AN EXPLORATORY STUDY OF THE ATTITUDES AND BELIEFS OF OLDER AFRICAN AMERICANS CONCERNING END-OF-LIFE PLANNING: A DEVELOPMENTAL PERSPECTIVE

A Dissertation

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the College of Social Work of The Ohio State University

By

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ABSTRACT

This descriptive and exploratory study, guided by a developmental framework, examined how the lived experiences of older African Americans, over the life course, informed their attitudes and beliefs concerning end-of-life planning. A focus group was used to pilot the study. Tape-recorded semi-structured face-to-face interviews were conducted with seven respondents using an open-ended questionnaire. Content analysis was accomplished utilizing grounded theory as an analytic framework. Following this analysis, six core categories emerged: (1) the experience of growing older; (2) coming to know death; (3) making sense of death and loss; (4) cognitive dissonance; (5) measured trust; and (6) race as a constant companion. The findings revealed that respondents had a positive attitude concerning the utility of advance directives, but a reluctance and ambivalence concerning executing them. Family centered decision-making and input were valued in end-of-life care and planning. These older individuals tended to look to their adult children to serve in the role of surrogate decision makers in the event of future decisional incapacity. There was a rejection of heroic medical care or technology in the face of futility. The respondents saw no nobility in pain and suffering and fervently desired effective comfort care in the event of terminal illness. Independence and productivity were most valued. Spirituality was at the core of how these older persons made meaning of death and how they found meaning and purpose in life.
DEDICATION

In loving memory of my late father, Edward Bradley, and late grandparents, Jossie Foster, Frank Foster, and Freddie Ashley, who valued education and taught me the morals and values that I now cling to.

and

In honor of my loving parents and siblings, Annie and Mathews Webster, Annie Pender, and Florence Jones whose love, devotion, and encouragement I cherish.

***********

To those brave men and women who paved the way and cleared the path before me so that I could experience this day, I extend my humble gratitude.
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Making end-of-life decisions is seldom an easy task. Furthermore, a difference in the cultural backgrounds of the medical provider and patient has the potential to result in increased difficulty in communicating about such decisions (Blackhall, Murphy, Michel, & Azen, 1999). Consequently, understanding how culture fundamentally shapes individuals’ meaning of illness, suffering, and dying (Kagawa-Singer & Blackhall, 2001) is key to developing effective cross-cultural end-of-life interventions and programs.

Culture, in this context, refers to the body of customary beliefs, social norms and material traits that constitute a distinct and complex tradition of a racial, religious, or social group who share a perspective about family and how life should be approached (Braun, Pietsch, & Blanchette, 2000). Culture is identified as an explanation for certain observed differences across racial and ethnic groups regarding knowledge, attitudes, and completion of advance directives (Klessig, 1992; Waters, 2000).

Though little is known about the knowledge, attitudes, and behaviors of ethnic and racial subgroups regarding end-of-life treatment issues (Caralis, Wright, & Marcial, 1993), it is understood that many factors influence individuals’ responses and decisions concerning care and treatment at the end-of-life. Cultural and ethnic values are integral factors that impact such preferences (Eleazer et al., 1999). Consequently, it is important
to understand the cultural, ethnic, religious and individual factors that influence end-of-life treatment preferences. Increased understanding concerning these factors will assist health care providers in gaining insight into this critical subject and promote recognition of their biases as well as the likely biases of their patients. As Secundy (1992) cogently states, “…It is precisely the cannons of “good medicine” that makes the effort to learn about the cultural milieu of our patients morally mandatory” (p. xix).

Given that the majority of both physicians and patients in the United States are White, the cultural perspective that the doctor brings to the clinical interaction may not be the most relevant to non-White patients, thus inhibiting physician-patient trust (Mebane, Oman, Kroonen, & Goldstein, 1999). Estimates suggest that by the year 2050, more than half of the United States population will be people of color from varying cultural backgrounds (Kadushin & Egan, 1997). Consequently, the full spectrum of treatment preferences must be considered in the development of guidelines and public policy relating to end-of-life treatment in a diverse society. “A one size fits all approach to medical decision-making is likely to fit relatively few” (Blackhall, Murphy, Frank, Michel, & Azen, 1999, p. 1788). In addition, the moral mandate (Secundy, 1992) to understand the patient’s cultural milieu extends beyond physicians. Developing such competence must be considered a multidisciplinary focus, in that advance care planning takes place across disciplines and in multiple settings.

Furthermore, advanced medical technology and the resultant ability to extend life raise ethical issues concerning quality of life and resource allocation (Mebane, Oman, Kroonen, & Goldstein, 1999). A better and more comprehensive understanding of ethnic
and cultural differences in end-of-life treatment preferences will necessarily promote more useful, equitable, and effective public policy that informs and facilitates ethical decision-making.

Statement of the Problem

In an ethnically diverse society, void of a shared religious or cultural tradition to inform health care guidelines (Mebane et al., 1999), the problem of how to make decisions regarding the allocation of resources and the use of life-sustaining technologies is particularly difficult. Thus, it is important that the multiple and complex factors that account for ethnic and cultural variations in end-of-life treatment preferences be identified and understood by medical providers and allied health professionals, in the interest of effectively treating and assisting patients and families in end-of-life treatment decision-making.

This is particularly germane with respect to the steadily growing older population, which promises to substantially impact limited medical and economic resources. For example, demographic projections suggest that by the year 2050 the African American population will increase from 12 percent to 16 percent (U. S. Bureau of the Census, 2001). In addition there is a high incidence of poverty among older African Americans. For example, in 2002, the poverty rate for older African Americans was almost three times that of older Whites (U. S. Bureau of the Census, 2002). According to the U. S. Bureau of the Census data, 8.3 percent of elderly Whites were at the poverty level in 2002, compared to a poverty rate of 23.8 percent for older African Americans, and 21.4 percent for older Hispanics. Moreover, higher than average poverty rates were reported for older
individuals residing in central cities. Related to their low-income status is the fact that African American patients make up a disproportionate number of medical expenditures, and their care is often sporadic and fragmented (Mouton, Johnson, & Cole, 1995). The poor economic circumstances common to a significant number of older African American persons, coupled with their tendency toward a desire for significant life sustaining medical care, and a failure to complete advance directives, poses serious economic and ethical dilemmas for health care providers and public policy makers.

**Significance of Problem to Social Work Practice**

The research problem has significant implications for social work practice and the quality and extent of the knowledge base in the quest to provide assistance, counseling, and guidance to older individuals from across a diverse spectrum. Increasingly, social workers must respond to bioethical practice issues involving the completion and implementation of advance directives, and related issues of rationing limited health care resources. In addition, social workers function as integral members of interdisciplinary health care treatment teams and ethics committees. Yet, insufficient education, training and knowledge are frequently cited and major barriers to improving end-of-life care in America (Christ & Sormanti, 1999, Kramer, Pacourek, & Hovland-Scafe, 2003).

Social workers, like other helping professionals, such as nurses and physicians, acknowledge their lack of training and knowledge deficits in practice issues that relate to death and dying (Csikai, 2004; Foster, Sharp, Scesny, McLellan, and Cotman, 1993). Moreover, according to Lennon (1992), the health care concentration comprises the third largest group of students in graduate social work programs. Yet, so significant and
prevalent is the knowledge deficit problem, that items relevant to educational resources and the preparation of social workers in end-of-life care emerged as one of the top 10 priorities from among 232 options generated by experts in the field (Kramer, 2003).

Of further significance is the fact that social work is the predominant discipline in providing supportive counseling and addressing psychosocial issues in end-of-life care (Coluzzi, 1995; Reese & Brown, 1997). For example, the Department of Veterans Affairs (1997), the nation’s largest governmental health care system, Office of Inspector General (OIG), notes that social workers are “clearly leaders” in counseling patients regarding advance directives in that system. Yet Kramer (2003) found, in her content analysis of social work textbooks, that a major deficit or limitation was the placing of emphasis on completion of advance directives with minimal attention to involvement and interaction with family members as part of the process. The need for improved education and training of social workers in end-of-life care is well established, and research that lends to the knowledge based is clearly needed.

Purpose

This study provided a unique perspective since research utilizing a developmental focus to examine the attitudes and beliefs of the elderly concerning advance directives or end-of-life planning is limited (Neimeyer, 1995). Such research generally focuses on the stage theory of aging to examine this subject. This perspective suggests that the test of late life is to develop a sense of integrity and an appreciation of how and why one has lived (Reker & Wong, 1987). Similarly, extant research lacks an integrative perspective or model that seeks to explain and shed light on the end-of-life treatment preferences of
ethnic groups. Furthermore, a preponderance of existing research is focused on a bioethics frame of reference (Miles, Koepp, & Weber, 1996). Moreover, much of the existing qualitative and quantitative research examining the attitudes and beliefs of older individuals regarding advance care planning lacks a readily identifiable conceptual or theoretical framework. Significantly, there is a failure to explore these constructs by integrating the idea of death into the personal histories of the respondents, recognizing that the individual’s understanding of death evolves over the life course (Despelder & Strickland, 1999). Research is required that clarifies and improves the knowledge of health care providers regarding the demographic, socioeconomic, psychosocial, and medical factors that influence decisions regarding end-of-life care for elderly African Americans and other minorities (Crawley et al., 2000).

The purpose of this phenomenological study was to expand the existing knowledge base by exploring the lived experiences of older African American respondents over the life course, and to provide added insight and understanding in reference to how these experiences direct and inform their attitudes, beliefs, and behavior concerning end-of-life treatment preferences and planning. The conceptual framework for the study was that of an ecological systems model from a life course perspective (Bronfenbrenner, 1995; Bronfenbrenner & Morris; 1998; Bronfenbrenner, 2000). This approach is unique in that it explores how attitudes about death and dying, and ultimately end-of-life treatment preferences, develop over the life course, coupled with the impact and interplay of historical influences across generations and within individuals’ lives. It was envisioned that a qualitative methodology would capture data not easily ascertained
using quantitative techniques, and would clarify apparent paradox and contradictions identified in prior research.

**Research Question**

How do the lived experiences of older African Americans, over the life course, inform their attitudes and beliefs concerning end-of-life planning?

**Personal Rationale**

My interest in this area of study is, in part, a result of many years of experience as a social worker in the health care field. In that role, I have had the opportunity to observe, educate, and assist patients in the completion of advance directives and advance care planning over a span of years. While functioning in this role, I observed that while patients consistently verbalized a strong belief in the concept of written advance directives, very seldom did they actually complete such documents. Puzzling was the noticeable paradox and contradiction between their stated beliefs and attitudes towards advance directives and their resolute stance in deferring to family or physicians in making end-of-life decisions in the event of decisional incapacity. Emphatically and convincingly, their often-heard response echoed in my hearing: “I don’t want to be a burden on my family, and I’d never want to be a vegetable.” Most often, I attributed my observations, this seeming contradiction, to death anxiety and the fear of dying, offering a simplistic rationale for a complex phenomenon. As I reflected, I yearned to know more
about how these individuals made meaning of advance directives and advance care planning. Hidden in their stories, I thought, were the answers to what was often labeled “contradiction” and “paradox.”

Secondly, I entered the study occupying multiple positions and voices, that of an African American female, a social worker, a researcher, and an advocate for equity and access in the area of health care policy for the elderly, minorities, and those of limited economic means. The growing body of knowledge that identified health care disparities and access as a growing concern and problem for African Americans on many fronts further fueled my concerns and interests.

Finally, ideologically, going into the study, I did not view the completion of advance directives as inherently “good” or “bad.” The jury was still out so to speak. Furthermore, while I believed firmly in the principle and value of autonomy and self-determination, I believed that the meaning of the concept should not be limited to a Western view, given the diverse citizenry of this society. Furthermore, I believed strongly in the value of a family centered approach to end-of-life planning, and thus I felt that while planning for one’s death is perhaps personal, I related to the communal nature of death and the dying process as it occurs in the African American community.

Key Terms

It is significant to note that the terms advance directives and advance care planning are frequently used interchangeably in the literature, often resulting in a lack of understanding and clarity of the two concepts. In this study, the term advance directive refers to “a written instruction, such as a living will or durable power of attorney for
health care, recognized under State law and relating to the provision of such care when
the individual is incapacitated” (Osman & Perlin, 1994, p. 246). In general, there are two
forms of advance directives: (1) living will, an instructional directive “that provides self-
initiated written instructions on life sustaining treatments that the person desires under
certain types of clinical situations” (Galambos, 1998, p. 276). The “clinical situations”
typically refer to a persistent vegetative state or a terminal medical condition; and (2)
durable power of attorney for health care “designates a surrogate who can make
decisions pertaining to medical treatment when the patient lacks decision-making
capacity” (Osman & Perlin, 1994, p. 247).

Pearlman (2001) suggests that the lack of clarity concerning the differences
between advance directives and advance care planning is one of a multitude of factors
that create an obstacle to successful advance care planning. Pearlman defines advance
care planning as a process designed to facilitate or enhance decision-making for the
patient who lacks decision-making capacity. This three-stage process includes: (1)
thinking of relevant values and preferences; (2) communicating the values and
preferences to family and health care providers that would be involved in future medical
decisions, and (3) documenting the values and preferences in an advance directives
document.

The extant literature uses the term end-of-life in reference to issues relating to the
subject of planning that involves making one’s medical treatment preferences known or
caring for individuals as they approach death. The term, end-of-life, as it relates
to advance care planning and as used in the discussion that follows refers to, “that time when death—whether due to terminal illness, acute or chronic illness, or age itself—is expected within weeks or months and can no longer be reasonably forestalled by medical intervention” (Rabow & Brody, 1999, p. 99).

The Patient Self-Determination Act (PSDA) is the legislative mandate that was enacted by the United States Congress in 1990. Implemented in 1991, it requires Medicaid and Medicare-funded health care organizations to provide written information concerning treatment options upon the individual’s enrollment in the health care facility (Galambos, 1998).

Finally, in this study, life-sustaining treatment is defined as any treatment that delays death, including cardiopulmonary resuscitation (CPR), dialysis, ventilator support, and supplemental nutrition and hydration (Despelder & Strickland, 1999).
CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

This chapter provides an overview of certain literature that has contributed to the existing knowledge base in the area of advance care planning. The review highlights, identifies, and emphasizes the very complex and multidimensional nature of end-of-life care and planning and the many factors and variables that require increased understanding in order to better shape and positively impact practice, public policy, and theory in the area of end-of-life planning. A review of advance directives completion rates and obstacles thereto is followed by a review of the significant issues that impact and inform the attitudes and beliefs of African Americans concerning advance care planning and the execution of advance directives. These include history and heritage, religion and spirituality, bioethical issues, social issues, and education (Crawley, et al., 2000). The chapter concludes with an overview of the theoretical framework that guided the study.

Advance Directives Completion Rates

As medical technology continues to advance and the range of health care choices become more complex, the preservation and fostering of end-of-life autonomy becomes an increasingly critical issue for the aged, health care providers, and society in general.
The many ethical dilemmas that are outgrowths of technology’s prolongation of life are ever present. There is an ongoing and emotionally charged debate that speaks to such dichotomies as ordinary versus extraordinary treatment, palliative care versus heroic intervention, and quantity versus quality of life.

To that end, the United States Congress enacted the Patient Self-Determination Act of 1990, in an effort to preserve end-of-life autonomy and to reduce the cost of unwanted aggressive health care. However, the Act has fallen short of accomplishing its major goal (Galambos, 1998). The critical mandate the Act was intended to address, that of American executing advance directives, continues to be a major challenge.

Research on advance directives completion rates for the general population suggests a somewhat wide array of data, from four to thirty percent (Caralis et al., 1993; Emanuel, Stoeckle, Etelson & Emanuel, 1991; Gamble, McDonald, & Lichstein, 1991; High, 1993; McKinley, Garrett, Evans, & Davis, 1994; Waters, 2000). Generally, these studies are based on predominantly White middle-class respondents (Murphy et al., 1996). However, conclusions from research that include patients from diverse backgrounds (Caralis et al., 1993; Garrett, Norburn, Patrick, & Danis, 1993; Klessig, 1992; Teno, Fleishman, & Brock, 1990) suggest that African Americans want more life-sustaining treatment; have discussed advance care planning less with physicians; have or want fewer living wills than their White counterparts; and are less familiar with the concept of advance care planning (Murphy, Michael, & Blackhall; 1996; Waters, 2000).
Obstacles to Effectiveness

Advocates of advance care planning point to studies that have repeatedly found that without the benefit of an advance directive, both family and physician proxy decision-makers err significantly when attempting to predict patients’ life-sustaining treatment preferences (Sulmasy, Terry, & Weisman, 1998; Uhlmann, Pearlman, & Cain, 1988; Zweibel & Cassell, 1989). However, there is a growing body of research that challenges the effectiveness of advance care planning as a means of improving end-of-life medical care (Danis, Sutherland, & Garrett, 1991; Teno, Lynn, & Wegner, 1997; Teno, Licks & et al., 1997; and The SUPPORT Investigators, 1995). In this regard, Ditto et al. (2001) tested the assumption that allowing surrogates to review or discuss a patient-completed advance directive would improve the accuracy of substituted judgment. They found that there were no significant improvements in the accuracy in any of the illness scenarios presented. Thus, they contended that the advance or “instructional” directive failed in its attempt to ensure patient self-determination in end-of-life decision-making.

Similarly, findings of the largest and most well known study, SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), documented that advance directives completed by patients contain little or no clinically useful information (Teno, et al., 1997); that advance directive documents are often not placed in the medical record; the existence of an advance directive often goes undocumented (Teno, Lynn, & Phillips, 1994; The SUPPORT Investigators, 1995); and even when the directive is reviewed by the physician, it is infrequently discussed with the patient or a family member (The SUPPORT Investigators, 1995).
In response to these obstacles Morrison, Olson, Mertz, & Meier (1995) suggest that in order to preserve patient autonomy, advance directive documents must be available, recognized, understood, and honored. Furthermore, there is a need to clarify and reconceptualize advance directives (McKee, 1999; Singer, et al., 1998) to promote their effectiveness in achieving the goal of increased patient autonomy in end-of-life decision-making.

Generally, it appears that social and cultural factors significantly inform the way people view medical care, sickness, and death and dying (Caralis et al., 1993; Mebane et al., 1999). In addition, it seems that ethnicity is a primary factor related to individuals’ perspectives toward end-of-life treatment preferences, planning and decision-making (Blackhall et al., 1999; Eleazer et al., 1996; Murphy et al., 1996; Waters, 2000). In fact, ethnicity may be more important than other socio-demographic factors including gender, age, educational attainment, marital status, and the presence of children (Eleazer et al., 1996). As Pellegrino (1992) so forcefully states, “ethnicity imprints every person, even those who think they’ve shaken off or rejected its embrace. It binds those with common roots and separates them from those with different origins” (p. xix).

This suggests that faced with decisions relating to life and death, patients draw upon a lifetime of experience for strength and guidance. However, it is not ethnicity alone but the social experience of different ethnic groups that help shape particular cultural organization and value systems (Klessig, 1992), which in turn inform and influence end-of-life treatment preferences and perceptions. Related thereto are multiple emerging themes that seek to identify and explain the many factors that contribute to the attitudes and beliefs of African Americans in reference to end-of-life care and treatment.
preferences. These include: (1) history and heritage; (2) religion and spirituality; (3) bioethical issues; (4) social issues, and (5) education (Crawley et al., 2000).

**History and Heritage**

The social experiences of different groups shape cultural and value systems, which inform life-support decisions (Eleazer et al., 1996; Klessig, 1992). The views of African Americans towards advance care planning are complex and diverse, shaped by both historical and contemporary events (Crawley, et al., 2000). Specifically, the *socio-historical* view hypothesizes that a history of political, social, and economic oppression and injustices influence the attitudes and behavior of African Americans concerning advance end-of-life treatment planning (Caralis, Davis, Wright & Marcial 1993; Crawley et al., 2000; Garrett et al., 1993; Klessig, 1992; McKinley et al., 1994; Mebane et al., 1999, Waters, 2000). Related thereto is a legacy of slavery and abuses in medical research that add further to the adverse social and historical circumstances and experiences of African Americans (Kalish & Reynolds, 1976; Mouton et al., 1995).

Due to these circumstances and experiences of the African American population in the United States, Garrett et al. (1993) propose that they are extraordinarily familiar with and prepared to struggle against death. Their view of “death as a struggle to overcome” (Crawley et al., 2000) may mean that while reliance on a minimal chance of a favorable outcome could conceivably seem unreasonable to medical providers, African American elderly individuals perhaps view this negligible chance as entirely reasonable.
in light of their personal history. For these elderly individuals, suffering is likely to be understood as an expected part of life rather than a basis to terminate it (Mouton, et al., 1995).

This suffering, reaction to oppression, images of survival, and coping skills are ever present in African American literature and music (Secundy, 1992). James Weldon Johnson’s, *Go Down Death*, lamenting death as the welcome friend—or Alice Walker’s *To Hell with Dying*—boast triumph over death and the power to overcome it (Secundy, 1992). Likewise, gaining an understanding of how African Americans make meaning of death and dying requires an appreciation of a persistent and lingering historical presence of violent death, often recounted in folklore from the past (Kalish & Reynolds, 1976). Could it be that a history of nearness to death— the consciousness of death-- makes life more precious (Feifel & Branscomb, 1973, as cited in Morgan, 1997)?

Linked to this historical presence of violence, injustice, poverty, and discrimination is the African’s American’s distrust or mistrust of the health care system (Blackhall et al., 1999; McKinley et al., 1994; Mouton, et al., 1995; Waters, 2000). This is apparent in African American respondents’ perceptions suggesting that a living will increases their feelings of hopelessness and will result in a decreased quality of medical care at the end-of-life (McKinley et al., 1994). Likewise, various studies suggest that patients’ race may have an impact on delivery of health services and medical outcomes (Borum, Lynn, & Zhenshao, 2000; Council on Ethical and Judicial Affairs, 1996). These racial disparities in health care treatment are evident in that once African Americans gain access to the health care system, they are still less likely than Whites to receive certain surgical or other therapies such as angiography, bypass surgery, and organ transplantation.
(Borum et al., 2000; Council on Ethical and Judicial Affairs, 1996; Epstein et al., 2000; Schulman, 1999). The most infamous Tuskegee Syphilis Study and its flagrant ethical violations, which lasted more than four decades (Mouton, et al., 1995; Reverby, 2000; Waters, 2000), adds significantly and adversely to African Americans’ feelings of distrust, fears of exploitation, and questions of equity in medical care and research. Garrett et al (1993) propose, “that Black individuals, who as a group have had limited access to care, and thus have forgone treatment without choice, are not inclined to forego treatment when given a choice” (p. 367).

As compared to Whites and other minorities, African Americans have higher mortality rates from conditions such as cancer, cardiovascular disease, acquired immune deficiency syndrome (AIDS), and homicides, which have been correlated with health care disparity and social injustice (Byrd & Clayton, 1991). These mortality rates result in a lower life expectancy for African American males and females when compared to Whites.

Religion and Spirituality

Consistent with the view of suffering and survival or “overcoming the odds” (Mouton et al., 1995) is the issue of religiosity and spirituality, and the role these concepts occupy in the life experiences of the African American population. The two terms are often used synonymously, however spirituality is a broader term than religion. “Spirituality is the attempt to understand or accept the underlying meaning of life, one’s relationships to oneself and other people, one’s place in the universe, and the possibility of a ‘higher power’ in the universe” (Rabow & Brody, p. 108). Religion is more
organized, with covenant beliefs or ideology, and is characterized by material and non-material symbols (Kalish, 1976). African Americans tend to characterize themselves as having more pronounced religious preferences than Whites (Kalish, 1976; Mebane et al., 1999), and are prone to feel guilty about withdrawing life-support measures based on religious values (Klessig, 1992). McKinley et al., (1994) report, that the African American race, stronger religious beliefs, and lower incomes are strongly associated with preference for life-sustaining treatment.

