of advance directive, higher rates of hospitalization, and higher use of expensive emergency services (Berkman et al., 2004; Hopp, 2000), the attitudes and beliefs endorsed by individuals in this study may not be representative of individuals with lower levels of education. The applicability of these findings to ethnic and racially diverse individuals may also be limited. The sparse literature on lesbians of color suggests that they face additional levels of discrimination and exclusion from the health care system, a victim of triple jeopardy—female, lesbian, and racial minority (Graziano, 2004; Stevens, 1998; Wilson &
Yoshikawa, 2007). Future research efforts may attempt to compare sexual *and* racial minorities with sexual minorities to assess any level of added distrust and concerns about end-of-life health care.

The present study also limited itself to exploring possible similarities and differences among lesbian and heterosexual women on beliefs and attitudes about hospice and palliative care. However, lesbian women are not the only sexual minority group and future research should assess how other sexual minorities (e.g., Gay, Bisexual, Transgender) compare to lesbian and heterosexual women on beliefs and attitudes about hospice and palliative care and potential barriers to utilization. As end-of-life care professionals strive to be culturally competent in their practices, empirically based information on how all sexually diverse individuals approach health care during the dying process needs to be available.

It is also important to note that this was a non-random study conducted in a limited area of the USA. Sampling bias may be a strong limitation to the current study. LGBT people are diverse in terms of cultural background, ethnic or racial identity, age, education, income, and place of residence. The degree to which sexual orientation or gender identity is central to one's self-definition, the level of affiliation with other LGBT people, and the rejection or acceptance of societal stereotypes and prejudice also vary greatly among individuals. For this study, lesbian participants were recruited through Colorado PRIDE centers and these women may hold different values and beliefs about the health care system than those who are more isolated or less connected to the LGBT community. Their responses may not represent those who would be uncomfortable disclosing their sexual orientation in any setting, even an anonymous on-line survey.
Additionally, an even smaller sample of those lesbian women participated in the interview and therefore may not represent the voices of all of the women who completed the survey. Replications with larger, more diverse samples would increase the ecological validity of the findings.

A distinction should also be made regarding hospice and palliative care beliefs and hospice and palliative care utilization. The current study examined beliefs and attitudes in the hope of making some inferences about potential utilization. However, none of the women in the study were assessed for current utilization or current diagnosis of a life-limiting illness. It is very likely that most of the women were answering questions about future behavior in a given situation and may act differently when death becomes an acute reality and/or their life circumstances are different.

Inadequate statistical power may also have been a limitation of the current study; specifically, there may have been inadequate power for the number of variables included in the regression analyses. The effect sizes obtained for the second block of the analyses were very large for those typically seen among the social sciences, suggesting meaningful differences, but the sample size was not large enough to reject the null hypothesis for the older heterosexual women group. This further highlights the importance of following the guidelines for power given by Cohen (1992).

The mixed and often surprising results of this study suggest further inquiry in several areas. Further exploration of the non-significant differences for sexual orientation on health care system distrust seems warranted given the seeming contradiction to the literature; in particular, researchers should conduct a similar study separating the constructs of distrust in competence and distrust in sensitivity. It may be that these are
highly correlated but distinct concepts for the lesbian population. A study could also be
designed to examine the possible explanation of an unknown variable unique to the
lesbian middle-aged women moderating the relationship between religious/spiritual faith
and comfort discussing pain management. Additionally, the positive relationship between
CAM beliefs and hospice beliefs and attitudes among lesbian older women was also
unexpected and very interesting; future research may test the hypothesis that this resulted
because older lesbian women view hospice and palliative care’s emphasis on comfort
over cure as more similar to CAM. In this case, hospice and palliative care services might
be considered, like CAM, more counter-culture and therefore, a more respectful, sensitive
service. This may also account for the more positive beliefs in hospice and more comfort
discussing pain management found among lesbian women. Furthermore, it would
behoove researchers to explore the influence of age on how lesbian woman advocate for
their health care needs. Based on this small qualitative sample of older lesbian women,
age brought with it boldness to obtaining sensitive health care. Validating this finding
with a larger sample and teasing apart all of the factors that are associated with this
boldness could elucidate valuable information.

Another possible future study could involve taking this study a step further from
understanding differences between sexual orientations to developing a cultural model to
better understand the unique intragroup differences for lesbian women. As stated above,
the degree to which sexual orientation or gender identity is central to one's self-definition,
the level of affiliation with other LGBT people, and the rejection or acceptance of
societal stereotypes and prejudice vary greatly among individuals. Specific subgroups
may exist within the lesbian population (e.g., “butch” and “femme”) which differ in their
attitudes, beliefs, and approaches to end-of-life care. A mixed method approach could also be applied. And, this study only scratched the surface of what is possible with qualitative research. Ethnographic studies, for example, have been applied to understanding homosexuality in the past (Weston, 1993) and could yield more comprehensive information about lesbian within-group differences as it relates to end-of-life care. Gathering this information on intragroup differences would be an important step in filling the current gap in the literature.
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