For African Americans maintaining life has required much energy, endurance, and resourcefulness, therefore, there appears to be a reluctance to let go when the situation appears “tough” or hopeless (Kalish & Reynolds, 1976). There is a resiliency, hope, and an appreciation for life that elderly African Americans attribute to their faith in God. A central theme of struggle and survival and the nobility of suffering are reflected in the poetry of Maya Angelou’s, Still I Rise (Crawley, et al., 2000): Out of the huts of history’s shame- I rise- Up from the past that’s’ rooted in pain- I rise.

The significantly lower suicide rate among African Americans, including elderly African Americans, may be substantially a consequence of this struggle and survival theme. For example, in 1999, the overall suicide rate for African American males was 10 versus 19.1 for White males. For African American females the suicide rate was 1.6 compared to White females who had a suicide rate of 4.5 (Hoyert et al., 2001). In the elderly population, African-American males had a suicide rate of 12.1, compared to a rate of 34.5 for their elderly White male counterpart. For elderly African American women, there was a recorded rate of 1.5 and a rate of 4.6 for elderly White females (Hoyert, Arias, Smith, Murphy, & Kochanek, 2001). The rates are based on per 100,000
population statistics. While these data suggest that suicide in the elderly population is largely a male phenomenon, when same-gender comparisons are made, based on race, the suicide rates for Whites are substantially higher than for African Americans. Elderly African Americans attribute their strong desire for life to their faith in God (Kalish & Reynolds, 1976), and are not as prone to choose suicide as an option.

Jackson (1977) presents a two-dimensional conceptual model for the complex and multifaceted way in which African Americans organize, perceive, and make meaning of death and dying. He draws upon the sacred and secular norms (Fulton, 1976) as part of this effort. The sacred norm suggests that African Americans focus on the metaphysical and supernatural concerns surrounding death, whereas the secular norm posits that African Americans view death as an inevitable and naturalistic outcome of a “normal life process” (Jackson, 1977).

Jackson (1977) challenges the idea that Christian religious views regarding death, that are held by many African Americans, depict pain and suffering as conditions not to be avoided but endured as part of a spiritual commitment (Crawley, et al., 2000). Furthermore, he questions the usual interpretation that African Americans understand and organize their beliefs and attitudes from a sacred approach (Jackson, 1977). Negro spirituals, often viewed as “other-worldly” offered dual language and symbolism of death and freedom (Brown, 1958, as noted in Kalish 1977). “Negro slaves ordinarily believed that Africa was heaven,” (Kalish, 1977) and that heaven within the United States was up North (Kalish, 1977). The lyrics of the Negro spiritual, “Before I’d be a slave, I’d be buried in my grave and go home to my Lord and be free” (Kalish 1976), reflect a theme of freedom, (secular) and going to a heavenly home, a sacred theme. An analysis of
African American writings is suggestive of a secular view of death, and the contention that these are largely sacred results from a misinterpretation of the duality of the messages (Jackson, 1977). This evaluation must be viewed as more explorative than definitive in the absence of scientifically planned and executed studies of the character of death among African Americans (Jackson, 1977).

Bioethical Issues

Our attitude concerning death is shaped by our philosophy, our view of the world and our place in it, and the way in which we define and perceive personhood (Morgan, 1997). Differing world-views, beliefs, and value systems that are not consistent with Western ethical principles, such as autonomy and truth telling, pose complex problems for medical providers and present a challenge to prevailing public policy. Such attitudes and values that are contrary to those of the dominant culture are ever present in a multicultural society.

For instance, many ethnic groups find the idea of terminating life support as offensive (Blackhall et al., 1995; Klessig, 1992), and prefer a family centered approach to decision making (Blackhall et al., 1999; Caralis et al; 1993). Similarly, all groups do not share truth telling as an ethical value. Truth telling emphasizes an egalitarian approach in which medical information is shared between the patient and clinician (Mouton et al., 1995). For some groups, there is a belief that the family, and not the patient should be told about a terminal illness (Blackhall et al., 1995; Murphy et al., 1996), as disclosure could be harmful.
This symbolizes the contrasting worldviews that account for racial and ethnic differences in end-of-life treatment choices and preferences. For example, in comparison to the Western emphasis on self and individualism, African American values have historically emphasized communalism (DeSpelder & Strickland, 1995). Figure 2.1 depicts these contrasting Afrocentric and Euro-centric ethos (Murray, 1992).

In a related vein, Barrett (1995) poses a model of the symbolized meaning of life and death for African Americans as compared to Whites. He uses the cosmogram to symbolize the African view of birth and death as part of a cycle, emphasizing death as transition rather than an ending of life. Barrett uses a linear model to describe the Western worldview of life and death as opposites as opposed to having a cyclical quality.
These models are not meant to indicate monolithic value and belief systems within ethnic groups. The concepts are highly relative and intended to indicate strong tendencies or predominant themes of the literature, art, or behavioral norms of large segments of the groups (Murray, 1992).

To more accurately understand how African Americans’ perceive the ethical principle of autonomy, which is at the heart of end-of-life planning and decision making, requires an examination of how they view the concept of personhood, quality, and sanctity of life (Murray, 1992). “The most important element in the development of attitudes toward death is the perception of what it is to be a person” (Morgan, 1997, p. 23). Morgan suggests further that members of a culture in which individualism is valued will have a different orientation than members of a culture that perceive each person as having meaning primarily as part of a whole. For example, Figure 2.1 highlights the
Afrocentric ethos of communalism versus the Euro-centric ethic of individualism. Based on these fundamental differences in beliefs, and the tenets of communalism, it follows that African Americans are prone to favor family-centered decision making in regard to end-of-life issues. Those who value the uniqueness of the individual or life from a Euro-centric view will perceive life with different significance than those who perceive the meaning of life communally, within a whole, the Afrocentric view. Similarly, the humanistic philosophy of the Akans of Ghana, West African represents that society’s orientation toward communalism (Wiredu, 1992). Their beliefs and customs impart the central theme that human fellowship is the most important of human needs (Wiredu). While the value and importance of material properties are not denied, it is considered secondary to relationships and fellowship.

Research findings suggest that African Americans desire and expect to live longer than Whites, contrary to actual data (Kalish & Reynolds, 1976). Consequently, paramount to any discussion of personhood is the concept of quality of life and longevity. The Afrocentric view privileges the quality of life. However, from this position “quality of life may be defined existentially—not merely by one’s capacity to function” (Crawley et al., 2000, p. 2519).

The following poem, On Aging, by the poet, Maya Angelou, very powerfully and clearly captures the will of the human spirit and the concepts of quality of life and personhood (Secundy, 1992, p. 150):
When you see me walking, stumbling,
don’t study and get it wrong
‘Cause tired don’t mean lazy
and every goodbye ain’t gone.
I’m the same person I was
back then,
A little less hair, a little less chin,
A lot less lungs and much less wind.
But ain’t I lucky I can still breath in.

Frankl (1984) adds further meaning to this poem, stating the following:

Just as life remains potentially meaningful under any conditions, even those which are most miserable, so too does the value of each and every person stay with him or her, and it does so because it is based on the values that he or she has realized in the past, and is not contingent on the usefulness that he or she may not retain in the present (pp. 151-152).

Finally, Murray (1992) suggests that the following issues should be explored regarding the African American ethical and moral framework:

- What are the pre-eminent ethical and moral principles that influence the culture?
- What is the concept of personhood in a particular culture?
- How is “health” or the state of wellness defined?
- What is the culturally derived relationship between the patient and the healer? How do they interact (p. 36)?

The desire for aggressive treatment interventions is present in African Americans regardless of the expected quality of life or futility of the effort (Blackhall, et al., 1999; Caralis et al., 1993; Garrett et al., 1993; 1996; Mebane, et al., 1999). These research findings suggest that the futility of any particular therapy is often based on the individual’s life experience and worldview. This raises provocative questions: For
African Americans, does sanctity of life preempt quality of life? Is how long they live of competing importance with how well they live (Garrett et al., 1993)? These questions and issues deserve further study for a better understanding of this very complex issue.

**Social Issues**

Views about death and dying and end-of-life treatment preferences are only partially shaped by racial identity. Additional factors such as education, socio-economic status, and gender are all a part of this multifaceted issue.

In the general population, people with advance directives are better educated and come from higher socioeconomic classes (Miles, et al., 1996). Galambos (1998) further states that those likely to complete advance directives are middle to upper class White females. This may reflect their greater trust in the health care system, a better ability to complete documents, or they may possess values that are especially favorable to advance care planning (Miles et al., 1996). Research findings consistently note that lower educational level and lower income are associated with a more positive attitude toward the use of life support (Blackhall et al., 1999; Borum, Lynn, & Zhenshao, 2000; Eleazer et al., 1996; Garrett et al., 1993; McKinley et al., 1996; Murphy et al., 1996).

African Americans who are better educated and of a higher SES are more prone to have favorable attitudes toward, and are more likely to have completed advance directives than lower income, less educated African Americans. However, they are still considerably less likely to do so than Whites with similar educational levels and SES (Murphy, et al., 1996; Waters, 2000). Garrett et al (1993), report that racial differences persisted when education was used as an indicator of socioeconomic status in their study.
Furthermore, Caralis et al (1993) findings suggest that while medical experiences and SES influence African Americans’ knowledge and understanding of advance directives, these factors do not significantly inform their attitudes and ultimate preferences and decision to complete advance directives. Consistent with this finding, Garrett et al (1993) found that highly educated African Americans were as inclined to choose life-sustaining treatment as those who were less well educated. This reinforces the premise that individuals’ attitudes and choices are influenced by deeply ingrained social and cultural values. In addition, it lends credence to Kalish’s (1976) observation, based on his extensive psychocultural study of death views, that the greatest differences in ideologies about death are associated with differences in culture—not differences in sex, age, and education.

With respect to gender differences in treatment preferences and attitudes, women are less favorable toward life-sustaining care across ethnic groups (Blackhall, et al., 1999; Garrett et al., 1993). Some researchers suggest that women’s disproportionate status as caregivers for sick relatives may be a contributing factor to their desire for less life-sustaining care (Blackhall et al., 1999; Eleazer et al., 1996). This is consistent with research findings that indicate that those respondents with personal experience with illness are more inclined to execute an advance directive (Blackhall et al., 1999; Murphy et al., 1996).

Finally, in regard to age, statistics from the General Accounting Office reported in 1995 (Galambos, 1998) indicate that only nine percent of patients under age 30 have an advance directive, compared with 35 percent of patients over age 75. These statistics
vary, but the data consistently suggest a low completion rate for all ages, although the elderly are understandably more inclined to have completed advance directives when compared to non-elderly persons.

Education and Access

Braun, Pietsch, and Blanchette (2000) suggest “few people are knowledgeable about the available technology and the implications for technology-related decisions or are prepared for the level of participation in decision making that is demanded of them” (pp. 3-4), as it relates to advance directives. In regard to this issue, African Americans seem to be less likely to be cognizant of advance directives and, even when aware of them, less likely to complete them, and tend to rely on a family-centered approach to end-of-life decision-making (Waters, 2000).

Recognizing that the provision of education to patients was an integral part of the mandate established by the PSDA, several studies were undertaken to determine the impact of an educational intervention strategy (Hare & Nelson, 1991; High, 1993; Sachs, Stocking, & Miles, 1992) in increasing advance directives completion by the elderly. These interventions resulted in only modest increases in usage rates.

Advance care planning education requires that medical providers are also well educated in this area as they are the most likely source of education. However, medical providers may also lack a related range of knowledge (Crawley et al., 2000)

Research Limitations for Reviewed Literature

Several limitations to external and internal validity are evident in the body of research reviewed. For example, several studies did not utilize random sampling
techniques; instead they used theoretical samples (Blackhall, et al., 1999; Garrett, Evans, & Danis, 1994; Vaughn et al., 2000). Other studies used convenience samples (Caralis, Wright, & Marcial, 1993; McKinley et al., 1994; Waters, 2000).

Some studies are open to regional and/or gender bias (McKinley et al., 1994; Murphy et al., 1996; Vaughn et al., 2000). There were studies that used Likert scaled questionnaires and/or rankings of responses (Murphy et al., 1996; Mebane et al., 1999) that limited the range and depth of responses. Further limitations are a result of retrospective chart reviews (Eleazer, et al., 1996; Vaughn, et al., 2000) in which there were no consistent and uniform criteria for documenting in the subjects’ medical records. Socio-economic status bias further limits generalizability in other studies (Caralis, et al., 1993; Waters, 2000) in which a majority of respondents were either low or middle income. Also, questionable validity and reliability of measurement instruments (McKinley et al., 1994) posed further threats to research rigor.

Those studies requiring face-to-face interviews generally ensured that respondents and interviewers were of a common race and used a common language. While these efforts were geared toward enhancing the validity of the data, such measures may conversely have limiting effects, thus failing to present a realistic and accurate picture. In fact, most health care providers serving racial minorities are White (Mebane, et al., 1999). Consequently, research participants’ responses to an interviewer of the same race may be very different from a response to an actual provider of a different race, and under more emotionally demanding circumstances.

In spite of these limitations, these studies bring to the forefront the complexity of ethnic and racial variations in end-of-life treatment preferences. The research also poses
many as yet unanswered questions about such differences, and frequently suggests a noticeable paradox between attitudes, beliefs, and behaviors of participants relative to advance care planning.

Theory

Bioecological Model from a Life Course Perspective

The ecological systems model from a life course perspective (Bronfenbrenner, 1979; Bronfenbrenner, 1995; Bronfenbrenner & Morris, 1998; Bronfenbrenner, 2000) is the theoretical orientation that guides this study. A theoretical orientation, as distinguished from a theory “establishes a common field of inquiry by defining a framework that guides research in terms of problem identification and formulation, variable selection and rationales, and strategies of design and analysis (Elder, 1999, p. 941). Bronfenbrenner (1979) defines the ecological model of human development as the following:

The ecology of human development involves the scientific study of the progressive mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings and by the larger contexts in which the settings are embedded (p. 21).

Bronfenbrenner (2000) further describes the set of “nested structures”, each inside the next, as micro, meso, exo, macro, and chrono systems of human development. These hierarchical structures constituting the environment operate as systems both within themselves and in relation to each other (Bronfenbrenner, 1979; Bronfenbrenner, 1995).

Contributions of ecological theory include (1) a systematic examination of macro and micro dimensions of environment; (2) emphasis on connections between
environmental settings, or mesosystem; and (3) consideration of sociohistorical developmental influences, or chronosystem (Santrock, 2004).

The ecological framework posits that development does not take place in a vacuum, but is embedded and expressed through behavior in a particular environmental context (Bronfenbrenner, 1979). Similarly, environmental factors play an important and determining role in how individuals think about and respond to death (Despelder & Strickland, 1999). Attitudes, beliefs, and behaviors concerning end-of-life are not formed in isolation from the rest of the human experience (Cavanaugh, 1998). As with other aspects of human development, the understanding of death evolves as experiences stimulate a reevaluation of previously held knowledge, beliefs, and attitudes (Despelder, 1999). These multidimensional, complex phenomena cannot be explained or understood within the scope of a single disciplinary approach or within a given period within the life span.

The life span development framework encourages attention to a very broad range of problems relating to attitudes and beliefs about death and dying (Kastenbaum, 2000). This thereby reduces the temptation to view attitudes and beliefs about dying within a narrow and overly simplistic perspective. The ecological approach as a developmental perspective counters a dissociative trend, and is integrative and interdisciplinary in its thrust (Bronfenbrenner, 1995). It draws on and posits relationships among concepts from various disciplines including the behavioral, biological, social sciences, history, anthropology, and economics. “Viewing development from an integrative frame recognizes that adults are far too complex to put in one box or another” (Clark & Caffarella, 1999; p. 6).
Likewise, in order to fully understand the very complex issue of how elderly African American veterans understand and make meaning of advance care planning, one must recognize how the biological, psychological, and sociocultural intersect and influence one another (Clark & Caffarella, 1999). The bioecological model in a life course perspective, links lives within context and highlights the impact of historical time. However, because African Americans are multiply positioned both socially and culturally, an understanding of the contextual issues and impact of history must be coupled with a consideration of how the intersection of race (Clark & Caffarella, 1999) further impacts the meaning that they give to end-of-life issues and planning.

**Life Course Perspective**

Whereas the bioecological model emphasizes development in context, the *life course* framework emphasizes development over time (Moen & Erickson, 1995). It focuses attention on the interaction of demographic, social structural, and cultural factors (Hareven 1996). Its core elements consist of *time, process, and context*. In addition, the perspective provides a focus for individual and societal linkage (Marshall, 1999). It sheds light on the ways in which the earlier life experiences of older adults, as shaped by historical events, and their cultural heritage have affected their values governing family relations, their expectations of kin supports, and their ability to interact with agencies and institutions (Hareven, 1996). This perspective establishes a framework for addressing issues such as cohort and cultural differences in the elderly population. Furthermore, it provides a view for explaining how a changing model of health care, from a paternalistic (Mouton et al, 1995) to a distant and impersonal system of care, may conflict with elderly
persons’ values and attitudes toward issues concerning end-of-life planning and treatment.

The three life course principles (Elder 1974; Elder, 1998; Hareven, 1978) include historical time and place, timing in life, and linked lives (Figure 2.2). The major dimensions of the perspective are depicted in Figure 2.3: (1) timing of life transitions in relation to external historical events; (2) the cumulative impact of earlier life events on subsequent ones; and (3) synchronization of individual life transitions with collective family transitions (Elder, 1998).

<table>
<thead>
<tr>
<th>Principle 1: Historical Time &amp; Place</th>
<th>The individual's own developmental life course is seen as embedded in and powerfully shaped by conditions and events occurring during the historical period through which the person lives.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principle 2: Timing In Life</td>
<td>The developmental impact of a succession of life transitions or events is contingent on when they occur in a person's life.</td>
</tr>
<tr>
<td>Principle 3: Linked Lives</td>
<td>The lives of all family members are interdependent. Hence, how each family member reacts to a particular historical event or role transition affects the developmental course of the other family members, both within and across generations.</td>
</tr>
</tbody>
</table>

Figure 2.2   Life Course Principles
Figure 2.3  Three Major Dimensions of Life Course Perspective

Historical Time and Place

The life course of individuals is embedded in and shaped by the historical times and places they experience over their lifetime (Elder, 1998). Cavanaugh (1998) notes, “our lives are anchored in the major events of particular historical periods” (p. 4). These historical forces play a very crucial role in complex cumulative patterns of individual and familial life paths, and may continue over several generations (Hareven, 1996). For example, in the study of Children of the Great Depression, Elder (1974), draws upon the concept of historical time and place to explain how Depression hardship impacted a cohort of young men and women over the course of their lives.

Similarly, research points to the significance of historical time and its influences on the attitudes and beliefs of African Americans concerning advance care planning (Mouton, et al., 1995; Waters, 2000). Blauner (1970) notes that the imprint of the dominant culture within which they have spent the past three centuries conceivably
determines African Americans’ response to death. This is consistent with the premise set forth by Fulton (1976) which suggests that the meaning of death for anyone is a result of the socially inherited ideas and assumptions that have been formed over the lifetime of the society in which one lives.

Timing in Lives

This principle of timing in lives suggests, “the developmental impact of a succession of life transitions or events is contingent on when they occur in a person’s life” (Elder, 1998, p. 3). It is related to what Merriam (1999) labels social time, “a culturally dependent time table outlining appropriate behavior at various stages in the life cycle” (p. 67). Based on this principle, perhaps developmental transitions among elderly African Americans, and their attitudes toward death are significantly impacted by the violent nature of their encounters with death and the early age at which they may have been introduced to death (DeSpelder & Strickland, 1999; Kalish & Reynolds, 1976; Secundy, 1992).

These variations in the life course, or non-normative influences, are a result of unanticipated life events or transitions and may be of a more dominant impact than the more common, socially expected, and anticipated life events (Merriam, 1999). This thought is reflective of the idea that, “an affective consciousness of death makes life more precious” (Morgan, 1997, p.15).

Also, in regard to death and dying, the final transition, how are African Americans’ attitudes impacted by the knowledge of a shorter life expectancy when compared to Whites? In an effort to identify what constitutes “a reasonably full and
satisfying life, Callahan (2000) notes that the federal government defines a premature death as one that occurs before the age of 65 years. While arbitrary in its selection, Callahan (2000) notes it is not an “unwise” age to select. He suggests that this is the age where one has “typically lived long enough to experience the range of human possibilities—to work, to learn, to love, to procreate, and to see one’s children grow up and become independent adults” (p. 655). In the case of elderly African Americans, at what point do they feel they have lived long enough to experience “the range of human possibilities” and how does this impact their transitioning into the end-of-life?

Linked Lives

The concept of linked or interdependent lives is central to the ecology of human development (Bronfenbrenner, 1979), and is expressed in models of personal networks and convoys of family and friends over time (Elder, 1998). The concept of linked lives posits the notion of synchronization in life planning and role sequence (Hareven, 1991). “Historical events and individual experience are connected through the family and the “linked” fates of its members” (Elder, 1998, p. 3).

Consequently, an examination of death and its effect on the family structure is key to understanding its resultant impact on family members’ attitudes, beliefs, and behaviors in areas such as life-sustaining medical care and death and dying in general. Kalish (1985) notes the following ways in which death impacts the family structure: (1) it removes the person from the family system, thus potentially leaving a vacuum in the role the deceased individual occupied; (2) the family system must reorganize minus the dead person, while lingering memories and influence of the deceased still impact the family
structure as it “re-forms”; (3) there may be an economic effect that negatively or positively impacts survivors; (4) the death of an individual may free survivors, both the elderly and the young, to pursue goals that were postponed due to certain circumstances (for example, care giving responsibilities); and (5) the death sets in motion various prescribed events including transfer of property and a change in living arrangements for surviving household members.

Wilkinson (1987) notes that kinship systems among African Americans tend to be interdependent and multi-generational. “They are characterized by intimate involvement and a set of unwritten obligations to consanguineal and conjugal relatives regardless of age” (p. 194). Kalish (1976) identifies opposing arguments concerning the stability and survival of the Black family structure. On the one hand it is argued that deprived socioeconomic conditions in which African Americans live mitigate against a stable and strong family system. Conversely, it is argued that the survival of the Black family, in spite of “immense stresses and disruptions is evidence for the existence of a strong underlying family structure” (Kalish, 1976, p. 106).

Sussman (1985) suggests that the pervasiveness of the extended family system is key to the survival of African American tradition and culture. This system characteristically views family members of the eldest living generation as symbols of unity, respect, and moral authority (Sussman, 1985). In a related vein, Johnson (1995) notes that the elderly in African American families are often at the top of the family’s “power hierarchy” and take an active role in the survival and management of the family, including childcare and important decision-making. In view of the integral role occupied by elderly African Americans, death or impairment constitutes a different kind of crisis
than in ethnic groups where the role may be more limited. These linked lives and intergenerational influences speak to the preference for a family centered approach to end-of-life decision-making.

Existing Theoretical Frameworks

The concept of “death anxiety” is an often-used framework in the literature that seeks to explain individuals’ responses to issues of death and dying (Cochrane, Fryer, & Oglesby, 1990; DeSpelder & Strickland, 1999; Kalish, 1976). This framework posits that there is a human tendency toward avoidance of situations that remind one of death. Death anxiety is defined as the fear of extinction, annihilation, obliteration, or ceasing to be (Cochrane, Fryer, & Oglesby, 1990). Related terms, fear of death, death concern, and nonspecific distress about death are contained under this generic term (Tomer, 1992, as cited in DeSpelder & Strickland, 1995). Measurement instruments such as the widely used Templer Death Anxiety Scale (DAS) tend to confirm findings that attitudes relative to death are complex variables (Fulton & Bendiksen, 1976).

A fear of dying and the failure to accept and recognize death as a natural part of the life course are cited as reasons for older adults’ failures to complete advance directives (Callahan, 1999; Fryback, 1999; Mucue, 1995; Winland-Brown, 1998). In a related posture, Finucane (1999) states that “in caring for a severely, progressively ill patient, what may be most difficult is moving through the transition from gravely ill and fighting death to terminally ill and seeking peace…. …” (p. 1670). These comments denote the ambivalence and struggle that are common in the Western culture in the area of death and dying.
Wong, Reker & Gesser (1994) identify the blurring of boundaries between terms such as fear, anxiety, avoidance, denial, and not wanting to die, as contributing to the inaccuracy of death anxiety or death fear measurement scales. Studies comparing death attitudes of the elderly with those of other age groups found that the elderly talk about death more often than younger individuals and express fewer signs of death anxiety (Kalish & Reynolds, 1976). Myers, Wass, and Murphy (1980) in their study of ethnicity and death attitudes found that elderly Black respondents indicated a higher level of death fear than White respondents. Bengtson, Cuellar, & Ragan (1977) found a declining level of death fear associated with increased age among African Americans, Mexican Americans, and Whites. Other studies have shown that those persons adhering to a religious belief system express less death fear or anxiety (Feifel & Nagy, 1981). Butler (1975) proposed that individuals are more afraid of a meaningless existence than of death, and persons who see their lives as fulfilling should show less death and more death acceptance. Kalish (1985) identified important questions to explore relative to the subject of death anxiety. For example, how do religious belief systems impact death attitudes? A second question is: “What are the predictors that will enable us to understand which people will become more anxious as they age and approach death and which people will become calmer and more accepting” (p. 167)?

In addition to death anxiety, another rationale for elderly persons’ failures to engage in formal advance care planning is a lack of perceived urgency in completing this task (Emanuel, Barry, Stoeckle, Ettleson, & Emanuel, 1991; High, 1993; Stelter, Elliott & Bruno, 1992). Numerous polls show that the vast majority of Americans are in favor of the “right to die” and do not want a medically prolonged death (Glick, Cowart &
Smith, 1996). Miles, Koepp, and Weber (1996) indicate that few people are unaware of advance care planning or object to advance directives. However, elderly persons express uncertainty about how to clearly document their wishes. Numerous theories and perspectives seek to shed light on issues concerning attitudes and beliefs about death and dying. However, a more all-encompassing integrative perspective is best suited for this multidimensional complex issue.
CHAPTER 3

METHODOLOGY

Introduction

The purpose of this exploratory study was to gain insight and understanding of how the lived experiences of older African Americans inform how they think about and assign meaning to end-of-life planning and care. Consequently, the central research question was: How do the lived experiences of elderly African Americans, over the life course, inform their attitudes and beliefs concerning end-of-life planning? Related to the central question were additional secondary questions were (1) how do elderly African Americans view and experience the concept of death, (2) how do elderly African Americans perceive the sanctity of life, and (3) how do elderly African Americans assign meaning to longevity and quality of life?

Few studies concerning African Americans and their attitudes and beliefs concerning end-of-life care have been guided by a qualitative methodology or exploratory focus. Furthermore, existing qualitative studies have not examined the subject from an in depth human development framework. Yet, the multi-dimensional and complex nature of end-of-life planning, for any group, requires an understanding of how their experiences over their lifetimes inform their attitudes and belief about such sensitive, personal, and critical decisions. Furthermore, the increased complexity of
medical technology that is capable of heroic efforts at prolonging and maintaining life add further to an already complicated issue.

Thus, qualitative research was well suited for exploring the socially constructed nature of reality and how social experience was created and given meaning (Denzin & Lincoln, 1994) by the ten older African American participants. A fundamental purpose of this method of inquiry is to identify and describe meanings, variations, patterns and processes of subjective experiences (Agren, 1998). It directs research toward how, not why persons organize and make sense of their world (Gubrium & Holstein, 1999). In addition, Padgett (1998) suggests the following rationale for a qualitative design: (1) to explore a topic about which little is known; (2) to explore a topic of emotional sensitivity and depth; and (3) to capture the “lived experience” from the perspectives of those who actually live it and create meaning from it. Pellegrino (1992) adds credence to the efficacy of utilizing a qualitative methodology for the topic under study. He argues that, “at most stages ethnicity plays decisive roles that are more qualitative than statistical” where end-of-life planning is concerned (p. xxi).

Through the process of story or narrative, the world of experience, and how it comes to be viewed as objective, from the respondents’ point of view, emerges. For the elderly, perhaps more than any other age group, narrative is the primary form by which human experience is made meaningful (Moore, Metcalf, & Schow, 2000). Narrative, in some sense, is history (Merriam, 1999). A narrative perspective seeks to understand human experience through the telling and retelling of the narrative.
Phenomenological Framework

A phenomenological perspective guided the study. This paradigm provides “broadly sensitizing orientations to the socially constructed features of experience, including aging” (Gubrium & Holstein, 1999, p. 286). Unlike theory, the focus is on the problem of everyday meaning in life, rather than causal explanation (Gubrium & Holstein, 1999). A phenomenological approach provides a useful and effective framework for examining and exploring how multiple factors in the participants’ lives, across the life span, interact to inform their current attitudes and beliefs concerning end-of-life treatment preferences, and how they define life and death. Consistent with tenets of a human development perspective, this approach lends itself to exploring life course events, including the impact of history, while clarifying experiences that have led to present attitudes and feelings concerning the topic under investigation.

In addition, phenomenology is an appropriate research strategy when the research question is aimed at meaning making and eliciting the essence of experience (Moore, 1994). It brackets, or sets aside, whether phenomena are real or not and examines the process by which experiences are socially constructed (Birrens & Bengston, 1988). Phenomenology’s emphasis is on understanding the world from the point of view of the respondent and not from the perspective of the scientific observer (Farganis, 1996).

Key tenets of phenomenology are the following:

1. Individuals approach the lifeworld with a stock of knowledge-resources, with which they interpret experience, grasp the intentions of others, achieve intersubjective understandings, and coordinate actions (Holstein & Gubrium, 1994).
2. The world is intersubjective and people create reality and are constrained by the preexisting social and cultural structures created by their predecessors (Ritzer, 1996).

3. The understanding of the social world is fundamentally distorted when knowledge is gained using the empirical methods of the natural sciences (Farganis, 1996).

4. Social scientists cannot have knowledge about an external world independently of their own lifeworld or lived experiences (Turner, 1998).

5. Individuals perceive that they share the same lifeworld and act as if they lived in a common world of experiences and sensations (Turner, 1998).

6. Observing “actors” in interaction, rather than radical abstraction, can provide enlightenment on the processes whereby actors come to share the same world (Turner, 1998).

In summary, phenomenology emphasizes the dialectical relationship between the way people construct social reality and the social and cultural reality that they inherit from those who preceded them in the social world (Turner, 1998). In phenomenological research, the researcher conveys a deep rich and thick description of how the participant believes, feels, and gives meaning to his or her circumstances or experiences. In such studies, the researcher’s goal is to take the reader to the heart of the respondent under study.

Grounded Theory as Inductive Analysis

Grounded theory provided the framework for a systematic way of gathering, organizing, and analyzing the narrative data that was obtained through recorded open-ended interviews. Grounded theory derives its theoretical background from Pragmatism and Symbolic Interactionism (Corbin & Strauss, 1990). It is a general methodology for developing theory grounded in the systematic analysis and gathering of data (Strauss, Corbin, 1994) that was introduced by Glaser and Strauss in 1967. A central feature of
grounded theory is constant comparative analysis; and thus the approach is frequently referred to as the constant comparative method (Strauss & Corbin).

Grounded theory provided an orderly approach in gathering and analyzing data; however, it is significant to note that qualitative research is rarely linear and zigs and zags depending on where the data lead (Padgett, 1998). It allows for the emergence of concepts from the data in a schema that allows for introspection, intuition, ruminating, and analysis (Orona, 1997). There is a constant interplay between data gathering and analysis.

The following are canons and procedures of grounded theory (Corbin & Strauss, 1990):

1. Data collection and analysis are interrelated processes.
2. Categories must be developed and related.
3. Sampling proceeds on theoretical grounds (the subjects or organization is representative of the phenomenon under study).
4. Analysis makes use of constant comparative analysis.
5. Patterns and variations must be accounted for.
6. Process must be built into theory.
7. Theoretical memoing is an integral part of the process.
8. Coding (axial, open, and selective) are fundamental analytic processes used.

In support of qualitative methodological triangulation, Morse (1994) suggests, “often more than one method may be used within a project so the researcher can gain a more holistic view of the setting” (p. 224). Strauss and Corbin (1994) add further
support to using grounded theory, combined with another method. They suggest that qualitative researchers who utilize grounded theory share with their counterparts the idea of giving voice to the participants studied. However, beyond this “they accept responsibility for an interpretive role. They do not believe it sufficient to merely give voice to the viewpoints of the people, groups or organizations studied . . . .Researchers assume further responsibility for interpreting what is said, heard, or read” (p. 274). In this study, the goals were to give voice to the respondents and to develop a thematic or theoretical perspective concerning the phenomenon that was studied.

Focus of Study

The focus of the study was to examine the narratives of the ten older African American study participants, allowing them to give voice to how they came to understand and apply meaning to their experiences relative to advance care planning. It was understood that cultural and ethnic values are integral factors that impact such preferences (Eleazer, et al., 1999), and guide responses and decisions. In addition, from a data gathering perspective, it was believed that (1) the elderly respondents could best share and tell their stories; it was they who could provide answers to what so often appeared to be paradox and contradictions; (2) that optimum understanding of the phenomenon could best be achieved by exploring from a life course or developmental perspective, as attitudes concerning life and death are formed over ones life-span; and (3) the complex, sensitive, and personal nature of the subject under study was also considered, and it was understood that insights into respondents’ attitudes and beliefs
concerning advance care planning required an understanding of how they give meaning to life and death. Consequently, the open-ended questionnaire was constructed in a way to capture pertinent information.

The semi-structured questionnaire contained seven questions that were initially purposefully broad; then the questions became more specific in order to facilitate capturing data specific to the subject. The purpose of the study was to gain insight and better understand the following:

- Tell me about your life and growing up.
- How have you experienced growing older?
- What does living a “good life” or “quality life” mean to you?
- How have you come to understand what it means to live a “poor quality of life”?
- What does living a long life mean to you?
- What meaning do you give to physical pain and suffering?
- What are your thoughts and feelings concerning living wills, or appointing someone to make your healthcare decisions for you, if you were too ill to make such decisions for yourself?

The questionnaire was field tested with colleagues at the researcher’s place of employment (in a health care setting) for clarity and length, with their understanding that the instrument would be used for interviewing older individuals with a range of educational levels. The questionnaire had undergone revisions prior to having been tested on colleagues based on consultation with members of the researcher’s dissertation committee. The questions that were identified were based on the literature and the theoretical framework that guided the study.
Participant Sample Selection

For a phenomenological study, Morse (1994) suggests a minimum sample size of six individuals. Data collection methods require in-depth conversations and reflective descriptions of lived experience. “The method of in-depth, phenomenological interviewing applied to a sample of participants who all experience similar structural and social conditions gives enormous power to the stories of relatively few participants” (Seidman, 1991, p. 45). However, in the end the point at which saturation occurs in data analysis determines the actual numbers. Saturation refers to the point at which the data become repetitive (Morse, 1994; Padgett, 1998). Also, of considerable practical importance are financial and time constraints of the researcher (Seidman).

The respondents who were a part of the study were selected on the basis of purposive sampling procedures. Purposive sampling is a technique of seeking out individuals, groups, or settings where the phenomenon or process being studied is most likely to occur (Janesick, 1994). The goal was to enlist those individuals in the project who were most likely to provide informative insights pursuant to the research question. According to Corbin and Strauss (1990), sampling in grounded theory “proceeds not in terms of drawing samples of specific groups of individuals, units of time and so on, but in terms of concepts, their properties, dimensions, and variations” (p.8). Thus participants are selected on the basis of their representation of the phenomenon selected for study.
Participation in the study required that perspective respondents meet the following criteria:

- Self-identify as African American relative to race (due to the focus of the inquiry)
- Be 65 years of age or older based on the definition of “older” for the purpose of the study
- Be void of cognitive or medical limitations having the potential to adversely impact their ability to participate in the semi-structured interview
- Not knowingly have a terminal illness

The study was open to both males and females as it was felt that each gender could provide enlightening and insightful narrative data on the research topic. In addition, the researcher considered the examination of potential gender differences as desirable, given that extant research suggests differences between males and females in advance directives completion rates (Blackhall, et al, 1999).

Procedures

Selection of Participants

The ten study participants (seven for the individually semi-structured interviews and three in the focus group) were recruited through two primary community-based sources, local African American churches and service organizations located in the Columbus, Ohio area. Gatekeepers, individuals who were in a position of authority to make decisions and have influence within the organization, were contacted by the researcher and advised of the study and its purpose. Padgett (1998) emphasizes the important role of gatekeepers in facilitating access to potential participants. For example,
during my recruiting efforts, I contacted the pastor of a local congregation; he in turn referred me to an associate minister for further assistance. A copy of the recruitment letter (Appendix A) was mailed or taken to the gatekeepers as a way of introducing the study, and gain their support. In two instances, I met with gatekeepers directly to establish rapport, answer questions, and to explain the procedural measures that addressed issues of ethics. Otherwise, contacts were accomplished through telephone conversations. Following these contacts, Gatekeepers, in turn, identified potential respondents and provided them with copies of the recruitment letters. One church maintained a list of its “senior citizens” so the information was readily available to the researcher’s contact person or gatekeeper, making follow up for him or her much easier. One large service sorority that was contacted included African American women, generally, who held college degrees, were of a wide age range, including older women. To strike a balance, and in an effort to identify a more heterogeneous pool of participants, I purposely contacted larger churches with congregations that varied in terms of socio-economic status and life experiences. Officers of two additional service and social organizations of which I had knowledge were contacted as a means of gaining entry to recruit additional participants. These were groups that included older women (65 and over) with a fairly wide range of demographic characteristics.

At the point the gatekeeper was given permission by the perspective respondent to divulge his or her contact information, the researcher was given the information for further follow up. Although the gatekeeper was given a copy of the recruitment letter, another letter was sent to potential participants once their contact information was available. In a couple of instances potential respondents initiated the contact with the
researcher directly, as my telephone number and that of my academic advisor’s were listed in the recruitment letter. However, in most instances, I initiated the follow up contact by telephone and letter once I was given the person’s name, phone number or address.

Recruitment activities took place over approximately a 10-month timeframe. Approximately 60 contacts were made by letter, or a combination of letters and telephone calls, before recruitment was completed. Several respondents were recruited as the study was underway.

As in any study where there is a time commitment on the part of the respondents, snags occur. For example, the researcher made appointments and visited the home of one potential respondent on two occasions to find no one home. In addition, two focus group participants did not report for their scheduled session because of inclement (extremely snowy) weather. A focus group that was meant to be comprised of five became a focus group of three. Sadly, two additional respondents died before their interviews could take place. Ironically, prepared for the first interview, I made my way to the library (on a Saturday morning), with tape recorder in hand, verbal scripts, and informed consent forms, only to find that I had been “stood up.” The respondent telephoned later, very apologetic, and noted that a friend had “passed.” The interview was rescheduled, and it took place as planned.

This was an active, busy group of individuals, and while they were genuinely interested in participating in the study, most noted the hectic nature of their schedules. Consequently, scheduling for the semi-structured interviews and doing member check follow up presented quite a challenge. However, there seemed to be a genuine desire on
their part to make a contribution to the project through their participation. Consistently, as the tape recorder was turned off, they wanted to know: “Did my information help you”? Or they commented: “I hope this helped you.” My answer was always an unequivocal, “yes.”

**Study Site**

The interviews proceeded in various locations and settings. Seven respondents were recruited for the individual semi-structured interviews and three participated in the focus group. The sites for the interviews were most often selected by the participants in an effort to facilitate convenience and comfort during the process. For example, the focus group session was held in a meeting room in a public library that was viewed as a central location for most participants. Another respondent arranged to meet the researcher at a restaurant located near her home. She made the arrangements and took care to ensure that there was adequate privacy and confidentiality. Two interviews were conducted in meeting rooms at respondents’ churches. In each case, the participant very willingly provided for the arrangements, as the locations were convenient and seemingly provided a certain comfort level. Four of the interviews were conducted in the homes of the respondents. In two of the interviews that were conducted in the respondents’ homes, their spouses were present, but respected the privacy of the interview.

Interviewing in the homes of participants provided another dimension for the researcher to observe. The interviews were conducted in a familiar setting that revealed further information concerning the respondent and his or her home and community surroundings, adding to the richness of their narratives and the researcher’s observations. For example, Mrs. B and Mr. R proudly shared with the researcher photographs of their
children and grandchildren. Mr. R and his spouse, with pride, displayed pictures of their four grandsons. They pointed out, with a proud chuckle, that each was enrolled in a different college. Mrs. B showed family pictures that included six daughters. The pride she felt was most evident as she spoke of her daughters.

Data Collection

Two primary methods of data collection were employed in conducting the research. First, individual, semi-structured tape-recorded face-to-face individual interviews (with verbatim transcription) were conducted using an open-ended interview guide to elicit rich, thick description (Denzin, 1989). According to Denzin, thick description “joins biography to lived experience.” Thus, it reports meanings, biography, intentions, and relational issues in a rich, dense, detailed manner.

Second, a face-to-face focus group was conducted, with the researcher as facilitator, as a means of collecting data and piloting the open-ended interview guide. The focus group session was tape-recorded and data were transcribed verbatim for analysis. The goals associated with the focus group were to strengthen and evaluate the appropriateness of the interview questionnaire and to elicit a range of ideas and issues that results from the synergy that is associated with group discussion. The group consisted of three female respondents (Mrs. C, Mrs. A, and Mrs. J.). The three focus group participants were not a part of the seven individual face-to-face interviews. Two individuals that were scheduled for the focus group did not report due to inclement weather and associated travel problems.
Morgan (1988) notes several ways that focus groups are useful: (1) orienting oneself to a new field; (2) generating hypotheses based on informants’ insights; (3) evaluating different research sites or study populations; (4) developing interview schedules and questionnaires; and (5) obtaining participants’ interpretations from earlier studies.

Consistent with Morgan’s assessment (1988) the group was useful in orienting the researcher to a new field and developing, testing the interview schedule or questionnaire, and generating hypotheses regarding how their lived experiences inform their attitudes concerning advance care planning. While the questionnaire was not modified, as the questions seemed to be clear and relevant, useful insights were gained concerning additional directions for inquiry on the topic of end-of-life care. In addition, experience in conducting the focus group had the impact of “smoothing out the wrinkles” (Padgett, 1998) in preparation for the interviews that were to follow.

The study proceeded with individual, semi-structured, face-to-face audiotaped interviews, using a structured model for in-depth phenomenological interviewing (Seidman, 1991). The model emphasizes that the first part of the interview concentrate on a focused life history, which was directed at having the respondents reconstruct their experiences consistent with the topic under study. Secondly, in the details of experience, respondents were asked to concentrate on more concrete details of their experience in the topic area. Finally, there was an emphasis on reflection on meaning where respondents are asked to reflect on the meaning of their experiences. Through this cumulative block building process, the final and central step is that of understanding and meaning making.
Correspondence was transmitted reminding respondents of the scheduled interviews at least a week prior to the interview date in order increase the likelihood of follow through. Likewise, in some instances telephone calls were made as reminders to participants. These contacts also presented an opportunity to determine if there were questions or concerns requiring attention prior to the interview.

Audiotaped interviews were conducted over a 14-month period, from February 2003 to April 2004. The interviews were 45 to 80 minutes in length, with an average length of approximately 60 minutes. Additional time was spent with participants prior to and after the interviews ended. Therefore, relevant unrecorded data and pertinent non-verbal observations were noted and maintained in the researcher’s field notes (Padgett, 1998) for future reference during data analysis and reflection. A skilled transcriptionist transcribed the taped interviews verbatim. Consistent with tenets of constant comparative analysis, the verbatim transcripts were read and re-read in preparation for a return to the field and to give guidance to the next interview. In addition, tapes were reviewed to promote “closeness” to the data, for clarity, and as a meaningful check and balance system that ensured accuracy of the transcribed narrative information.

Prior to initiating the interviews, including the focus group, the informed consent document, (Appendix D), approved by the University’s Institutional Review Board was reviewed, and any questions were answered. The respondents and researcher signed the document and respondents were given a copy for their records.
Description of Participants

A more detailed overview of demographic characteristics of the participants is included in Chapter 4, and includes Figure 4.1, which graphically summarizes demographic characteristics of the participants, including the three respondents from the focus group (Mrs. C, J, & A).

Of the ten participants, seven were female and three were male. All were African Americans. They ranged from 66 to 82 years old and the mean age was 72.7 years of age. None of the participants were personally known to the researcher in an effort to maintain ethical boundaries and to reduce bias or other potential adverse impact based on familiarity. Five of the respondents were married; four were widowed (females) and one was separated. Each of the three male participants was married. Overall, they were well educated and had held very responsible positions with stable careers. Eight were retired, one semi-retired, and a third continued to practice as a protestant minister, though retired from other employment.

In terms of their health status, they generally felt they were in good health, though experiencing some of the chronic illnesses that often accompany the aging process. One respondent had experienced serious illnesses. They were active in their churches, service, or social organizations. All, except one, had children. Three of the ten had completed advance directives and six had executed estate wills. For the most part, they came from large families, except for one who was an only child. They tended to be closely associated with their families. Although the research topic was very personal and in some regard sensitive, most responded very openly during the interviews. For many the process seemed cathartic.
Data Analysis

According to Corbin and Strauss (1990) data collection and analysis are an interrelated process. “In grounded theory, the analysis begins as soon as the first bit of data is collected (p. 7). Addison (1999) takes analysis a step further by arguing that sound analysis begins prior to data collection in that the researcher begins to reflect, clarify, and note his or her stance or philosophy concerning the phenomenon under investigation. The central task of the analysis is to “create the harmonic sound of data coming together in narrative form to make sense of data collected” (Maykut & Morehouse, 1994, p. 145).

Grounded theory tenets (Glaser & Strauss, 1967) served as the framework for organizing and analyzing the narrative data due to the systematic focus of the perspective. Constant comparative analysis (Strauss & Corbin, 1990) was the key concept used to analyze the narrative data that included transcriptions of tape-recorded interviews and field notes. This is an iterative rather than a linear process that involves a back and forth movement between an inductive and deductive focus (Padgett, 1998). Inductively, themes emerge from initial coding, then one returns to the data to ensure that it is coded in accordance with themes, a deductive process, then combing back through the data, new codes or themes may emerge, once again an inductive process. Likewise, Addison (1999) emphasizes the “circular character” of the analytic process.

Content analysis was ongoing throughout data collection (Morse, 1994). The purpose of this process was to refine the process of inquiry for future interviews, and to identify emerging themes (Padgett, 1998). Analysis of the transcribed narratives and field notes was accomplished using a data analytic model developed by Maykut and
Morehouse (1994), a time-intensive, yet useful process. The model includes several steps, including cutting and pasting data manually. Prior to beginning the steps, transcripts and tapes were reviewed thoroughly to enhance familiarity or closeness to the data. The steps included further reviewing the transcripts lines by line and (1) coding data pages to their sources—for example page five of the transcript for Mr. T was coded T/5. This facilitated ease in identifying the source of data as analysis progressed and data became more voluminous; (2) data were unitized. Unitizing the data required drawing a line to identify a unit of meaning, which later would be used to define or build larger categories. Again an identification label was placed at the left margin. For example, T/E-20 referred to page 20 of the transcript for Mrs. E; (3) units of meaning were cut apart and taped to index cards. As each new unit of meaning was identified, it was compared with other units of meaning; (4) discovery required the use of a large sheet of paper (I used poster board.) to note emerging themes and patterns; concepts or themes that overlapped were combined; (5) unitized data cards were linked with a category on the discovery poster. Cards not fitting a discovery category were set aside for future possibilities or inclusion; (6) rules of inclusion were written that served as the basis for grouping in a category; (7) once data cards were clustered and assigned to a category based on the rules of inclusion, they were examined once again for overlap for further reduction or combining of relevant categories. I found it useful to sort the units of meaning using color-coded index cards to identify those units that were associated with the same theme. For example, units of meaning applicable to “meaning in life” were
assigned to blue cards, and units of meaning related to “coming to know death” were attached to yellow cards. This was an effective way of quickly identifying like units as I began writing.

My field notes included a reflexive journal, analytic memoing, and interview summaries. Field notes are useful for recording nonverbal data, including reflexive thinking of the researcher and occurrences that are not captured on tape. The reflexive journal serves as a record of the researcher’s thoughts, feelings, and hunches in regard to the research. In this regard, Addison (1999) noted that the researchers’ understanding inevitably influence how they carry out their observations, the focus of inquiry, what data are collected, and how it is interpreted. Analytic memoing is generated during data abstraction and explains the decision-making behind emerging codes or themes, and is basic to an effective audit trail (Morse, 1994; Padgett, 1998)). I wrote my thoughts as they came, whether it was during a review of data, or seated in a restaurant having a meal. Interview summaries were completed during the process of reviewing the respondents’ transcripts as a ready reference to the most salient points that emerged from the transcript and field notes.

For the field note journal, I organized notes (Richardson, 1994) according to (1) observations—what one sees, taste, feels, (2) methodological—reminders, prompts—for example, how to collect data, (3) theoretical (e.g., hypotheses about emerging data), and (4) personal (e.g., feeling statements). This proved to be an excellent way of organizing field notes. Typically, I wrote what came to mind, and organized comments into these categories at a later time. Field notes were analyzed along with transcript data during the above noted data analytic process.
Finally, I discussed emerging themes, hypotheses, and questions with colleagues and co-workers (including nurses, social workers, and physicians) in my place of employment, a healthcare setting. It was useful to discuss these ideas and issues for their feedback, input, and for further insight from multiple disciplinary perspectives. In addition, it was the intent of the researcher to maintain self-awareness concerning potential researcher bias related to the subject under study, and thus the potential for inaccurate or inadequate interpretation of the data. This interaction soliciting and receiving feedback from staff, across disciplines, continued the duration of the data gathering and analysis process.

Trustworthiness

Trustworthiness refers to the rigor or validity of the study, and the extent to which findings are authentic and their interpretation credible (Lincoln & Guba, 1985). Various strategies are available to the qualitative researcher to enhance the rigor of the research project. The fact that scientific methods are an inadequate fit for qualitative research does not relieve the researcher of the responsibility to apply rigorous methods to enhance and enrich the investigative process and outcome. These procedures serve as checks and balances on the accuracy and rigor of data and analysis. The ultimate test of trustworthiness is that the report carries “sufficient conviction” to enable the reader to have the same experience as the original observer and have an appreciation for the account (Addison 1999).

Well-known terms associated with the quantitative methodology, such as internal and external validity, reliability and objectivity (Lincoln & Guba, 1985) have “cousins”
in the naturalistic method. Lincoln & Guba (1985) suggests that terms that imply methodological rigor using a qualitative methodology include, credibility, confirmability, dependability, and transferability. Corbin and Strauss (1990) argue, “…the grounded theory approach accepts the usual scientific cannons, but redefines them carefully to fit its specific procedures” (p. 16).

Credibility

According to Lincoln and Guba (1985) credibility refers to the extent to which findings and interpretation are reflective of the participants’ point of view. In this study, credibility was achieved using the following processes: (1) triangulation of methods, (2) member checking, and (3) peer debriefing.

Triangulation

Triangulation refers to using two or more sources to achieve a comprehensive picture of a fixed reference point (Padgett, 1998). In this study both data triangulation, the use of more than one data source, and methodological triangulation, the use of multiple methods or perspectives to study a single topic (Padgett, 1998), were employed.

In regard to data triangulation, the focus group served as a pilot for gathering data and testing the semi-structured interview instrument. This served to enhance the process by providing valuable insights to guide the study with the onset of data collection during face-to-face individual interviews. Secondly, methodological triangulation was employed given that a phenomenological perspective was used to guide data gathering and grounded theory principles were employed for purposes of data analysis.
Peer Debriefing

Peer debriefing refers to peer support groups or an individual who serves as an impartial peer in sessions that focus on analysis and bi-directional feedback concerning issues that relate to the research process, analysis of data, and personal issues that arise out of field work. The emphases are on exploring facets of the inquiry that might otherwise remain unexamined (Lincoln and Guba, 1985) and providing support. Peer debriefing facilitates confirming that findings from the data are “worthy, honest, and believable” (Spall, 1998). Relative to peer debriefing, the researcher met with a colleague and fellow doctoral student who was also engaged in conducting a qualitative dissertation project. We met quarterly, approximately three hours for each session, from the onset and throughout the course of the project. In addition, I acted as a peer debriefer to the debriefer as she conducted her research project that was concurrent but more advance than my study. Thus, a solid rapport was established over a lengthy period of time. Each of us was very familiar with the other’s project. In addition to face-to-face meetings, we e-mailed back and forth for support and feedback, at least monthly, to discuss day-to-day issues as we proceeded with the research endeavor. We kept notes, shared and discussed references that were further enlightening to the project. The support was needed and most useful.

Member checking

Member checking entailed returning to the field to seek verification or confirmation of the accuracy of data from respondents (Lincoln & Guba, 1985). Member checks were accomplished for seven of the ten participants. This was done in the form of
interview summaries, which were either delivered or mailed to the respondents, depending on their preferences. Each was telephoned to discuss his or her preference and given a choice concerning a face-to-face member check or combination telephone and transmittal of the interview summary by mail. A comment sheet was attached to the detailed interview summary for comments and clarification of narrative. An explanation was given concerning the nature and goal of the member check activity. A couple of member checks were accomplished by telephone in addition to the respondents reviewing the written summaries for comment. Three of the individuals returned the summaries with comments or clarification on a few issues. Of the three individuals where a member check was not possible, one had developed a serious life-threatening illness, one moved, and the other I was unable to reach.

Confirmability

Confirmability is the process of confirming and measuring the accuracy of the data and the extent to which it is grounded in the stories of respondents or researcher bias (Lincoln and Guba, 1985). Processes used to enhance confirmability included the maintenance of a detailed reflexive journal, triangulation of data sources, and an audit trail. The reflexive journal included a record of the researcher’s feelings, interpretations, hunches, and preconceptions (Taylor & Bogdan, 1998). It was useful to include catchy phrases in situations that stood out. For example, the researcher labeled one set of observations “missed opportunities” where follow up was needed for clarification of data because the line of inquiry was such that the opportunity was missed during the initial interview. Secondly, the triangulation of data sources was accomplished by conducting
a face-to-face focus group section and face-to-face open-ended interviews. And finally, an audit trail was maintained that documented the various aspects of the study. Such notes and documents included observational, personal, theoretical, and methodological notes.

**Dependability**

Dependability addresses the reproducibility or reliability of the study for future inquiry by another researcher (Lincoln and Guba, 1985). First, the establishment of a procedural audit trail was intended to enhance replicability of the study, although the audit trail was not intended for exact replication (Schwandt & Halpern, 1988). According to Lincoln and Guba, leaving an audit trail requires adopting a “spirit” of openness and documenting each step of data collection and analysis. These documents included raw data, field notes, interview transcripts, and memos. Secondly, the use of two data collecting methodologies, a focus group and individual face-to-face interviews adds to the dependability of the study. Thirdly, triangulation of methodologies by combing phenomenological and grounded theory perspectives adds strength to the study and thus the dependability of findings.

**Transferability**

Transferability refers to the extent to which study findings are applicable to another context (Lincoln & Guba, 1985). Corbin and Strauss (1990) note that, “in grounded theory representativeness of concepts, not of persons, is crucial…. The aim is not to generalize findings to a broader population, per se” (p. 9) but to build a theoretical explanation by specifying phenomena relative to conditions that bring them about, how
they are expressed, and the consequences of those actions and interactions. This study achieved transferability through thick description for those desiring to make a transfer of the findings to determine if transferability can be viewed as a possibility (Guba & Lincoln, 1985).

**Ethical Concerns**

The researcher recognized that issues concerning death and dying, or reliving one’s life experiences had the potential to evoke strong and sometimes-painful emotions. Thus, there was sensitivity to the nature of the topic under study. The researcher went into the study with more than 25 years of experience in medical social work and work with older persons. In addition, the researcher brought considerable experience in the area of advance care planning. There were no problematic responses during the conduct of the study, and for the most part, respondents seemed to appreciate the opportunity to tell their stories.

Selection criteria was also aimed at ensuring that vulnerable populations as it relates to this topic, were not included in the study. Thus, individuals who were cognitively impaired, mentally ill, or otherwise incompetent or incapable of successfully participating were not considered for participation.

Written informed consent (Appendix D) was obtained from each of the ten respondents. In addition, it was emphasized to respondents that they were free to withdraw from the study at any time during the process without fear of retaliation.

Patient anonymity was maintained at all stages of the study process by the safe storage of data related to interview notes, transcripts, or correspondence, and pseudonyms
were used for identification purposes. At no time will respondents’ names be released when sharing results concerning the study findings. At the conclusion of data analysis all audiotaped interviews will be erased and destroyed. The study received initial review and was monitored throughout the process by The Ohio State University Institutional Review Board for the protection of human subjects.

Methodological Limitations

The study, because of the nature of the topic, included a sample of ten older African Americans who reside in a single geographic region, and who were selected on the basis of purposive sampling. Phenomenological research and analysis, because of time intensity, is not well suited for studying large samples. Consequently, study findings may not be generalizable to other populations. However, the study generated hypotheses that may be useful for further inquiry, both quantitative and qualitative, that further illuminates the themes identified in the present study.
CHAPTER 4
DATA ANALYSIS AND RESULTS

Demographic Characteristics of Study Participants

Participation in the present study required that respondents meet the criteria of being an African American, male or female, and age 65 or above. In addition, eligibility for the study required that participants not knowingly suffer from a terminal illness and possess sufficient cognitive ability to successfully participate in semi-structured narrative interviews. Each of the ten participants met the identified criteria. Figure 4.1 provides details of the demographic characteristics of study respondents.

The mean age, based on nine of the eligible sample was 72.7 years, with a range extending from 66 to 82 years of age. The tenth participant confirmed meeting the age criteria, as she was “over 65”, however, she stated a preference not to divulge her exact age to the interviewer. Consequently, the mean age is based on 9 of 10 study participants.

Two of the respondents had completed a living will and durable power of attorney for health care, while one had completed a living will only. Of the ten participants, six had executed estate wills. Each of the three respondents who had completed advance directives also had estate wills.

Of the seven respondents who did not have advance directives, all except one noted a favorable opinion concerning the efficacy of advance care planning.
Furthermore, they indicated their plans to complete advance directives in the future. They had undertaken varying degrees of planning to accomplish this task. Mrs. H, the 82-year-old, widowed, retired LPN, indicated no plans or a desire to execute advance directives. However, she expressed no opposition to the principle or goal of advance care planning, but stated it simply was not necessary in her particular situation.

One respondent had personally experienced life-threatening illness in the form of colon cancer. In addition, she was diagnosed with a heart condition that required the placement of a pacemaker. None had ever been on mechanical life support or faced with the prospect of such for themselves. However, each had experienced close-up and personal situations with family members or close acquaintances in which life support was required, or loved ones suffered from terminal illness. Four of the participants had experienced the death of a spouse; each of these was a female respondent. One male participant had a wife who suffered from the devastation of Alzheimer’s. Three of the ten recalled situations in which it was necessary for them to make decisions concerning loved ones in reference to comfort care versus life-support. Each selected comfort care when faced with this choice. In neither case had the relatives executed advance directives; nonetheless, each noted a level of comfort with the decision that was made.

The study participants, on average, were well educated. Two had bachelor degrees; three had graduate degrees (including a law degree); three had some college; one was a high school graduate, and one completed the tenth grade. All except two were fully retired from employment. The lawyer continued to put in a few hours each week in his law firm, and the minister continued to work in the ministerial field, but was retired from other employment. All were actively affiliated and part of local protestant church
congregations. The sample was better educated than the general population and their elderly cohort. Furthermore, an even wider disparity was noted when their educational level is compared to their elderly African American counterparts. Not surprisingly, given their socio-economic status, most considered the level of their medical care and coverage adequate, and they generally felt comfortable with the quality of the medical care that they received. Conversely, one female participant, who held a bachelor’s degree, and was separated in terms of marital status, noted a less favorable economic situation. She verbalized strong reservations about her ability to access quality medical care because of her economic situation. The two who had the least amount of education, a high school graduate and a respondent that completed tenth grade, still seemed quite comfortable, overall, with their economic situations.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Living Will</th>
<th>Durable POA for Health Care</th>
<th>Estate Will</th>
<th>Educational Level</th>
<th>Profession</th>
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<td>Mr. T</td>
<td>71</td>
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<td>No</td>
<td>No</td>
<td>Yes</td>
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<td>Retired Carpenter</td>
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<td>No</td>
<td>No</td>
<td>No</td>
<td>Graduate Degree</td>
<td>Retired Principal</td>
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<td>Mr. W</td>
<td>80</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Law Degree</td>
<td>Semi-retired Lawyer</td>
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<tr>
<td>Mrs. B</td>
<td>Over 65</td>
<td>Married</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Some College</td>
<td>Protestant Minister</td>
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<tr>
<td>Mr. R</td>
<td>68</td>
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<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
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<td>Mrs. A</td>
<td>70</td>
<td>Separated</td>
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<td>Yes</td>
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<td>No</td>
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<tr>
<td>Mrs. C</td>
<td>69</td>
<td>Married</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Graduate Degree</td>
<td>Retired Teacher</td>
</tr>
</tbody>
</table>

Mean Age = 72.7  
Age Range = 66-82  

Figure 4.1  Demographic Characteristics of Participants
Participant Interview Summaries

Participant interview summaries follow as a means of providing a closer look at the seven respondents who participated in the individual interviews. This provides more in-depth details of their familial histories and life experiences. Given the exploratory nature of this qualitative study, the open-ended interview guide was quite broad based in nature, and became more specific, though still somewhat broad, in order to elicit rich narrative from respondents. In addition, the broad based nature of the inquiry served, to the extent possible, to minimize influencing their responses. The interview guide follows:

- Tell me about your life and growing up.
- How have you experienced growing older?
- What does living a “good life” or “quality life” mean to you?
- How have you come to understand what it means to live a “poor quality of life”?
- What does living a long life mean to you?
- What meaning do you give to physical suffering and pain?
- What are your thoughts and feelings concerning living wills, or appointing someone to make your healthcare decisions for you, if you are too ill to make decisions for yourself?

Mrs. E

Mrs. E is a 66-year-old, widowed, retired high school principal and seasoned educator. She has two adult sons and several grandchildren. Philosophically, Mrs. E views age as “just a number” and has always felt a desire not “to get old.” She considers age to be relative, as it is defined by one’s activity level and outlook on life. In other

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words, age is not limited to chronological years, as it is largely a function of attitude and behavior. Consequently, she sometimes wishes she were back in the role of educator, around children in the school district. Being surrounded by children much of her professional life significantly influenced her youthful and optimistic outlook on life.

For Mrs. E, growing older has come in the form of noticeable physical changes, slowing down and declining in stamina. She notes examples of rising from her chair to experience her knees “cracking,” or standing to find that her “back pops.” Nevertheless, Mrs. E perceives these changes as a “few, minor, irritating physical kinds of things.” She is aware of their presence but maintains many of the activities that she values and has enjoyed over the years. However, some physical “ailments” have forced her to give up two of her longtime favorite activities, swimming and tennis. Yet, Mrs. E maintains a rather ambitious and productive schedule as a caregiver to an aged mother, an actively involved grandparent, a member of her church congregation, and as an active and productive member of her sorority.

Thus, the quality of Mrs. E’s life is not defined by physical changes, such as the “popping” and “cracking” that she describes. To the contrary, she considers the current quality of her life to be the best that it has ever been. Retirement affords her an element of time that a successful, yet demanding professional career, coupled with many other extra-curricula activities, never allowed. For example, now there is time for “concentrated” and lengthy daily meditation at the start to her day. In the past, competing responsibilities and priorities of home and career created a hectic pace, pre-empting the ability to do some of the simple, yet valued, enjoyable, and meaningful activities. The ability to better manage her day creates a kind of serenity in which she is
“at peace” with herself, finding release by not worrying about aging and tomorrow, living in “the now.” Mrs. E views the peace that she describes as a function of her positive mental outlook and spiritual insights and affirmations. “I confirm to myself constantly what I am, who I am, and who I belong to.” Spiritual connectedness is a core element of who Mrs. EH is and how she perceives her life.

With the sudden death of her husband seven years ago, came a turning point in Mrs. E’s spiritual life. Her spouse’s unexpected death led her to realize and appreciate the fleeting nature of life and thus the need “to make every moment count,” a creed, she explains, that she has lived by since experiencing this devastating and unexpected loss.

While living her life in a way to maximize the moment, Mrs. E also gives significant and detailed consideration to preparing for life’s “eventualities.” It was at age 50 that she began to plan and think about the type of medical treatment she would desire should she suddenly become impaired and unable to make health care decisions for herself, including issues surrounding the use of life support. While she has given careful thought to this matter, she has found it most difficult to document her wishes and preferences in writing.

This difficulty in executing advance directives documents presents a cognitive struggle for Mrs. E. On one hand, she knows very clearly that death is inevitable and unprompted or caused by the completion of such documents. However, on the other hand, there is the feeling and nagging thought that she is “saying yes to it [death], and it [death] may happen and become a part of reality quicker” than she would want. In her “mind” she feels that completing advance directives will “hasten” death to a reality, but conversely, in her “mind,” she knows “that’s not true.”
In spite of the cognitive struggle, Mrs. E expresses certainty that she wants to provide her two sons with written instructions to ensure that her end-of-life wishes are respected. She has had many discussions with them concerning her preferences, and it is her youngest son that she has informally chosen as her primary surrogate, to make decisions if she is unable to do so. The selection of her youngest son as a surrogate decision maker is prompted by the fact that her eldest son “doesn’t want to talk about those kinds of things.”

She emphasizes to her sons that she wants to avoid placing any undue caregiving burden on them should she become dependent. Consequently, she gave them detailed verbal instructions concerning her wishes. For example, she desires to be placed in a very nice multi-level assisted living community, with people of similar age and interests. As her care needs advance, she wants to be relocated to a higher level of care, preferably in the same facility. Being a primary caregiver for her mother, has prompted her to plan in such a way as to protect her sons from feeling that they are obligated to care for her in their homes should she reach a phase of life where she has similar needs as her mother. She takes this stance in spite of the sense of responsibility and obligation she feels towards caregiving for her elderly mother.

Mrs. E experienced first-hand, the role of one’s family as surrogate decision maker when her father suffered and died with terminal cancer. He had not completed advance directives, and her mother, as his spouse preferred not to make the difficult decisions. The physician’s assertion that Mrs. E did not have the legal right to make the decision and that the medical staff would “have to act in her father’s best interest” was unsettling for her. She steadfastly asserted herself, insisting that the family should be the
end-of-life decision maker in this instance. She facilitated the coming together of the small family nucleus, reaching a consensus not to maintain her father on what she viewed as futile life support. Mrs. E tape recorded the decision-making session as a means of addressing future concerns or questions from family members, and to facilitate her mother’s memory of what had taken place during the decision making process.

Had her father executed advance directives, Mrs. E notes that she would have honored them. However, in the absence of directives, written or verbal, she considered what she would have wanted had it been her. Given that she and her father “were so close” and similar in their way of thinking, she feels very comfortable with the decision that was made by the family, and places great value in a family centered approach to decision-making in the absence of written instructions. She feels this process does not place any one family member in jeopardy of potential “finger pointing” by other family members.

Considering her father’s situation, Mrs. E would not want to be placed on life support if it simply prolonged the dying process. It is important to her to spare her family the pain and suffering of being onlookers to a painful death, based on her experience with her father. Moreover, she would want to be kept free of pain and suffering in the face of terminal or life threatening illness.

While Mrs. E rates the current quality of her life as the best that it has every been, she feels that “the best is going to come in my seventies.” To a considerable degree, a portion of her life “revolves” around her mother. She expresses disappointment that the plans she envisioned for the two of them following her retirement have yet to be realized. Mrs. E notes: “We were going to follow the sun so we would never be in a time like this”
[referring to the harshness of Winter]. She holds fast to her commitment to care for her mother for as long as her health permits. However, should the time come when this is not possible or feasible, she will place her in an assisted living.

For Mrs. E quality of life in later years means to be active, “to be up and out.” Even if her mobility is inhibited, she “would not be inhibited in the least” to engage in meaningful and familiar activities. This is indicative of her belief and philosophy that “age is just a number.”

Mrs. D

Mrs. D is a 73-year-old, widowed, retired music teacher, with two adult children, a son and a daughter, and one grandson. She was widowed in 1977.

Music has been a lifelong interest and pursuit, as she began playing at her church in West Virginia at the age of 12. She grew up as an only child in West Virginia, in a coal-mining town. She was raised in a family that gave her lots of love, and although she was an only child, she experienced the frequent companionship of other children throughout her childhood, as there were other children frequently in the home. She excelled academically and recalls being skipped from the third to the fifth grade.

Growing up, Mrs. D describes her neighborhood as racially mixed. However, the schools were essentially segregated, with black children attending one school and white children another. The children played together, but did not come together in either the neighborhood schools or churches. In terms of making sense of this racial separateness, Mrs. D “didn’t think a thing about it;” it was just the way life was. But the differences and racial separateness became more apparent as she reached high school. The White
children became more distant and were not as much a part of the lives of the black children as had been the case when they were younger. But it really never bothered her very much.

Mrs. D recalls coming of age during WWII and seeing men return home from the war. She remembers as a young girl hearing people on the streets discussing the fact that the country was at war; she recalls feeling “terrified,” fearing that her father and uncle would be required to go and fight in the war as well. This was a “traumatic” time for her.

After college, Mrs. D was married and later gave birth to a son and a daughter. She faced widowhood early in life, in her mid-forties, when her husband died at age 46 after a 10-year illness. It was following her husband’s death that she began to reflect on what she calls “the innocence of life.” Innocence of life, to Mrs. D, means an understanding and acute awareness of the temporary nature of life: “It’s not there always and, therefore, it is important that one prepares for “eternal life.” Moreover, she began to search for meaning and purpose in life. She came to the realization that she was not fulfilling her purpose; and God, indeed, had a purpose for her life. She understands that this divine purpose is to help others get to know and accept Jesus, to come to him as a means of preparation for eternal life.

Mrs. D reflects on sitting with her husband in their backyard, counting their blessings. Yet sadly, within eight years, “they were all gone”—her husband, her parents, and then his parents. She felt, among other losses, a loss of protection—“Almost like somebody has been looking out for you all through your life and all of a sudden, I’ve got to be sure that I look out for myself.”
Suffering such tremendous losses was “heavy” for Mrs. D. This heaviness was best described as being thrust, without preparation, into total independence. She thought, “I’ve got to learn. I’ve got to know how to do this. I’ve got to know how to do that. Everything is depending on me. If it’s to be, it’s up to me.”

Now, Mrs. D has come to understand and make sense of the many losses in her life through her faith in God, and she realizes that it is her faith in God that gave her strength. “God is in control.” The lightening of the “heavy” experience, she attributes to Him and the knowledge that with God’s help, she could and would triumph over adversity.

Similarly, Mrs. D has come to understand, the nature of irreplaceable and recurring loss. Regardless of one’s faith, the loss is still very much experienced and felt deeply. While the relationship or the individual is irreplaceable, pursuing and building other relationships is paramount to weathering the storm and rebounding. Recently, she noticed that she’s “lost quite a few friends and that she must continually renew or make new friends.”

As she grows older, Mrs. D acknowledges physical changes that require a more extensive “checklist” to ensure that all essentials are in order, including the eyeglasses, the hair, and the teeth—that everything is on straight and in place. Additionally, she has noticed that she is much slower. Even so, she continues to maintain a rather ambitious schedule of activities as the Music Director at her church, a productive member of her sorority, and an active grandparent. Overall, she considers herself in good health in spite of the slower pace.
When Mrs. D thinks of “quality of life,” her focus is health. For her, having a “reasonable amount of health” is maintaining independence and staying active, enjoying and doing some of the things that have brought enjoyment to one’s life over the years. In addition, having financial and material resources play an important part in the quality of one’s life. A poor quality of life constitutes simply “existing from day-to-day” even though one is not necessarily ill. It is failing to contribute and perhaps abusing oneself through the use of alcohol or other drugs.

Living a long life to Mrs. D means “to stay” or to live as long as possible because she doesn’t know anything about “the other side of life;” in other words, death is unfamiliar. Even so, she questions whether she would want to live to be very old if she is burdened with a poor quality of life in terms of living with poor health, lacking independence in performing activities of daily living, and lacking the material or financial resources to adequately subsist. But a most dreaded loss is that of her mental alertness and orientation. She “could handle everything except senility.” She just doesn’t know how that “would work out.”

Pursuant to quality, Mrs. D feels that a person can still lead a productive life, a quality life, in spite of serious and physically limiting disabilities. As an example, she notes a friend who continues to perform as a concert pianist although she has experienced the amputation of both legs.

Regarding pain and suffering, Mrs. D gives no particular meaning to physical suffering and pain. She does not feel that it is necessarily retribution for or a consequence of one’s sins. As a matter of fact, she points to her father who was a “good man” who suffered and died from a “mean disease,” cancer.
Given that she does not wish to suffer or receive medical treatment that could conceivably simply prolong the dying process, Mrs. D has executed both a living will and durable power of attorney for health care. In addition, she has an estate will. Her decision to complete the documents was not prompted by any particular set of circumstances or events. Her stated rationale is that she was not getting any younger. She notes the observation that she has never seen anyone on a respirator come off and be well again. In addition, she would not want to put her family through the emotional trauma or financial strain of such an ordeal.

She trusts her son and daughter as joint decision-makers in regard to the durable power of attorney for health care. She is confident that they will adhere to her wishes as outlined in her living will. Her attorney has copies of her documents, and she has copies as well. While her children do not have copies, and have not reviewed the documents, they are aware that she has them and where to access them should the need arise. She has not had any extensive conversations with them about her wishes because “they don’t want to talk about it.” In her opinion, their resistance to discussing the subject is a function of their reluctance to face the fact that she is going “to leave them”—to die someday. Consequently, she urges them to accept and realize this fact, but doesn’t get into this subject “that much.”

Similarly, Mrs. D has not discussed end-of-life treatment wishes, or the fact that she has advance directives, with her primary care physician. While she hasn’t given much thought to discussing her treatment preferences with him, she notes that she would feel comfortable approaching him about this issue. As a matter of fact, she would feel most comfortable approaching him, rather than having him approach her. Should he
approach her first, she chuckles, this might be an indication that he thinks she’s going to
die. In spite of the lack of discussion about advance care planning, Mrs. D still feels
confident that her physician “would do what’s best for” her.

Mrs. D acknowledges the value of family discussion and involvement when
making decisions about end-of-life treatment for a loved one. However, she also feels
that where too many people are involved there is potential for confusion and conflict.
Nevertheless, she considers it feasible for each person to express their opinion and have
input, as the individual is perhaps equally important to each of them. Coming to a
consensus would be ideal.

Mrs. H

Mrs. H is an 82-year-old, widow, and retired Licensed Practical Nurse. She is the
seventh of ten children in her family and considers herself fortunate to have been raised
in a loving and close-knit family. Mrs. H has no children, but has nieces and nephews
with whom she has a close and loving relationship.

Mrs. H related her experience as a child with the loss of a “little white mouse”
whose name was Elmer. Elmer failed to shred the “new clean paper” that was placed in
his cage, and as a result fell victim to the cold and died. Mrs. H tells of the elaborate and
well-planned burial that followed, with her sister in the role of the preacher. Elmer was
put to rest in a matchbox lined with cotton in their yard. When a friend came by the
home and suggested that the children were “crazy” for burying a mouse, Mrs. H’s mother
responded: “They know exactly what they’re doing.” Although Elmer was a mouse, the
experience had meaning in terms of loss due to death, as they cared greatly for about the
little white mouse.
Mrs. H’s philosophy concerning living, dying, and growing older is guided by her ever abiding faith in God, and a strong belief in the value of a positive outlook on life. In her view, attitude is a strong determinant of how one looks at, and faces life’s eventualities and challenges, including death, loss, and growing older.

To Mrs. H “death is a part of living.” She is practical and realistic in her view that “we’re going to live, and we’re going to die.” Her Christian beliefs take away any fear of death, and she is comforted with the knowledge of everlasting life, understanding and believing that physical death is not the end of life for “Christians.”

Her feelings about loss and death are spiritual and very much reality based as well. For her, death is a given, but for “Christians death is a sleep” and there will be a reuniting with loved ones. While she understands the importance and value of grieving and a period of mourning following loss, there is comfort in the knowledge of this reuniting, and she feels strongly that persons suffering the loss of a loved one must “get over it,” loss, and move on with their lives.

Mrs. H is emphatic in her assertion that she seldom thinks of dying or making end of life plans because her focus is on living. She thoroughly enjoys retirement, is very active volunteering (e.g., grandparent reader), and is an active member of her church congregation. Furthermore, she values and emphasizes the importance of helping others and being of service. For a period of time following her retirement, she found her days to be very long as she engaged in various activities helping those in need. Mrs. HP feels that there is no lack of opportunity in the community to serve others. It’s a matter of putting forth the effort, having a positive outlook and attitude, and not allowing oneself to be boxed in and limited because of age.
Consistent with her positive outlook, Mrs. H places great emphasis on practicing a health conscious lifestyle in terms of diet and exercise. Consequently, she has maintained good health, visits her physician very little, and is not on prescription medication, except occasionally. She considers the side effects from many prescribed medications as more harmful than helpful. Even as a practicing nurse (LPN) she had nagging concerns about the negative effects of medications on patients.

Mrs. H is favorable towards longevity as long as she maintains her health, independence, and a “clear mind.” She does not want to be a “burden” on family members, although she feels that her niece and nephew would take care of her—but they have their lives to live and she has a strong desire to avoid having to depend on family for her care. Because of her desire not to be a burden to family, she has made her wishes known—that they place her in “one of the nicest nursing homes” in the event she is unable to care for herself. She prays fervently to the Lord to keep her healthy, and does her part by exercising and eating properly. In spite of all of this, she acknowledges a passionate belief that God is in control and that he has her life “mapped out.”

As an LPN, Mrs. H witnessed the pain and suffering of her patients. She prays that she doesn’t ever experience pain and suffering in the event of a serious or life threatening illness. She would not want “to go through” some of the situations and conditions that she witnessed of many of the patients for whom she cared during the many years she was a nurse. Similarly, she expresses concern about the pain of abandonment by families, a situation that many older individuals experienced in the nursing home where she was employed. She is encouraged however, that should pain and suffering be her plight, God will give her “the strength to bear it.”
Mrs. H sees changes in the medical establishment in the past 20 years that cause concern. She notes a “don’t care” attitude, at times, on the part of nurses and doctors, such that an older individual may be made “comfortable,” but not given necessary therapy or “tender loving care.”

Discussing the level of medical treatment that she would want if she could not make her own health care decisions has been something of a challenge for Mrs. H. When she attempts to approach the topic with her nieces and nephews she notes that they tend to avoid the subject by responding that she will live a very long life. She senses that they really don’t want to talk about it. And yet, she feels confident that she can rely on them to be attentive and respectful of her needs and wishes, and they will be there for her should the time arise.

Mrs. H does not have a living will, durable power of attorney for health care, or an estate will, and doubts that she would ever complete one, although it would probably be a good thing to do, she hasn’t given this much thought. She is enjoying her life in her later years and focuses on living and making meaningful contributions through service to others.

Mr. T

First and foremost, Mr. T describes himself as a “Christian.” At the age of 71, and recently remarried, he attributes his longevity to his “walk with Christ,” and his obedience to the teachings of his parents. Were it not for his Christian walk, he seriously doubts if he would be alive today, considering the unfortunate things that can happen to one who is out of sync with Christian precepts.
Mr. T was born and raised in Columbus, Ohio, the sixth of seven children in his family. He has two remaining siblings living, a brother and a sister. He is an Army non-combat veteran of the Korean Conflict, where he served as a medic. Mr. T has two adult daughters, and was recently remarried four months ago. He is a retired carpenter, and an officer in his church, a large protestant congregation.

Mr. describes his parents as “loving people” who had a wonderful and devoted marriage. They valued and lived by Christian principles and proceeded with care and caution in “how they carried themselves and how they interacted with their children.” Mr. T, with obvious adoration and love for his deceased parents, proclaims that they “loved the Lord,” and the “dynamics” of his parents’ love was “unparalleled” with any relationship that he has experienced or witnessed. His mother, he describes as a “strong-willed” woman, though loving and gentle. His father he remembers as kind and most loving individual.

While he considers himself as having been “born to poor parents,” they were “crafty,” and it was only after he graduated from high school that he realized that he was poor. This realization came about when his mother shared that they were unable to buy a suit for his graduation from junior high school. In spite of their economic state, his mother made certain that torn clothes were mended and that the children’s clothes were clean, although worn repeatedly. He recalls his mother having sent him, along with his siblings to bed, then washing and ironing the clothing that they removed prior to retiring to bed, to ensure that their clothes were ready to be worn the following day. Early on he learned the importance of using his funds wisely and saved money from his paper route to purchase clothing for himself.
Mr. T recalls growing up in Columbus, reflecting on the tremendous change in the City, from being “more like a little village” to a thriving major city. He points to the city’s mass transit system as an example of the changes, recalling the “streetcar tracks” and “trolley buses.” Growing up in Columbus, Mr. T did not “experience prejudice” early in life, and never lived in an all-black neighborhood; his neighborhood was racially mixed. He is of the opinion that “back then” how one was treated was based on “character” rather than skin color. Even so, he recognized that there were certain places in town “where being black did make a difference.” He chose not to go to such places, for example restaurants, as he could not afford them anyway. He questions why he would have wanted to be in a restaurant “with a bunch of white folks” when he couldn’t afford to eat there, “or even purchase a cup of coffee.” Consequently, the issue of racial intermixing or integration wasn’t a “big deal” for him.

He did not fully escape the ugliness of prejudice and racism, however. He recalls as a child being called a “nigger” by some little white boys once, but this incident, he and his brother “took care of” themselves. In a related vein, he recalls vividly being scolded by his mother, as he took a new phrase home that he learned in school, “white cracker.” It didn’t take long for him to realize that there would be no such language in his parents’ household. After all, his mother had taken in a young white woman because she had no place to go, and there was no room for hatred or name calling under any circumstances, and certainly not on the basis of one’s skin color.

Later in life, he relates an account of a reference to “nigger” by a white person, at age 21. He had recently been inducted into the Army, and was traveling through the State of West Virginia. As he prepared to eat at a local restaurant, accompanied by a
fellow white soldier, he was told: “We don’t serve niggers here in the restaurant. You have to go around to the side door.” He quickly cautioned his white companion to say nothing or that both of them would potentially be killed. He had been forewarned of what could happen simply by challenging white people in the south. Consequently, he clearly understood that both he and his white companion could be killed. As a white man “siding” with a black man, this young white soldier was not immune to such a predictable fate.

When he finally reached his destination of Camp Pickett, Virginia, he was cautioned not to go into town, with the warning that he could be killed by merely holding his head up while speaking to whites. He wasn’t used to walking down the streets with his head held downward. But, with interest, he observed that most blacks did not and dared not look white persons in the face while addressing them.

Interestingly, most of his remaining experience as a soldier, a military man, was a “joy ride.” Though trained as a medic, he escaped the horrors of caring for casualties of war. Although, he was trained for service in Korea, his enlistment time was up before he was scheduled to report there for duty. Fortunately, the racism and prejudice that he experienced early on did not repeat itself. To the contrary, officers and enlisted men alike treated him with respect. He found himself being called upon for prayer and teaching the Bible to fellow soldiers.

Having had these experiences and growing older, Mr. T is at peace with who he is and finds contentment with this knowledge. “I enjoy me,” he states; and with that he
enjoys growing older. Growing older for him—“It’s not miserable.” Moreover, time that is associated with advancing years has afforded time and experience with people that he would otherwise have never come to know.

When Mr. T considers the difference between someone who is enjoying life, as he is, and someone who fails to experience such joy and satisfaction, he considers “attitude.” The ability to maintain a positive outlook “plays a very big part in how you fare as an older person.” For Mr. T, growing older in no way means an end to learning or pursuing better conditions and circumstances. For example, he enjoys driving a new car and being introduced to the new gadgets and the comfort of new and improved technology. Conversely, the positive and optimistic outlook does not blind him to the reality that aging can and does result in a decline in one’s vibrancy and vitality. He recognizes that he doesn’t talk as fast, think as fast, or make up his mind with the speed that he once experienced. But he’s content with the knowledge that it takes more time, and at times more effort, to perform some of the activities that he enjoys and values, and those activities that are of necessity. Even so, he is not disturbed. To the contrary, he finds that a slower pace makes for a more enjoyable journey.

As a matter of fact, Mr. T would advise individuals in generations that follow to “find a way to live your life slower than the pace that zips out and goes around you.” Time cannot be recaptured; as one ages, efforts to relive what was can be elusive. Key to success in this effort is the ability to follow the proverbial figure of speech: “Take time to smell the roses.” He would warn and remind younger persons to understand that having fun does not necessarily translate into enjoyment. “Slow down,” are the words of wisdom that he imparts. “What’s the purpose of getting there early or before you’re due”? 
Mr. T knows that life can be and is rather short, even given longevity. Of seven children in his family, three remain. Mr. T recalls the loss of his elder brother, who was mentally retarded and had learning disabilities, at an early age. He remembers that he was a pre-teen and his brother was approximately 30 years of age. Mr. T reflects that this was his “first experience with death.” His older brother was “the first to leave the family.”

Upon reflection, he recalls not “feeling bad” because his brother was going “to meet Jesus anyhow.” Mr. T is certain of this because if his brother “sinned” during his lifetime, he didn’t know the meaning of such an act due to his retardation. He did not perceive his elder brother to be cognizant of sin. With his passing, he felt secure and comfortable in the knowledge that his brother was in a better place. In addition, his mother shared with the family her prayer that his brother “would leave before she did, because no one would care for him as she would.” As Mr. T “grew older and became more knowledgeable,” he felt as though his brother’s death was an answer to prayer. As a matter of fact, he “thought that it was kind of great that the Lord would answer his mother’s prayer and take brother before he took her.” That way, no one would mistreat him. For he had experienced the pain of walking down the street with his big brother and having people laugh at him because of his “feeble” condition. To have someone laugh at his bother was unpleasant to say the least, and the experience left Mr. T with some agonizing memories and bitter feelings about man’s inhumanity to man.

Mr. T also recalls his father’s illness and suffering from cancer. Daily, his father dealt with the pain from this harsh and devastating disease. Finally, he recalls, his father asked the church congregation “to stop praying that the Lord heal him.” Interestingly, he
remembers feeling somewhat “relieved or glad” for his father, as he knew that his dad was in a position to “make a good judgment call” about what he did or did not want. There were no written instructions in place, but his dad gave the family verbal instructions as his illness advanced. Without debate or discussion, his father’s instructions were followed.

Mr. T adored his father, one of the most loving persons that he ever knew. During his father’s illness, he “ministered” to him. He acted as his father’s masseuse” in an effort to massage and relieve the perpetual pain that he suffered. He massaged his stiffened legs that were so thin and affected because of the ravages of the disease, weight loss, and inactivity. Other times, “ministering” was in the form of talking to him, or just sitting with him, ministering in silence, just being there.

Later, maybe 25 or 26 years ago, while in his 40’s, Mr. T “lost” his mother. Unlike his father, she did not experience the physical pain and suffering. A stroke left her with memory loss, but she was maintained in her own home with family looking after her and making certain that she was cared for and safe.

Mr. T was not sure if these experiences had in any way shaped or impacted how he felt about death. “It may have”, he noted. But he was never one who looked on death as “necessarily awful…it didn’t have to be all that good, and yet, it wasn’t all that awful to me”, he explained.

Mr. T has not completed a Living Will or Durable Power of Attorney for Health Care, nor has he completed an estate will. However, since his marriage four months ago (at the time of the interview), his daughters have talked to him about a living will. In addition he has discussed the topic “in passing” with his new wife. His daughters would
have taken care of these issues previously, but now that he is married, his circumstances are different. He has not made any definite plans to pursue completing the documents, but is giving this some consideration.

Where life-sustaining care is concerned, he would not want to be on any type of life support “for any long, long length of time if, in the doctor’s opinion, it will have no real impact and it is unlikely that he would “get any better,” or it would simply prolong the dying process. He is comfortable with some of the medical care he receives, but “a little bit” uncomfortable with it as well. He doesn’t feel that the doctors are as “conscientious” as he would like to see them. He doesn’t consider his concerns to be related to his race or the race of the medical provider. He is concerned that “when they [doctors] get to know you, they relax and they take you for granted.” In spite of these observations, in general he feels comfortable communicating with his physicians concerning his health care needs and wishes.

Mr. R

Mr. R, age 68, was born and raised in the central Ohio cities of Plain City and Columbus. He is married, with two adult children, a son and a daughter, and five grandchildren. He retired from his position as a retail buyer approximately two years ago; his wife is retired as well. They have lived in Columbus, Ohio continuously since they bought a home there in 1958.

Their is a very close-knit family, and the pride and value of family is demonstrated in the prominent and lovely display of photographs of family members in the home. Both Mr. R and his spouse are active members of a local protestant church.
Mr. R recalls his experience growing up in Plain City, a small community located about twenty miles northwest of Columbus. He relates that very few blacks resided in there when he was growing up, perhaps 50-60 in a population of about 2,000. There were about five blacks that attended his high school. During his youth, he did not sense prejudice or racism in Plain City and never experienced racial problems. However, in neighboring small communities of West Jefferson and London, it was well understood by blacks that there existed prejudice in these towns. While he did not spend much time in these communities as a young person, older residents “passed down” the news of the existence of racial prejudice. He recalls vividly when London opened its public swimming pools, blacks were not welcomed. However, because it was a public facility, officials were without recourse in banning black individuals from the pool, and there were no further problems.

In terms of family and loss, Mr. R recollects the passing of his elderly grandmother when he was a young adult, maybe 21 or 22 years of age. She was in her 80’s and had been ill off and on for three months. He states that she was the first person that he “ever watched die.” He was at her bedside when she passed. It didn’t “hit” him at the time that she was passing, perhaps because there were other family members around. But when it “was over,” her passing, he “took it hard” and was grief stricken because he was very close to her, having been the only grandchild for a number of years.

He experienced the loss of other family members and acquaintances after that, but the death of a gentleman who was a co-worker, who committed suicide after he retired and moved to Florida, stands out. Mr. R was approximately 25 years old at the time. He remembers the death with sadness, and feels “it was quite a waste” because this
gentleman was “brilliant,” a very, very smart man.” In an effort to make sense of what caused him to take a gun and end his own life, Mr. R wonders if he might have had cancer or another serious illness or disease. He still wonders if he might have left a “note” that would have shed light on this very final and seemingly senseless act.

Speaking of the experience of growing older, Mr. R feels positive overall because he and his spouse have generally good health. Neither has faced a life-threatening illness, and they feel fortunate that this is so. In addition, both continue to live active lives. For example, every Saturday morning at 6:30, Mr. R reports to his church to arrange for seating in the sanctuary. He has volunteered and committed himself to this project for about two and a half years. Also, he does all of his yard work and other chores around his home.

Mr. R feels he has “a few more good years,” given that his mother lived to age 79 and his father to the “ripe old age of 83.” Regarding longevity, he is not opposed to living to age 90, or 100 even, as long as he is not a burden to his family and his health is “decent.” Decent health and not being a burden translates into independence in activities of daily living and doing some of the things that he enjoys. He would not want to rely on family or friends to come in and check on him everyday or “to depend on someone to always be doing something for you.” He thinks of his 96 year old cousin who recently returned from a visit to California, and the 83 year old neighbor down the street, who did well living alone until the last six months of his life. For him, these are examples of a quality of life that would support a desire for longevity.

Where quality of life is concerned, Mr. R rates the overall quality of his life as good and places great emphasis on the need for reasonably good financial health as well
as physical health. As a matter of fact, at this point he views his financial well-being, having the material and economic means to support himself and his spouse, as better than it was ten years ago. In terms of his health, it has been necessary to seek medical attention infrequently. Recently, when he underwent his annual physical, his doctor began treating him for hypertension, which is under good control. He also feels that he should probably take off a few of the pounds that he put on during the physically inactive winter months.

Although it is difficult to rate the many possible scenarios regarding physical illness or mental decline, Mr. R thinks of “not being in your right mind” and “blindness” as a dreaded and “kind of terrible thing,” given the very negative and profound impact on one’s independence and self-reliance.

If he reaches a point in his life where he requires family to care for him, to avoid being a burden, “the only thing left to do is go to a nursing facility,” he notes. He would not want to go, “but if that’s the best…what else are you going to do”? Part of being independent would be to take his own showers and baths, but if he had to depend on someone for these things, “you have to accept it; but you wouldn’t want it that way,” he stated.

Recently, Mr. R and his wife began thinking about planning for the future. Neither he nor his spouse has completed advance directives (e.g., living will, durable power of attorney for health care), but they are thinking seriously about completing these documents, along with their estate will. They are also considering whether the purchase of a pre-paid burial plan is in order. Mr. R explains that the rationale for beginning to make such plans is a consequence of their “getting older.” Their daughter’s recent
discussion with them concerning the need to plan is also a motivating factor. Furthermore, Mr. R has experienced firsthand the need for such documents in that he is “taking care” of an elderly cousin who has experienced two or three strokes, and she executed these documents during an admission to the hospital.

Mr. R and his wife plan to appoint their son and daughter as joint decision makers in regard to the durable power of attorney for health care. He feels very confident that his son and daughter will cooperate with one another and honor any wishes that he and his wife might outline for themselves. Mr. R makes it clear that he would not want to be placed on life support if it is unlikely to increase the chances of recovery and would only prolong the dying process. However, he would want to be kept comfortable and free from pain. He feels that with medication and treatment that is available currently, this should be very possible. He does not see a reason, religious or otherwise, to endure pain and suffering.

In regard to experiencing a loved one or friend on life support, Mr. R recalls that the woman for whom he worked was on a respirator, and she requested that the respirator be discontinued. It was her daughter who assisted in making the decision, but Mr. R is very much aware of the details. She was taken home where she passed the next morning, sitting in her recliner. He hadn’t really given the issue of life-sustaining care much thought prior to her death. He’s not sure if it made a significant impact on how he views advance care planning.

Mr. R also relates his experience with his mother after she suffered a stroke. She spent twenty-nine days in the nursing home before passing. When the nursing home staff called to say that she was getting worse, and inquired if they should refer her to the
hospital for treatment, he asked them not to admit her, as he felt that his mother, who had not completed a living will, would not have wanted to “be put on a machine.”

In regard to his wishes, Mr. R feels that their children are aware of what treatment he would or would not want in the event he could not make his own medical decisions. However, should he complete a living will spelling out his wishes, he will give his children copies for their records. Even so, if there were no living will to guide them, he feels confident that his children would follow his wishes, and they know and understand them.

Mr. R feels that he receives quality medical care when he needs it, but is quite pleased that he has been in good health, and, thus has accessed care infrequently. The race of the doctor does not matter to him. His main concern is that the doctor knows what he or she (the doctor) is doing. He has not discussed his wishes or preferences concerning end-of-life treatment with his family physician. However, he feels that it is best for the patient to initiate the conversation with the doctor since it may be somewhat uncomfortable for the doctor. His personal physician is his wife’s cousin, and he feels pretty comfortable initiating the conversation with the doctor.

Concerning the quality of medical care, Mr. R would like to believe that individuals, regardless of whether they have medical insurance or financial means to access care, receive “the same kind of care” as those who are insured or have the money to access care. Even so, he acknowledges that the phrase “money talks” may have some meaning, and uses an example of a millionaire who gets the organ transplant more readily than someone without funds as an example of money talking.
Mr. R thinks that if African Americans’ desire to want more medical care at the end-of-life it’s possibly related to their having been “deprived” for so many years, and therefore they want “a little extra now, maybe to make up for what their ancestors didn’t get. People just want to be treated better than their ancestors,” he commented.

Mr. W

Mr. W’s Christian values and Christian walk in life are at the center of how he views his life and how he looks at loss and death. At age 80, he is married, a semi-retired lawyer and father of two adult daughters and one grandchild.

An accomplished man, a lawyer, and the son of a lawyer, Mr. W recognizes very clearly that as a black man in America, he was the exception rather than the rule relative to his family background and socio-economic status. Being the son of a lawyer “in those days” thrust him into a status that was considered “high up” and, as such, as a young man he had “lots of ego” and contemplated that he would “set the world on fire.”

As a young man, seeking to live up to his aspirations and the expectations of others, he studied hard and served in numerous organizations, typically in a leadership capacity. His career choice was strongly influenced by his father’s profession. The power of this influence led him to reject his father’s encouragement to become a physician. So influenced was he by his father’s chosen profession of law, he “couldn’t see anything” but law as a vocation. He has never second-guessed his decision to follow in his father’s “footsteps,” and is satisfied with his choice of occupations, feeling he has done well in his pursuits. He strongly values “working for people—with people” and feels that he was called to be in a “social work type of work.”
Mr. W acknowledges that he was principally driven to excellence and leadership roles quite early in his life because of a passionate desire to demonstrate that he was just as good as whites in his abilities, and did not take a backseat in performance. When he entered the armed services as a young man, during WWII, he states he learned one of life’s lessons—that he “was just an ordinary person.” There was a turning point in his way of thinking, a reframing of his notion of the place he occupied in society, even as the son of a lawyer.

Thus, experiences in the military hold particular significance for Mr. W in his transformation from being “looked on highly” to becoming “an ordinary Joe.” The experience of confronting a military officer and being “busted” from a staff sergeant to a private taught him a never forgotten lesson: “You aren’t as good as you think you are.” This was a defining moment in his life that left a deep and lasting impression that he was accomplished, yet ordinary.

As a black attorney practicing during the height of the Civil Rights era, he recalls the experience of being viewed as inferior by the courts. Moreover, he remembers a time when even the black populous preferred obtaining the services of a white attorney to that of a black lawyer. He is proud however, that he, along with other black attorneys, made a difference and was instrumental in opening up the courts and paving the way for blacks to begin to experience success in the political arena.

Despite success in making an impact in these critical areas, Mr. W reflects on the Civil Rights Movement of the 60’s and 70’s with admitted regret. Although he was active behind the scenes during this momentous period, he views his failure to participate
more openly in the struggle (i.e., traveling to the south) as an act of cowardice. He reminds himself now that the Lord would have been there “to protect” him in such circumstances, in the face of personal danger.

Mr. W vividly recalls his visit to his mother’s home in the State of Virginia and seeing the signs to the restrooms marked “Colored Only.” Such signs symbolized boundaries and borders and were potentially deadly if defied. He had read about the beatings and lynchings associated with this very oppressive period. Such knowledge instilled a crippling, yet realistic fear, and admits that ‘til this day he feels the pain and regret of not being more openly involved in the struggle for equality for blacks. While he is proud of the many contributions that he has made to the cause of blacks, and people in general, these accomplishments are somewhat tainted by this sense of having failed to step out, take the risks, and trust God for protection.

Mr. W’s fervor for being active, excelling, and contributing to humanity at various levels and in numerous arenas remains with him. This is demonstrated by the many activities of which he is a part—his church, the Lion’s Club, Bridge Club, American Legion. In addition, he continues a part-time law practice—a list that is not intended to be exhaustive. At one point, he was tempted to rest on his laurels, having paid his dues; it was time “to sit back and let those young people work.” However, with further reflection, he determined that if one still has good health, “you ought to keep on doing.” Thus, he has “kept on doing” and making meaningful contributions.

For Mr. W, the wisdom and experience that comes with age has presented him with numerous opportunities to provide counsel to others. Furthermore, he believes strongly in assisting others with material needs and sharing his prosperity with those who
are less fortunate. Giving back and using one’s talents wisely and unselfishly are tenets that drive the way he lives his life. He believes that there is a definite purpose to “God keeping” him here, and service to others is key—socially, civically, and personally.

However, with increasing years come challenges. In spite of a very active life at age 80, Mr. W acknowledges that as he ages, he is physically unable to do some of the things that he once did in his younger years, but he has not allowed this to significantly hamper the overall quality of his life. A most significant challenge is the illness of his wife who was stricken with Alzheimer’s and is currently being cared for by their daughter. Nonetheless, Mr. W is of the opinion that “age has been a very, very good thing” to him. With age has come wisdom and faith that God will provide answers to life’s troubling questions and conditions.

Mr. W sees longevity as a function of divine purpose and service. He has experienced the death of many of his friends, some dying quite young. At age 80, he has outlived most of his friends and family members. There are very few of them left, he notes. During WWII, two or three of his close friends “didn’t make it,” having died in combat. In addition, he lost many friends and family members to illnesses such as cancer and heart disease. He states that there are times when he asks himself: “Why am I still here?” Again, the answer he finds in God’s divine purpose for his life.

Mr. W’s acceptance and coming to understand death, as a young man, including the death of his young friends to war, is rooted in his religious upbringing and spiritual connectedness and insights. While “it’s a blow” initially, and there is the question of why the Lord took the loved one, why the loved one died, “pretty soon you outgrow it
and realize this is God’s will,” he reflected. The sense of loss and grief are relieved by the “pleasant memories,” although there is sorrow that they are gone. There is hope and trust that they are with the Lord, he stated.

Over the years, Mr. W indicates that he has learned to accept death much more readily. In his later years, he is less prone to question, “Why did God do this”? In some instances he has even felt a sense of relief, and viewed the passing of a love one as a release from pain and suffering. In spite of the emotional pain, life goes on. “It doesn’t cause the world to come crashing down”, and someone ultimately comes along to fill the vacant spot or role of the deceased. That is not to say that they fit perfectly into the shoes of the deceased, but progress continues and there is a rebounding.

With loss and grief there is pain and suffering. Mr. W “hates” to see pain and suffering and would not want to suffer in the event of serious or life threatening illness. He does not consider there to be any nobility in pain and suffering. He observed his mother suffer the devastation of diabetes, requiring the amputation of her leg, but he is still thankful that neither of his parents appeared to suffer harshly at the end of their lives. He has witnessed women in his church who have demonstrated that one can enjoy a reasonably good quality of life even given poor health and physical handicap, including the loss of limbs. He observes that they have a way of uplifting those around them. He expresses great admiration for their strength, courage, resilience and faith in God, moving on in spite of their circumstances.

Despite his admiration for these individuals, Mr. W would “hate to get in the position where someone would have to take care” of him. He values immensely his independence. Consequently, he notes that he would want “to go quickly and quietly”
and have his mental faculties intact. Nevertheless, should a debilitating illness be his plight, he would want to be an encouragement to others and make the best of his life, following the examples of individuals who have been an inspiration to him. He doesn’t believe in and is strongly opposed to giving up.

In regard to medical care, Mr. W feels that patients should respect the advice of their physicians. He reasons that there is no need to pay a doctor for services if one fails to comply with their advice and counsel—as one would follow the advice of a minister or a lawyer.

Overall, he is pleased with the medical care that he receives. Mr. W considers the disparity or potential disparity in health care as a function of socioeconomic status rather than race. Those who can afford health care have equal opportunity for quality care. But he expresses concern for individuals who are low income, uneducated or on public assistance in regard to health care access and quality medical care. He wishes that the government would do more to ensure quality medical care, no matter what the socioeconomic status of the individual happens to be.

Mr. W and his spouse completed advance directives documents, the living will and durable power of attorney for health care several years ago. As an attorney, he advises his clients to complete advance directives and the estate will for several reasons—to avoid confusion and family conflict, as a means of making their wishes known should they become unable to speak for themselves, and to promote stability and continuity in the family system.

Mr. W feels that he has everything “in pretty good order” where advance care planning is concerned and trust that his two daughters will carry out he and his wife’s
wishes. He has confidence that his daughters will respect and conform to his stated preferences, although they are reluctant, especially the eldest daughter, to talk death.

As an attorney, Mr. W sees value in having family members, or significant others included in the discussion of advance directives with his clients, especially with older persons. This facilitates all involved having a better understanding of the rationale for completing advance directives and the implications for their use.

In recent years, Mr. W observes that there is an increase in the number of people completing advance directives, but continues to be surprised at the fact that often people don’t have advance directives, estate wills or a general power of attorney. Moreover, he sees it as something of a “tragedy” that more blacks are not completing advance care plans. He reasons that this is particularly important since blacks “have advanced to the point where” they have something in terms of material assets and can participate in economic areas from which they were once excluded. Mr. W is of the opinion that “fear, that old phobia” plays a significant role in the reluctance of individuals to prepare, discuss, and consider the need to plan for these eventualities.

Mrs. B

Mrs. B is a woman who puts her spiritual and Christian walk first and foremost in her life. She does not allow herself to be limited on the basis of the expectations of others. She is a woman who has, throughout her life, pursued multiple interests and vocations, including work as a certified home health aid, activities director, ordained minister of the gospel, preacher, missionary worker and bible school teacher. Her
primary work at this juncture is that of a protestant minister. She prefers not to
tell her age, but readily acknowledges that she is “over 65.” She is married and has six
adult daughters.

Mrs. B has been a minister for more than 20 years. Prior to her “calling” to the
ministry, she had “a deep burning” in her life, a “calling” that she could not express.
Following the acceptance of this calling, she began studying very diligently to prepare to
“preach the gospel to the lost world.”

As the youngest of 13 children she grew up in Tennessee on a 500-acre Cherokee
Indian reservation, being of African American and American Indian heritage. Mrs. B
describes her life growing up as a “beautiful life” with loving, though strict, parents. She
feels fortunate in that her material needs were always well met by loving parents.

Mrs. B’s father emphasized very early in her life the importance of each of the
children attending college and furthering their education. True to her father’s teachings
and wishes, she developed a deep and abiding thirst for knowledge and continuous
learning, regardless of age or circumstances. Possessing a strong belief and holding
strong values regarding learning and higher education, Mrs. B has attended local
universities taking such courses as gerontology, leadership development and law, to name
a few of her educational endeavors.

The love of education, life long learning, and professional excellence has greatly
influenced her and her husband of more than 50 years in the rearing of their six
daughters, each having a college education, and the youngest holding a law degree. Mrs.
B is understandably very proud of the success that she and her spouse continue to
experience as parents, and their daughters’ individual and collective success in life. Her
smile, as she speaks of each of her daughters and proudly shares their photographs, is
unmistakable evidence of her deep and abiding love and devotion towards her family.
Similarly, her passion and commitment to serving her fellow man are evident, not only in
her ministerial duties as a minister, but also in her contributions and service to her
neighborhood and community.

Mrs. B thrives on staying active, being energetic, persistent and determined. As
an example of her zest for life, she describes past experiences of playing ball with a
group of young people from her church, refusing to give up as she searched for the last
word to complete a cross-word puzzle, or being dressed in “little white tennis shoes,”
bobby socks, and braids as she walked across the college campus—never allowing her
age to deter her in pursuing those things that she enjoys.

In spite of her very positive outlook on life, her life has not been void of
challenges and losses. Prior to her birth, “four or five” of her siblings died at a young
age—one, she recalls at about the age of ten with meningitis, and another with
pneumonia. At the age of seven or eight, Mrs. B recalls that she “lost” a cousin. This
cousin was a married, young adult at the time of her death, and she was one whom Mrs.
B looked to as a surrogate mother. She often went into “the city” to spend weekends with
this beloved cousin.

Mrs. B had a difficult time “getting over” this significant loss and recalls that she
“wanted” to be alone.” She wondered: “Jesus, why [did] you take my cousin?” She
longed to know if He [Jesus] could bring her cousin back. She relates that she expected
an answer. She reflects on her mother’s words: “Well, you know, we didn’t come here
to stay”—her mother’s way of letting her know that everyone would die someday. As a
child this was a very painful truth that her mother pointed out, that family and loved ones would “leave one another one of these days.” She remembers, as a child, responding inwardly: “Oh, not my family; not my family.”

Mrs. B recalls that indeed “they started leaving”, her father (who was already older when she was born), sisters, brothers—her sister-in-law who died very recently (just prior to the interview). Of twelve siblings, Mrs. B has one brother remaining. As she grew older, she “could accept knowing that the Lord [was] taking.” There was a transformation from a young child who wondered why in the loss of her cousin, to an individual who had become spiritually grounded, and found answers to the questions of her youth through biblical and spiritual truths.

What is more, she credits the Lord with giving her “strength through it all,” and she attributes her mother’s teachings as well. With the many losses that she has experienced, she continues to gain strength from the knowledge that she will reunite with loved ones, that they will be a family again, in eternity. This knowledge and belief comforts her. She recognizes that with spiritual and mental maturity she is better able to understand her mother’s words. “But the main thing was that [family] was going to be together again.” This is important to her in the acceptance of the loss of loved ones to death.

The same faith and beliefs that sustained her in the aforementioned losses “kept” her as she faced serious personal illnesses. She feels passionately that one must not give in to infirmity and illness. She has experienced multiple and serious medical challenges to test her faith and her resolve.
Mrs. B places her trust in the Lord when facing life’s turbulence and uncertainty. Some years ago she was diagnosed as having a cancerous colon polyp, which was surgically removed. However, when the doctor suggested chemotherapy as an additional treatment measure, she declined further treatment. This decision was based on her fervent belief of God’s ability and assurance of healing—His divine healing power. Furthermore, she trusted in His “will for her life” and she stood with the confidence that He would bring her “through.” While chemotherapy was a means of healing, she sought divine healing, and joyfully shared that she has experienced no further problems in this area.

The affirmation of her faith was also a sustaining force when Mrs. B was diagnosed with a heart condition that necessitated the placement of a pacemaker. With victorious fervor and passion, she explained that the elevated blood sugar that was present prior to the need for a pacemaker has not returned because of divine healing. Her strong faith led her to affirm: “Well, I’m not looking for it to come back”! There is an unyielding belief on her part that one must take a stand; and that stand is driven by one’s faith.

As an ordained minister, Mrs. B has had numerous opportunities to minister to the dying and families of dying individuals. In so doing, she counsels and encourages them to respect the end-of-life wishes of their loved ones. She believes in and values family centered decision-making in those situations where advance care documents are not available for the dying individual who cannot speak for him or herself. In these end-of-life counseling endeavors, she generally views her role as a spiritual advisor, as one who provides emotional support and spiritual guidance, leaving final and specific decisions to
the family or individual. In regard to life support, she sees no value in maintaining an individual on life-sustaining treatment if it only serves to prolong an inevitable death. She believes this is a time to “release [the individual] to God.”

Regarding her own end of life planning, Mrs. B has not completed a living will or durable power of attorney for health care, but anticipates calling her family together in the very near future to discuss her wishes. She expresses very definitively that she does not wish to be placed on life support measures “whatsoever” if this would only prolong the dying process. She would “like to go peacefully” and however “the Lord sees fit.”

She plans to put her wishes in writing and have her family sign concerning their awareness and agreement to carry out these wishes, with the goal of minimizing disunity. She is confident that the two daughters that she plans to appoint to “take charge” of her affairs will adhere to her wishes—will “follow her footsteps.”

Mrs. B has several beliefs and practices in regard to successfully traveling life’s rough roads: (1) “You can make it you try”; (2) “I never give up” when met with challenging situations; (3) Don’t entertain negative thoughts and practices; (4) God heals through miracles; and (5) there is eternal life after physical death.”

Core Categories

This section focuses on an examination and interpretation of core categories that were identified during the analytic process, having utilized the framework outlined by Maykut and Morehouse (1994) as a data organizing and analyzing procedure. Maykut and Morehouse note that in this approach, labeled “interpretive-descriptive”

The skilled researcher becomes adept at weaving descriptions, speaker’s words, fieldnote quotations, and their own interpretations into a rich and believable descriptive narrative (p. 122).
According to Corbin and Strauss (1990), “concepts that pertain to the same phenomenon may be grouped to form categories” (p. 7) which are more abstract that the concepts they represent.

- The Experience of Growing Older
- Coming to Know Death
- Making Sense of Death and Loss
- Cognitive Dissonance
- Measured Trust
- Race as a Constant Companion

**The Experience of Growing Older**

Respondents’ views regarding growing older reflected a philosophy and belief concerning the very relative nature of aging and time, the sacredness and fleeting character of life, a belief in divine intervention, life after death, and that earthly time gives way to “eternal life.” They consistently stressed the need to remain generative, encouraged, and hopeful when the inevitability of time presents expected and unexpected challenges.

Given the challenges and changes that come with passing time, the process of growing older or becoming old is experienced as a time of replaceable and irreplaceable losses. Such losses they attributed not merely to death but also to losses experienced due to changes in physical ability and stamina, or mental agility and wit.

Thus, the extent to which losses and challenges were experienced impacted how they viewed and expressed a desire for longevity. Consequently, longevity, and a desire for such, was a *conditionally* sought after feat. They identified very specific conditions and circumstances under which longevity was attractive to them. These situations were
noted without hesitation, and were measured and evaluated on the basis of quality as they defined it. Maintaining physical and economic independence, staying active, enjoying good health, and being generative were criteria that qualified for the desire and attractiveness of a long life. Conversely, they very clearly identified those circumstances and situations where the desire for longevity would be significantly tempered and lose its attractiveness.

Time and Aging

Study participants were asked the broad and open-ended question: “How have you experienced growing older”? The goal of the inquiry was to elicit rich thick description of their philosophies, beliefs, and attitudes that were an outgrowth of their experiences associated with growing older.

Mrs. E, a 66-year-old, widowed, retired principal, and mother of two adult sons, shared her longstanding philosophy about what age and aging means to her. In so doing, her words reflected a complex and somewhat contradictory view concerning how she viewed age and how she makes sense of growing older.

Mrs. E: “Well, philosophically, I’ve always thought age is just a number, and I’ve always said I didn’t want to get old. And I really wish I was still in the school district around kids because kids tend to keep you young…”

In a similar vein, Mrs. H, an 82-year-old widow, and retired LPN, with no children, has a very definite way of looking at age and aging and is quite adamant in explaining her distaste for the term old. “You know, I never think of growing older. I… you never hear me say old in my vocabulary. I never use the word old. I enjoy my older age…”
Furthermore, Mrs. H chastised her elderly cohort for what she interpreted as negative and fatalistic ideas about aging. There’s more to life than waiting to die, she exhorted:

“And I hear people say, ‘Oh well,’ one lady said, ‘I’m just waiting for the Lord to call me.’ I said, ‘Girl, stop talking about that.’ You know, think positive. You have a nice place to stay. You have children to come in and see you. Try to get out and do something instead of sitting around worrying about when the Lord’s going to take you, put you to sleep and all that. There’s more to life than that.”

Mrs. E was in agreement with Mrs. H, as she reflected on experiencing the sudden and unexpected death of her husband seven years ago, and with this experience, an epiphany that speaks to the meagerness and fleeting nature of time, a precious and scarce commodity in which there is no room to be wasteful:

“But on the day he passed, I left home that morning and he was in great spirits… And we just had a very nice conversation, and about two o’clock in the day he sent me flowers… So I got home about eight o’clock. And when I turned the light on in the family room, he had expired. And, you know, that brought the realization to me that, hey, life is very…I mean, we have to make every moment count. And uh—so I just sort of lived by that ever since…”

Similarly, Mr. T, a 71-year-old, recently remarried, father of two adult daughters, and retired carpenter, responded to the question of how he has experienced growing older, and voiced a strong sense of his identity as one who is growing older. Furthermore, he expressed appreciation for the added time that growing older has given him to experience meaningful relationships.

“I can truly say that I like who I am. I’m not confused by who I am. I enjoy me and I’m enjoying getting older. I’m not miserable…. It’s something that I enjoy because it’s afforded me time and it’s afforded me experiences with people that perhaps I would never have had a chance to meet or interact with. And I really enjoy it [growing older].”

The wisdom that is acquired over time has taught Mr. T to take time to smell the proverbial roses. He cautioned the younger generation and emphasized that time cannot
be recaptured. “Take time,” he declared. The wisdom of growing older has taught him to slow down. He asked, “What’s the point of getting there early or before you’re due”? Then, he warned with fervor:

“When you get there you have to wait. So take your time…. We can only look back and say, ‘Oh, I had fun, but translate that into enjoyment and you really can’t say that you enjoyed too much because you were too busy doing all the things that had really no meaning, no purpose, no value, no direction…Find a way to live your life slower than the pace that zips out and goes around you… Fill you life, but don’t fill it to overflowing…. Enjoy what you have when you have the facilities [sic] and when you are able to enjoy it.”

Mrs. E agreed with Mr. T concerning the prudence of limiting life’s hectic pace:

“You know there was a time in my life when I met myself going and coming…. I had school responsibilities; I had home responsibilities. I had tried to take all of these things and balance them together. And while I though I had a good quality of life at that point, I had a hectic life, really hectic life. And so, now I’m just sort of at peace with myself.”

And like Mr. T, Mrs. E noted satisfaction with who she is and where she is in life.

“I’m just very happy. I’m just very, very happy with myself at this point in my life… I don’t worry about aging and tomorrow. All I try to do now is to live in the now.”

Mr. W, an 80 year old, married, semi-retired lawyer, and father of two shared his perspective on how he has experienced growing older. His perspective emphasized the value of being productive and active as one who is older. Like Mr. T, he too, related wisdom that is a product of time.

“For a while there, when I first became older, I said, ‘Well, I’ve paid my dues. I want to sit back and let these young people work.’ But then I’ve heard the ministers preach it, and I’ve heard other people say the same thing—well, if you still have your health, you ought to keep on doing. So I’m doing more now than what I use to do before then, ‘cause I’d quit. I said I’d just let them [young people] do the work; I’ve paid my dues. I’ve done all I can do in the community. Let’s let these young people work. And now I’m starting back to work—doing work in the church and in the community. I think I still need to work as long as I feel good…. I think age has been a very, very good thing for me. It’s helped me
become more—uh, I guess wiser. It’s been a big influence to help me help other people and that’s what we’re here for because God doesn’t have hands or doesn’t have arms or shoulders or feet. And so, we have to be God’s helpers.”

Responding to the question of how he has experienced growing older, Mr. R, a 68 year old, married, father of an adult son and daughter, and a retired carpenter, suggests a certain comfort level with growing older.

“Well, it hadn’t bothered me a whole lot because both of us [referring to his wife] still have our health. You know, we have little things that pop up but nothing real serious. But I haven’t had any real hang-ups about it. I do volunteer work over at the church, and that kind of keeps me, you know, we—every Saturday morning I’m over there at 6:30 [a.m.] and we put the chairs down on that main floor—setting up 120 chairs. There’s about four of us who do that every Saturday morning.”

Mrs. B, a married, “over 65-year-old” (she chose not to divulge her age), mother of 6 adult daughters, and a protestant minister, talked about spiritually triumphant experiences and her faith in a divine being, as she reflected on what growing older is like for her. Again, like other respondents, she made the connection concerning the value of being and staying active.

“You know—but I thank God because I have been through many things and God got me through it ‘cause I’ve been through a pacemaker operation. You know, God brought me through that. And I’m still active… he [her physician] always said, ‘You wore your heart out because you’ve been a busy lady.’ And when I got to the hospital, he said, ‘your heartbeat is down to 40. Now, if you let it get down to the 30’s you’d be out of here…. I said I wasn’t worried.” I said, ‘You know, whatever the Lord’s willing for my life’… That’s what I try to live by. I can’t live one week at a time, but I can live one day at a time…. But I said, ‘But I thank God for allowing me to not feel old. I feel young inside and that makes me look active on the outside.”

For the most part, each of the respondents demonstrated a zest for life and a determination to fight against any adverse odds that may be associated with increasing years. By no means do they appear to be in denial concerning any adversity that time and
living bring. However, they believe that they still have contributions to make and are unlikely to allow themselves to give in to adversity, the aches, the pains, or the losses that come with time. They are prone not to allow their ages to define or limit them.

**Growing Older as Challenge and Change**

In spite of the many positive experiences and philosophies that the participants espoused concerning growing older—wisdom that comes with time, maintaining a productive lifestyle, and viewing aging as an opportunity-- for this cohort of older persons, aging encompassed a myriad of experiences that posed significant challenges. These challenges can best be characterized as losing, replacing, and rebounding—losing loved ones and losing certain physical and mental abilities. Associated with the losses, however, respondents addressed replacing and rebounding despite challenging blows. These experiences were poignantly captured as they told their stories of what it has been like to become and experience increasing age.

Mrs. D, a 73 year old, female, widowed, mother of an adult daughter and son, and a retired schoolteacher, recalled multiple losses through death, that came within a relatively short period of time. Central to her comments was the idea of unintentional abandonment by her family, a longstanding and valued support system. Losing them required her to become self-sustaining—rebounding and replacing following loss that felt “heavy.”

_Mrs. D_: “Here recently I’ve come to notice that I’ve lost quite a few friends.”

_Interviewer_: “Lots of losses”?

_Mrs. D_: “Yeah. And uh—even the people that I first, you know, was in contact with, here in the church, a lot of them are gone. And we have to continually renew or make new acquaintances, associates and…” [Voice trails off]
Later, as she referred to recurring familial losses, Mrs. D recalled:

“Then when it got to my parents, it seemed like everybody just went within a short period of time. My husband passed before my parents did—and then my mother and my father, in that order…and his [referring to deceased husband] mother and his father. In a period of say eight years, they were all gone. And here I am—almost like somebody has been looking out for you all through your life, all of a sudden, I’ve got to be sure that I can look out for myself.”

Interviewer: “What did that feel like?”

Mrs. D: “It was heavy. Yeah. But I knew that with God’s help…”

Interviewer: “Describe heavy for me.”

With laughter, Mrs. D responded:

“It’s uh—I’ve got to learn. I’ve got to know how to do this. I’ve got to know how to do that. Everything is depending upon me. If it’s to be, it’s up to me. And there’s nobody here for me to consult with or help me make decisions about certain things.”

Mrs. H recalled her experiences as a nurse and recounted how growing older can mean an absence of family, and an abandonment by the living as compared to Mrs. D’s feelings of abandonment by the dead:

“I find it’s very sad at times—when I was working in the nursing home, a son or a daughter, or maybe both, would bring a father or a mother there and leave them and never come back. And then when there’s—there’s nobody there with them when they’re dying, except the nurse who has developed a relationship…. And when you call them and tell them that Mom’s quite ill or their Dad’s quite ill—then they come in, sometimes, you know—‘What happened?’ ‘Well, I was busy.’

She inquired with dismay and bewilderment to the families: “But you were too busy to come back for something like that”?

Mr. W recalled the deep pain of losing loved ones and acquaintances, but he suggested that life goes on and there is a rebounding and replacing:

“I hate to say, at this stage of life, it is hurting to have someone that you like and you associate with, and you know, close to you—it hurts to see them pass away. But I feel it’s God’s will. It’s not what we want. I’d like to have them all here
now, but it’s what God’s will is. And, it’s not the old saying that only the good
die young. It’s just a matter that God picks the time that they should go. And why
they should go? I don’t know. It doesn’t cause the world to come crashing down,
because I’ve learned from my own experiences that someone has to come along to
take your place. See, I’ve been president of a number of organizations and when I
stepped down as president, someone else took over and did even a better job than
I did…so there’s always someone coming along to take your place.”

There is the change and challenge that comes with losing loved ones to death, and
similarly, there is change and challenge in losing physical or mental ability or
experiencing a generation gap. Nevertheless, the respondents remained encouraged.

Mrs. C, a 69-year-old, married, mother of two adult daughters and one son, and a
retired schoolteacher, shared her experience concerning changes in physical abilities:

“I have seen many changes. For example, when I built my house in the 1960’s, I
could run up and down the steps very easily. Now, I find myself walking, at 69
years old, walking up those same steps and sometimes going slowly due to
arthritis or maybe some aches and pains, depending on the weather. I think I
could give the weather report by how I’m feeling some days. But I’m looking
forward to a very long life. I’m not on any medication and I’m quite healthy.”

Likewise, Mrs. E explains growing older and its physical impact:

“…But my experience, as I get older, has come in the form basically of physical
things that I’ve experienced. When I rise from a chair, my knees crack. When I
stand up sometimes, my back pops. I can’t stand as long as I, you know, used to.
So basically, the aging process for me has been a few, minor, irritating physical
kinds of things. The other thing I’ve experienced about aging has been that—I’m
slowing down a bit in terms of my physical activities. While I would really like
to play tennis, as I once did, and like to swim, these physical ailments keep me
from doing that.”

Like Mrs. C, Mrs. E considered the quality of her life as “very, very good”, in spite of the
changes that have taken place as a consequence of the aging process.

In response to physical and mental changes, Mrs. D referred to the checklist that
is now necessary, and the slower pace at which she accomplishes tasks. With laughter,
she observed:
“Physically, when you get ready to go out, you can’t just jump up and go out like you used to. You got to see is my hair on straight? Do I have my glasses? Are my teeth in? You’ve got a bigger checklist to go down to make sure—am I ready to go out? It takes more time for me to get ready and I find that I’m much slower. As a slow person anyway, it takes more time for me to go out and the like…what was the question again?”

Mr. W suggested that growing older was being left behind to ponder the existential nature of his life and why he was spared:

“I’ve had several of my friends die of cancer and heart attacks…. I’ve had a couple die from—older, older; as people get older they die from a lot of other things, but primarily cancer and heart conditions. People pass away, people who were bigger and stronger than I was, big and healthy—and women who, voluptuous, you know, nice, well built, and they passed away too. Why am I still here? Unless God has a reason for it…I’ve outlived both my parents…all the other folks are all dead. I only have one aunt left. She’s a hundred and three years old. She’s still living.”

For Mrs. D, growing older has also meant loss through generation gaps and the lack of commonness of experience that is challenging and a consequence of time and changes:

“I’m closet to my cousins on my mother’s side because they’re nearer my age. We grew up together. Those cousins—they are younger than I am because I taught them. And when we get together for holidays and things, I don’t have anybody to talk to, really. I remember, my dad said—now my dad lived to be 84—yeah, 86. But I remember him saying he didn’t have anybody to talk to who knew about the things that were going on when he grew up. And I’m beginning to experience that, especially when I’m with them.”

Mrs. E reflected on the disappointment of having planned and reached retirement after many years as an educator, to find herself caring for an elderly sick mother. Nonetheless, she indicated that she looks forward to and is optimistic about future years:

“As I age—and I still think maybe the best is going to come in my seventies. Because right now I have restricted myself to my mother’s wishes and my life revolves around her, which is not the way I’d like it to be—see, when I retired, I had this whole thing in my mind what my mom and I were going to do… We were going to spend—we were going to follow the sun so we would never be in a
time like this [referring to the glistening snow outside]. So we were never going
to be in the snow…. but once I retired that never happened. You know, it just has
not happened….”

Successful Aging and Quality of Life

Notwithstanding the many challenges and adversities that respondents’ view as
accompanying the aging process, this cohort of older respondents expressed a general
attitude of optimism about the quality of their lives. Furthermore, they held very definite
views concerning the importance of a positive attitude, maintaining good health, financial
stability, and staying active, both mentally and physically.

For Mrs. B, maintaining a good quality of life means persistence and overcoming
the odds associated with infirmity:

“… Keep going and stay as active as possible. Because we have a program
sometime in this neighborhood—I’m constantly telling these people when I meet
with them, ‘Don’t give up.’ I mean regardless of what type of ailment you have
in your body, go as long as you can stand it because sometimes you can make the
things become better by exercising certain part, by pushing on your limbs, and
will not get stiff on you, you know.”

Likewise, Mr. T suggested that successful aging requires that one continuously
strive for and maintain openness to lifelong learning:

“He [the elderly individual] doesn’t have to stop learning. He doesn’t have to
stop enjoying the things that come into his life that can and would make it better. I
loved growing up and I loved my old cars, but I also am happy and thrilled that I
can drive one of the newer ones that ride differently…. they have more gadgets
for me to learn about, and I don’t mind learning about them.”

This openness to continuous growth, Mr. T acknowledges, is not without an
awareness of changes in mental aptness, but such changes he readily and
unapologetically accepts and feels that they can be positive:

“I know that I don’t think as fast about some things as I once did. I don’t even
talk as fast as I once did. I don’t make my mind [up] as fast as I once did, but I’m
not disturbed because I don’t. I know that I have it to do and so I do it, but I take more time to do what I do now and I enjoy it better.”

Mrs. B related firsthand experience of refusing to give in to physical maladies she faced and the importance of maintaining a positive outlook:

“And then all the sudden this attack hit my body, this accident-- a little arthritis this side [pointing to her right side] in the back. And so, and then in this leg here. I imagine it’ll be the same thing, have a little arthritis in it, you know. And at times it’s good where I can walk real good, and at times when, like weather changes, temperature changing—you know you used to hear the older people saying when the weather changing…. I don’t try to complain about nothing, you know, but if people ask me about it, then I tell them…. If I’m really hurting bad, I’ll tell you, ‘well, today, you know, it’s kinda uncomfortable with this arthritis…. but I’m doing fine otherwise.”

Mrs. E demonstrated an adherence to Mrs. B’s advise relative to persistence and refusal to succumb to physical adversity or limitations:

“This time last year, my left leg, I had tendonitis in it. I had to wear this tan boot, ugly, atrocious thing; and then on the other side I could wear a shoe. And hey, I said to my self, I renamed myself ‘Shoe-Bootie.’ And then, hey, I went where I wanted to go. I said I’ll make my face look as attractive as I can. I’ll wear the most sparkling looking clothes, so that by the time people get to my feet, it wouldn’t matter what I had on…”

Mrs. H saw staying active as key to an acceptable quality of life:

“I enjoy my older age. I mean, even after I retired, I was so busy…. I was taking people back and forth to the hospital, to the doctor, taking them to the grocery store, getting their medication for them, filling their syringes, you know, for giving their shots for diabetes, and my church work. I was so busy… If I would leave sometimes at nine o’clock in the morning, and sometimes I wouldn’t come back home sometime until six, six-thirty at night… And then I was a grandparent reader at the public school for six years…. After a person retires, and I find this very true with older blacks, they don’t want to do anything. They just want to sit.”

In a similar vein, Mr. W emphasized that retirement is not synonymous with inactivity, but rather, to the contrary:

“Years ago, people got retired, you know, they’d go home and sit in a rocking chair; that’s just two or three generations ago—sit in a rocking chair and that’s all
they would do. And then after a week or two, they’d just dry up and go on away from here. But people who retire now, there’s so many things you can do… Right now, for example, I’m playing Bridge. I’m going to senior citizen places, playing Bridge with these people my own age or younger…”

Mr. W also viewed growing older and enhancing the quality of one’s life to mean staying active and involved by passing on to others the wisdom and know-how gained from many years of experience:

“I gained a lot of experience which I passed down to other people, been doing a lot of counseling. Young attorneys coming out didn’t know their ass from a hole in the ground so to speak, ‘cause you learn everything in school but you don’t learn how to be practical and then out in the field…”

Mrs. C’s comments suggested firm confidence in the quality of her life and longevity as she has managed to live the “clean” life of which Mrs. J spoke: “My blood pressure is very normal. I never had high blood pressure. And, I never smoked or drank. So I am looking forward to reaching 100.”

Mrs. D: “Well, quality—when I think of quality, I first think of health. You know the quality of life cannot be good if you’re not healthy. So if you have a reasonable amount of health and can get around and be independent and not just be independent, but to do some of the things you enjoy doing…”

Mrs. H, comments on her efforts to insure quality in her older years through healthy habits.

“I drink anywhere from six to eight glasses of water a day. I don’t eat—don’t make a practice of eating meat. And I don’t—not to boast or anything like that, but I try to stick with my vegetarian, vegetables, vegetarian diet.”

Mrs. J, a 76-year-old, widowed, mother of two adult daughters, and a retired Supply Data Specialist, gave her views regarding what determines a good quality of life.

“Attitude…and I think clean living and faith has a whole lot to do with your quality of life…and taking care of your body. Don’t abuse your body. Like I’ve…you know, I never… I always try to eat healthy, you know—and not smoke, which, that’s not good for your body.”
About Poor Quality of Life

Respondents also assigned meaning to their perception of a poor quality of life.

Mrs. D: “Well, when the person is ill and then when the person is just existing from day to day, although they may not be ill. They don’t do anything with their life—may not be making any contribution or they are abusing themselves with alcohol or drugs or things like that.”

Mrs. A, a 70-year old, separated, mother of two adult daughters, and a retired social worker reflected on quality of life. A poor quality of life is “not enough money to maintain yourself or declining health.”

Mrs. C commented that financial health is not meaningful, void of one having good physical health:

“My brother hit the million-dollar lottery. However, yesterday when I went to see him on his 67th birthday, he was quite ill. He had a kidney transplant. He has a pacemaker, and today he’s in intensive care. So, you need to prepare, but also you need to take good care of your body and not abuse it with maybe alcohol and cigarettes. I think those are two of the major abuses that I see African Americans suffering from…”

However, Mrs. C later acknowledged the importance of financial health to a good quality of life:

“So I think the quality of life is very good if you have prepared yourself as a young person for your old age. I think you have to prepare yourself in several ways, but especially financially. And then determine what you want when you are young rather than waiting…”

Mrs. E’s retirement aspirations have been radically tempered by the need to care for her elderly mother. She expressed regret and disappointment that her post-retirement dreams and plans have yet to be realized. Nonetheless, she felt that the quality of her life is the best that it has been.
Mr. R responded to the question of how he rates the quality of his life presently compared to 20 or 30 years ago. He responded by discussing his financial well-being:

“We [referring to spouse] have an unusual situation. Where I worked, where I retired—the lady that owned that business—I helped take care of her for a number of years. She was ill and I took her to the doctor and all this type of thing. And in her will, when she stipulated that I was to get my salary just like I still worked there, as long as I live. And then if I pass away before my wife, she gets it… So financially, we’re better off than we were 10 years ago, five years ago, or whatever.”

Similarly, responding to the interviewer’s request to describe what a poor quality of life means to him, Mr. R stated: “Your surroundings. It would be your financial atmosphere.” Regarding what it means to have a poor quality of life health wise, he explained: “Someone, you know, got lung problems, heart problems, whatever. That would not be a real good quality of life… I would think that probably not being in your right mind would be really bad. Or, if you were blind—I always thought that would be kind of a terrible thing.”

In a related vein, Mrs. D identified dreaded conditions pursuant to quality of life: “I think I could handle everything except senility, and I hope I keep my mind.” Later, during the membercheck, and responding to my comment that it appeared that experiencing senility would be more disturbing than the loss of physical health, she responded:

“At the time that I talked to you I had not had any pain to be concerned about. However, since that time I have experienced some pain and my thinking has changed. I would rather be senile than have physical pain. If I become senile, I won’t know anything about what is going on, but I will not have any pain.”

Mrs. D’s change of heart concerning most dreaded conditions is a very powerful and telling statement concerning how one’s philosophy and outlook may undergo
changes in light of firsthand experience. It also speaks to the importance of the statutes that allow the individual to modify or terminate advance directives documents with changing circumstances or treatment preferences.

Quality of Life of Others

In spite of respondents’ stated views concerning a quality life, or the lack thereof, they expressed admiration and respect for those who would have a poor quality of life due to their physical maladies and limitations, but make heroic efforts to overcome such challenges with courage, strength, and resilience.

Mr. W responded to the interviewer’s inquiry of how he viewed the situations and circumstances of others who face significant challenges due to physical disability:

“…I’ll give you an example that I think of. There’s a lady in my church right now, had an awful stroke several years ago. No one thought she’d ever live. Doctor even told her she wasn’t going to live. Well, she never, she was never off a wheelchair since then…. And she’s still living. She still comes to church and she’s still—talks to people on the phone and encourages them; and now she’s got a special job at our church. If there’s any program to go on, they call upon her to contact each person by telephone, and she loves that she uses the phone and calls and takes care of that. So she does her work.”

Mr. W responded to the question of how he might rate the quality of life if he lost a limb, or if he were dependent on someone else to take care of him:

“I would accept it, although I am proud, like some people are. I’d hate to get in the position where someone is going to have to take care of me. My ambition, like anyone else’s… If I were going to go, I want to go quickly and quietly; and I want to have all of my faculties when I go. In other words I don’t want to be a cripple that someone’s going to have to take care of; have to dress, to wash, to take baths, to carry around…. I don’t want to be like that. I don’t want to be all crippled up like that. That’s my ambition. I hope that someday I just have a heart attack or God calls me with a stroke or something like that. That’s my ambition. Now, if I get to the point where I’ve got to lose a leg or have a stroke and I can still come and go and do things—If I have to be that way I’m going to try to be like them because they have given me inspiration…. And I feel I’m going to try to
do the same thing. Encourage people to help other people and do work for themselves, keep themselves going, ‘cause I just don’t believe in going just sitting at home.”

Mrs. D described a friend whom she perceives to have a good quality of life in spite of serious illness and physical disability:

“Yeah, I’ve… I have a girlfriend in Birmingham, Alabama. She is a musician. I met her at West Virginia State in the music department, and she has had both legs amputated but she still does concerts. There’s nothing wrong with her hands…. And her mind…. Last time I talked with her she was preparing her music for a concert at her church. They have to sit her up on the piano bench…”

Mrs. D reflected on the ingredients that went into her friend’s triumphant attitude and strength of spirit, in spite of adversity. “I think it’s her belief in God, her faith that keeps her going—and family. She has a supportive family… and very good friends.

Mrs. E responded to how she would be different from her 84-year-old mother whose mobility is challenged, requiring the use of a walker:

“Well, for me, I would want quality. I would want my life to be more active. I would want to be up and out. You know, and the moment I could move, whether I’m on the walker—I would just not be inhibited in the least of going on my walker to the mall and walking through the mall. My mother won’t do that. My mother will not do that. Okay, if I had to be on the walker, I’d take my walker and go to church!”

Conditional Longevity

Respondents were asked how they gave meaning to living a long life. Their views toward longevity were of a conditional quality. Furthermore, their language was often characterized by if and as long as when they pondered the conditions under which they would embrace a long life. The desire for a long life was not evaluated and valued on the basis of years, but within the framework of functional ability.
Mr. H explained how she gives meaning to living a long life and under what conditions she would want to live to be 90 or 100:

“If I’m healthy, fine. I want to live a long life. But if I’m not, if somebody has to help me or wait on me and I… I guess, I don’t want… I don’t want to depend on anyone. I want to be able to help myself like I am now doing. You know, I take care… I take care of my own apartment. I do my own laundry. I keep it clean and things like that. I mean, but as far as looking forward to a… I don’t know. As I say, if I’m healthy, a long life would be fine because my mom lived to 98; my dad lived to 88. And everybody says, ‘And everybody says, ‘Well, you’ll live to be 100 as active as you are.” But if my mind’s clear…”

Mrs. H continued, expressing the conditional nature under which longevity would be welcomed, while acknowledging the limits of her control. Similarly, Mrs. J responded relative to how she makes sense of longevity as long as certain conditions are present:

“…As long as I’m healthy, I think it’s wonderful. Get to see my grandchildren grow up…. As long as you feel—as long as you have—and I already choose to think that when you’re happy, you’ll have perfect health…”

Mrs. E saw longevity as being worthwhile as long as she had the ability to be productive:

“Well, when I think longevity, I envision myself as still being productive and an outgoing person. And I still want to, as much as I can, to be making a contribution to others…”

Decent health and freedom from being a ‘burden’ on others were the criteria that Mr. R described as he thought about living to a ripe old age:

“You know, I wouldn’t mind living to 90, or 100 even, as long as I’m not a burden on someone and my health is decent. I have a cousin over in London, Ohio, and she just got back from California. To look at her, you’d think she was probably 75; and her sister lived to be 101.”

Responding to the question of whether he has ever thought about what he would want should he become mentally or physically dependent, Mr. R. spoke of limited options:
“Probably, if you don’t want to be a burden on someone, the only thing left to do is go to a nursing facility…. I wouldn’t want to go but if that’s the best, you know, what else are you going to do.”

Uncertainty about the “other side of life,” death, and whether one has good health influenced Mrs. D’s desire for a long life, as she responded to the interviewer’s inquiry concerning what meaning she attached to living a long life:

“Living a long life here on earth means to stay or to live as long as possible on this plane because death and the other side of life is unfamiliar…I think it depends upon, like, go back to the quality of life. If the quality of life is good, well, sure you want to live. But you wouldn’t want to live if the quality of life is not good, I wouldn’t say.”

At the age of 82, Mr. W suggested that living a long life sometimes means outliving friends and family members:

“Well, I’m surprised. I’m really surprised. ‘Cause the old expression was that only the good die young. And I’ve had… a lot of my good friends have died young, but I’ve outlived most of the people in my—that came along with me. There are very few of us left… But so many of my friends have gone, died. Peers, my peers in law, peers in other organizations, they’re gone. I’ve outlived both of my parents. I’ve outlived my sister who’s two and a half, a year and a half older that I was…”

Coming to Know Death

Participants first came to know death [a phrase borrowed from Mrs. J] in a variety of ways and at various stages of their lives. They recalled what it meant at the time and how the experience impacted their beliefs, thoughts, and attitudes about death and dying. They remembered the burial rituals, the fear associated with death, and how experiencing death over time allayed many of their fears and their anxieties. Coming to know death at the various stages of their lives, age differentiated loss, was recalled by relating their emotions, experiences, and feelings.
Mrs. C, a 69-year-old, married, retired schoolteacher, has executed a living will, but no durable power of attorney for health care. She recalled the death ritual she experienced as a child:

“We used to have, in my family, when I was a child—people would be brought back to the home and put on the bed or else in a casket in the home. And so, I was never afraid of the great-grandmother or that older aunt, or whoever had passed, because they had loved me and cared for me and I wasn’t afraid. But then as I grew and people were in a funeral home, I still was not afraid…”

In response to the question of whether this experience was somehow beneficial to her, and allayed her fears as a child, she explained and recalled the intricate details of culture and tradition:

“Yes, because I knew, well, for example, Aunt Ester…Aunt Ester must have been ninety-something. And I was a little girl, and at that time the body was washed and the person was put on some fresh clean clothes from top to bottom and laid on the bed. And then someone sat up all night; not me, but someone sat up all night with the body. And people came and stayed with the family. They brought the food and stuff for the family…but the funeral home came in some kind of a long wagon and, like a car, a motor vehicle. My father had a Studebaker, so I’m not sure that this wasn’t a Studebaker funeral car, but anyway, took the body to the cemetery—well, to the church. And then, the funereal was at the church, but the wake was at the home. And then in the south, you were buried by the church, you didn’t have to buy a spot…”

Mrs. H, an 82-year-old, widowed, retired LPN, does not have advance directives. Unprompted, and very early into the interview, she tells the story of her first close-up experience with death as a young child. She carefully, and with precision-like detail, shared the story of Elmer the white mouse, with an almost fairy tale-like quality:

“Yeah, well (laughter). I remember this thing. We had a little white mouse and his name was Elmer—and one of my sisters said—we kept him in the kitchen, and back then, you know, you didn’t have furnaces or things like that. And when the fire went out in the stove—I mean, that was it! The house got cold. And my older sister said, ‘You’re going to have to clean that cage out’, Elmer’s cage…Well, we put new paper in there. We took all the shredded paper out and put new paper in there, and for some reason, he didn’t do it. He didn’t shred up the paper like he normally did and we came down that next morning. When we would
always come downstairs, we would hear him scratching on the cage and we didn’t hear him that morning. And we wondered—looked over and he was dead. And so my sister that’s older than me, she was the preacher in the family. We got a matchbox and put some cotton in it and put Elmer in the box and went out in the yard—it was cold—right out in the side yard and dug a little hole and buried him…”

Mrs. H also recalled vividly how family friends responded to their burial ritual for their beloved Elmer, the deceased white mouse:

“But anyhow—and then a friend of ours came by and he looked at us and he went on the porch and he knocked on the door. And Mom let him in, and said, ‘Lydia, are your kids crazy? I asked them what they were doing and she said they were out there burying a mouse.’ And she said, ‘they know exactly what they’re doing…”

Mrs. H responded to the interviewer’s question regarding the significance of the life, death, and burial of Elmer. She gave meaning to her loss:

“Well, yeah, I guess, it’s just like you lose a loved one and you feel very sorry—we cried about it. We stood out there—it was cold but we stood out there and we cried because Elmer was a part of us as children. You know, he… when we got him, he was a little mouse and then we saw him… got a little bigger, you know, didn’t get too big. Had those pink eyes and things, you know, and after he died, I mean… we were very sad about it.”

Mrs. J, a 76-year-old, widowed, retired Supply Data Specialist, who has an estate will, but has not executed a living will or a durable power of attorney for health care, remembered (during the focus group) her ongoing fear of the dead and the failure of her father’s effort to calm those fears.

Mrs. J: “…I was always afraid of dead people myself. I was always afraid of dead people when I was little. When somebody died I was really upset. And I remember my dad always saying…said, ‘Dead person can’t hurt you; only a live person can hurt you.’ That’s what he use to tell you all the time.”

Mrs. C: “Didn’t take away the fear?”

Mrs. J: “No, didn’t take away the fear, and I didn’t know death until…in my twenties, 21, 22. My sister suddenly lost her husband, and he was young.”
Interviewer: “But that was the way you came to know death?”

Mrs. J: “That’s how I came, uh-huh. And it was a shock, so that’s how I first came to know death.”

Interviewer: “After that experience—previously you were fearful, and then you experienced death, and what happened?”

Mrs. J: “Well, I was still afraid of it but not quite as much. And just came to realize that it can happen to anyone. It doesn’t matter about age.”

Interviewer: “You’re not afraid of death?”

Mrs. J: “Because I’ve had experience…And I’m not afraid of it.”

Mr. T, a 71-year-old, married, retired carpenter, who has not executed advance directives, either a Living Will or Durable Power of Attorney for Health Care, related how he experienced as a pre-teen, the loss of his 30-year-old mentally challenged brother. He responded to the interviewer’s inquiry of how he experienced and felt the loss of his brother with a moving recount of bittersweet childhood memories:

“I… I didn’t feel… I don’t feel bad because the brother was, to my knowledge, going to meet Jesus anyhow… because if he sinned, he didn’t know it. He wasn’t that cognizant of sin…. and it was…. My mother had shared these things with us. She prayed that brother would leave before she did because no one could take care of him as she would…. And she treated it as though it was an answer to prayer. And so as I grew older and became knowledgeable, I felt like it was an answer to her prayer as well. And as a matter of fact, I thought it was kind of great that the Lord would answer her prayer and take brother before He took her. … And so that no one else would mistreat him because of his condition. We would walk down the street with him and people would laugh, and it would anger me that they would laugh at my brother because of his condition, with him being feeble like that. It’s not a pleasant…it’s not a pleasant thing to have someone laugh at your brother or your sister.”

Mr. T responded to the interviewer’s inquiry of how the experience with his brother’s death shaped his thoughts, feelings, and beliefs about death as he grew up:

“I don’t know that it did. It may have; but I never looked on death as being something that was necessarily awful… It didn’t have to be all that good, and yet,
it wasn’t all that awful to me. It was something that happens. It’s something that just happens. We all experience it. We can’t live here in this world and not have the experience eventually.”

Mr. T goes on to recall the extended illness and death of his beloved father, whom he idolized, as Mr. T entered mid-life.

“… When Dad died, I was there, of course, I was ministering to him… He’d been sick and I saw that—and he’d asked the church not to pray for him anymore, to stay here, because he was tired. His body was daily trying to overcome the pain of this cancer and he wanted to leave and go be with the Lord. And he sent word to the church to stop praying that the Lord heal him.”

What about medical decision making for his dad during his illness? Did he or the family act as a surrogate decision maker? Mr. T responded without hesitation and with a strong sense of certainty.

“ No, he’d tell us what to do and we’d do it. We just did it…. He told us verbally and we just did it…. Dad was the priest of the home and what he said—just carried out what he said…. There was no discussion. You didn’t discuss what Dad said. Dad was the priest.”

As a non-combat veteran of the WW II era, Mr. W told the story of early memories of the loss of young friends and military comrades to the horrors of war during his young adult years:

“Well, during World War II there were two or three fellows that I was pretty close to and they went in the service, and they were killed in the service—very, very good friends of mine. They were in school with me ‘cause I didn’t go into the service until the war was just about over. My dad was on the draft board and he permitted me to continue on through school. He maneuvered it so that I was able to get my undergrad degree before I went in service, but a couple of my friends went early and they…they didn’t make it. They were in actual war and they got killed.”
Mrs. D recalled her early experience with death as a little girl and again in young adulthood:

“When I was in elementary school, this little girl was in my class who passed. I remember that as a first… first loss that I remember. The next one that had a real impact on me—was I lost my girlfriend at 30; she was 30 years old.”

And during the early years of mid-life, Mrs. D experienced the death of her husband following a lengthy illness. She recalled death’s grip and its swiftness in taking her husband and other family members: “My husband passed before my parents did—and then my mother and my father, in that order—and his mother and his father…but in a period of eight years they were all gone. And here I am.”

Mr. R related his story of early experiences with death as a teenager and what the experience was like.

Interviewer: “Did you ever have an experience at a young age, or something that sticks with you where someone died, someone passed, either a friend or family member?”

Mr. R: “My grandmother passed when I was a teenager and she’s the first person I ever watched die.”

Interviewer: “You say you watched her. [You] actually were there”?

Mr. R: Uh-huh. I was at her bedside when she passed away.”

Interviewer: “Do you feel comfortable talking a little bit about that…and what it felt like, what the experience was like”?

Mr. R: “Well, it’s one of those things that it didn’t hit me at the time it was happening, because there were other people around, you know, and all this kind of thing. But after it was over with, because she and I were pretty close—because for a number of years I was the only grandchild. And she was real close, and I took it hard afterwards, but like I said, at the time it didn’t bother me that much when it was happening.”
A second death that stood out for Mr. R was the death by suicide of a co-worker.

Mr. R was 25-years-old at the time of the tragedy:

“…And one man, he’d retired and he went to Florida; and he committed suicide…. But this man that took his own life, it was quite a waste to me because he was a very brilliant man. No one really knew—his family might have. I don’t know if he left a letter, a note or anything—but he took his life with a gun. And I always figured he probably had cancer, or something, and didn’t want to suffer. But he was a very, very smart man.”

Mrs. B remembered in vivid details the pain, disappointment, and unanswered questions, as she experienced her first loss to death when she was age 7 or 8:

“I lost a first cousin. My aunt’s daughter passed; that was the first one that I can remember that passed, you know. And she was just like my sister—well, like my mother. She was older than I was, and she was married… I used to stay with her when I was a child, back and forth, Friday night, Saturday night. They would allow me to go into the city part where she lived and I could stay all night with her from Friday to Sunday evening…. Yeah, she was young…. I was real small, you know, and she would buy me clothes I didn’t really even need… And that was the first death, you know. And I couldn’t get over it with that one… I wanted to be alone. I knew everybody was gathering together, and I would stay in my little chair. And I would walk out from the house and sit out from them and, you know, just sit. I didn’t know anything about salvation like I know now, but I would say…. ‘Jesus, why you take my cousin? I love her. Can you bring her back?’ You know, and I was expecting an answer.”

Making Sense of Death and Loss

The respondents, through multiple means, engaged in a process of making sense of death, loss, and grief. The goal of this meaning making exercise was to find solace, hope, and strength—to successfully cope and prevail as they confronted the inevitability of aging and ultimately their death, or the death of a love one. Making sense of death and the need to plan resulted in spiritually, experientially, and time-based perspectives. The perspectives were not mutually exclusive and most respondents looked to more than one perspective while seeking meaning and making sense of death and loss.
Spiritual Perspective

In the spiritually based perspective, respondents turned to their belief in an omnipotent, omnipresent, loving, all knowing, and all-wise God. Everlasting life, or transition to the other side, as written and taught through biblical scripture provides answers to the mystery of what happens after death.

Mrs. B, while recalling the difficulty she had in letting go and coming to grips with loss due to death, shared how she came to know, understand, and accept death:

“...Growing up I finally, it finally dawned on me.... You have to realize, you know, Mamma would say, ‘You know, we didn’t come here to stay.’ You know, she always kept that before us, we got to leave one another one of these days. And I would say to myself, ‘Oh, not my family, not my family.’ But they started leaving. The Lord gave me...strength where I have been like the backbone of my family. I’ve stood there with all of them and they even let me speak at my mother’s funeral.... So God has given me strength to stand up thorough it all.”

“As I grew older, I could accept knowing the Lord is taking us. ‘Cause the way my mother sat and talked with us, it let us know that we got to leave here. We got to go... And I kept that in the back of my mind. There’s another place for us and we going to be real happy back together again.... You know, and that’s what I could not get across until I got older. But the main thing was that we was going to be together again.”

Mrs. H gave her very unequivocal and pragmatic views on death and coping with loss, coupled with a spiritual perspective:

Well, I feel about death... I think death’s a part of living. You know, we’re going to live and we’re going to die. The Bible says, ‘Once appointed for man to die... I’m not afraid of death because I think to the Christian, death is just a sleep. That’s all.”

“...You know when I lost my gentleman friend about six years ago.... He was at hospice, and after he passed the hospital called and wanted to get me in a group, a grieving group, and they... two people came out to my apartment at the time asking me questions. I told them, ‘I don’t need it.’ And they looked at me and they said, ‘Well, you really don’t need it because your outlook is so different from other people’s.’ He led a good Christian life. He was obedient to God and I expect to see him, I said, ‘at the first resurrection.’ I hope he comes up in that first resurrection, because the Bible said if you come up that first resurrection,
that’s the most important one. And I told them. And they left; they said, ‘we won’t need to come back.’ I said, ‘no, you need not come back….’ You can grieve a little while, yeah. And then get over it. You know, that’s the way I look at it.”

Mr. D responded to the interviewer’s question concerning how she makes sense of her multiple losses due to death that occurred over an eight-year time span:

“Well, how you make sense of those losses is through your faith. When you know that whatever happens, God is in control and you have no control over it. But, uh… and nobody really ever fills anybody else’s shoes. You know, you don’t ever feel that kind of relationship that you have with someone else… And uh… you just feel the loss.”

Recalling her husband’s death in his mid-forties, Mrs. D noted certain realities, and coming to understand and make sense of death requires that one understand his or her divine purpose:

“Well, after he passed and I realized how… the innocence of life and that God didn’t take me, that he had something else for me to do… I realized that life is… let’s see how I should put this… that life is… it’s not there always and we have to prepare for eternal life—and that god puts us here for a purpose… My purpose is to help other people get to Him.”

Mr. W explained how he made sense of the death of young comrades in the military as he entered young adulthood:

“I accepted it. I’ve been in church all my life. My parents took me to Sunday school and I’ve been going to Sunday school ever since I was knee high to a duck. My mother and sisters together, and a young friend of ours in the neighborhood, took us to Sunday school when we were young and I stayed in Sunday school and church all my life. And I read the Bible, and I feel it’s God’s will. So I learned to accept it. It’s a blow for the first time when they first pass away… for maybe a week or two, you just… you know, you think ‘Oh Lord, why did they take so and so?’ And you know, it’s kind of hard… but pretty soon you outgrow it and you realize this is God’s will…”
Mr. W also saw death as a release from suffering, and in the last 25 years of his life has become more accepting of death:

“Years past I would’ve said, ‘why… why did God do this? Why did he do that?’ Except for my parents, I knew they had to go and I expected that ‘cause we knew they had reached the age, and they were suffering. Some people suffering, and I like to see them go because of the fact they’re suffering—get them out of their suffering. Those who die suddenly, it’s very hard to accept those but I’ve learned to accept it more so in my last 25 years than I did before that.”

Mrs. C, gave a spirited and emotionally charged testimony of how she developed her present attitude concerning death and loss:

“I’m a Christian person who believes that… that the number of my days are already known to God. I believe the number of hairs on my head is known to him. And someplace in the Bible He said to one of the prophets, ‘I knew you when you were in your mother’s womb.’ And so I am not a fearful person. I went to Israel on a tour. I was baptized in the river Jordan, and so I’m not afraid to die… I love God and God loves me… And so, I guess I grew up with the attitude… and in my family the people prepare for death.”

Mrs. B unabashedly and unapologetically made clear her views on the use of life sustaining technology, bidding her family to allow the Lord to “take” her as He “sees fit”:

“I don’t want to be put on life support what-so-ever! Whenever my time comes to go, just let me go peaceful and however the Lord sees fit to take me. And don’t try to preserve life, you know… And I told them, I said, ‘I didn’t want an overly long funeral because I’m gonna live my life while I’m living it…. I said you realize I’ll be gone back to the dust, you know, carryin’ on over a shell… And I said, ‘don’t do that.’ I’m gonna be standing up there looking down at you…”

Mrs. B, with feeling and in precise details also recalled giving similar advice to family members when her sister-in-law lay connected to life-sustaining equipment that prolonged her life. She related her story with passion and fervor…with the delivery and tone of the minister that she is:

“When my sister-in-law was on the life-support and her brother and sister all came up from Tennessee, and they stood there. And I said, ‘It’s just a machine.’ I said, ‘Don’t prolong her because she’s ready to go.’ I said, ‘this girl is saved.’ I said, ‘She’s ready to go; don’t prolong it’… So they got over there to the side and
they decided that they were going to pull the machine. And the moment they pulled it, out she goes. And they started crying and whatnot, and I said, ‘Now, wait a minute; you done what she would have you to do… release her… ‘cause you gonna see her again… get your life in tune with God so you can meet her again…’ I feel like I don’t need to go on life support because, in the first place, I don’t believe in anything artificial… I believe the life that God gives us, we should live it, and when He calls us in we should be ready and not try to preserve it against His will. Because I believe that He’s got a particular time to come and when that time comes, I believe that we should be willing to go.”

Mr. R, with a chuckle, responded to the interviewer’s inquiry concerning the role that spirituality plays in the medical care that he would or would not want if faced with terminal illness:

“Yeah, what’s the old saying, “Everyone wants to go to heaven, but no one wants to die.” But, your spiritual, you know, what we’re taught and what have you, that helps a lot… And I’ve never been to a funeral where the minister says you’re going to hell, you know. (Laughs)

Mrs. B relates her experience of having faced a life threatening illness, cancer. She recounts her story and the determination to rely on her faith in God for healing.

“Cause I was going to the doctor and the doctor said I have three little polyps on my, you know, whatever you call them. And he said, ‘we tested one’, and he said, ‘one of them is cancerous.’ And he said, ‘So I’m going to have to move it.’ And he said, ‘might have got it all, but I’m not for sure; but I’m going to have to give you chemo.’ And I said, ‘what?’ He said, ‘I need you to come back.’ So, my girls were there, they say, ‘Momma, you’re going to take it?’ I looked at them and I said, ‘no!’ That Tuesday I went to the doctor, kept my appointment… Got over there and he had all those bottles sitting up there and table out there. You know, he said, ‘Come to get your chemo?’ I said, ‘Nope.’ He said, ‘You didn’t?’ I said, ‘I come to tell you I am not going to take it.’ I said, ‘My mind is made up. I’m trusting God all the way. I’m not taking it’…. I haven’t taken it yet and I’m still praising God, and God brought me through.”

**Experiential Perspective**

Respondents’ attitudes and beliefs were significantly impacted by their personal experiences, observations, and exposure to the deaths of loved ones. There was an emotional quality that is a direct result of these experiences. Actions or decisions are
aimed at preventing negative conditions and consequences based on present or prior experiences. Whether the respondents have completed advance directives or not, experience seems to drive their way of thinking and making meaning about end-of-life care and what they would want for themselves.

Mr. R and his wife were seriously considering completing advance directives at the urging of their daughter who has had recent experiences with the death of an in-law. In addition, he told of two very personal experiences concerning making decisions in regard to end-of-life care for his former employer and his mother. But first, he responded to the interviewer’s inquiry concerning his preferences in regard to life support: “No, I wouldn’t want to be on life support. If it’s final, then it wouldn’t do any good…no, I wouldn’t want to be on it.”

Responding to the question of whether he has ever experienced anyone on life support, Mr. R reflected on his former employer:

“Um-hum. Yeah, now, the lady I worked for, she requested not to be on any life support. They put her on it for a while because she had emphysema real bad, and they took her off of it, and she was able to understand what they were saying, because they had the tube down her throat and all this. And her daughter told her that they were going to take the life support off of her, and she said, ‘you know what this means?’ And she shook her head, ‘yes.’ And so they took the life support off her… and they took her upstairs to—like a hospice facility, apparently just so she could pass away. And the daughter said, “Would you rather go home.’ This was in the evening and she said ‘yes.’ So they got an ambulance and took her home. And she didn’t want to go to bed; she wanted to sit in her recliner. And she died the next morning… Now, I wasn’t there when she died, but I was there shortly afterwards; and they called me. I had been there early that morning, because they said it didn’t look good…. I went down to the store because I had to go to the bank. And they called me about 11:30 or 12:00; she had passed away.

Mr. R also recalled his experience with his mother as she neared the end of her life:

“My mother—My mom had a stroke. She had one or two strokes—well, she might have had two, and the last one was pretty bad... So they moved her to a nursing home. She was in a nursing home for 29 days before she passed away.
So they called me from the nursing home and said she was getting worse, should they take her back? And I said, ‘no’, just make her comfortable because I knew she wouldn’t want to go back and be put on a machine, you know, anything like that.”

Mr. R responded to the interviewer’s question: “Had you ever had the opportunity—had she talked to you beforehand, before she became very ill, about what she would or would not want if she were in a situation where she could not make her own decisions? Did she have a Living Will?”

“No, she didn’t. She only had it [living will] after she got to the hospital, you know, the attorney drew it up after she got to the hospital. She never really said… She talked about everything else but that… I knew that’s what she would want… I had no problems with it.”

Mrs. E had not completed advance directives; even so, she readily admitted there is value in advance care planning, and a need to plan for “eventualities.” Her husband’s sudden death impacted how she “looks at life” and considers the fleeting nature of time. However, she related that she continues to wrestle with an admittedly irrational concern—that if she reduces her end-of-life wishes to writing, this could hasten her death. She responded to the interviewer’s inquiry of whether she had completed advance directives or, if she has considered the type of medical treatment she would or would not want if faced with a life-threatening illness:

“Well, you know, I’ve thought about it and I keep saying I’m going to do that and… you know, when you sit down to do it, it’s harder than you think to do that. And one of the things I have as a goal for this year is to do that and to do it very quickly. So, to that end… yes, I’ve thought about, you know, if I were on life support, what I would want and who would make decisions if I, you know, if I could not make decisions for myself.”
Mrs. E continued, as she responded to the interviewer’s question of whether her first preference was to make the decision for herself, or if she feels most comfortable having a surrogate decision maker act on her behalf:

“I want to make the decision for myself and... I have two sons... And I talk to them often about the eventuality of when I’m not here; and each of them knows who I want, which of them I want to make the decision for me first. And I told them that. And you know, ever so often, my youngest is the one that I said, ‘I want you to make these decisions for me. And I’ve told him what I want him to do in the event that I will pass on suddenly or before I had everything down in writing...”

Mr. W, who has completed both a living will and durable power of attorney for health care, related the lessons he learned over time as a practicing attorney, and how the experience had impacted the way he thinks about various aspects of legal planning, including advance directives. Such planning, he suggested, can prevent confusion, uncertainty, and conflict. He responded to the question of how he makes sense of the importance of completing advance directives for himself, and, in addition, how he advises his clients:

“Well, for one thing, I’ve had so much experience where I’ve seen people who get into a situation where they couldn’t, they have a stroke, get into an automobile accident, and wind up, lots of confusion... And I’ve seen so many husbands who, for example, pay all the bills and they know where everything is and they wait until they either get a stroke, or they die, and the poor widow comes in, and she doesn’t know what to do. She’s all confused, ‘What am I going to do?’ So I advise them now when they come in, not only make a will, but husband and wife should get together and explain to each other where they keep their valuables and things like that, and what they should do in case something happens.... Especially, I find it to be true where there are two families. For example, man and woman marry later in life and they both have had children by prior marriages, as long as they’re together everything is perfect, but as soon they pass away, these children on both sides come up and it’s going to be a battle. So I advise them by all means, have these instruments.”
Mrs. D, had completed both a living will and durable power of attorney for health care and very clearly expressed a desire to avoid the financial and emotional trauma associated with a lingering death:

“Well, I’ve never seen anybody be on a respirator and come off and be well again. So why go through all this, the trauma that it puts the family through, emotionally and financially. So I… And it’s not doing the person—it wouldn’t be doing me any good. I’m just there.”

Likewise, Mrs. C related that she doesn’t wish to be maintained on life support for any appreciable amount of time because she has witnessed the financial devastation of a prolonged death. The high cost of end-of-life care that is potentially futile was a major factor in her decision to complete a living will:

“When it’s impossible for you to be anything but a vegetable… So I made the decision not to have the life support longer than two or three days, or whenever the doctor says that it’s hopeless, then let me go home and be buried or whatever…. But now she [referring to her daughter] knows it’s my wish to withdraw all this extra life support, to lower the bill, not keep me on for six months or six weeks or whatever, and having to pay all the money to all the doctors and the hospital. Then that can go to the family and my heirs.”

Time-Oriented Perspective

The time-oriented perspective on death and loss is characterized by logic and reasoning in which time is a primary consideration. There is an “if-then” quality to the respondents’ way of thinking concerning the need for advance care planning.

Mr. R gives his rationale for plans to pursue executing advance directives in the near future:

“Well, we’re getting older and my wife’s been talking to me about it. I have a cousin that I take care of right now. She had two or three strokes. I take care of her, and we have filled out the papers for her when she was in the hospital, Durable Power of Attorney and a Living Will, and that kind of thing. And something that I just never have done, but I’m going to be calling my attorney here, probably in the next month, next few weeks; and we’ll get the ball rolling on that.”
Mrs. D also speaks to the issue of time when responding to the interviewer’s question of whether there were any precipitants to her decision to complete advance directives:

“No, I just thought that they all need to be done and I’m not getting any younger, so…”

Mr. T, following a recent marriage is considering a Living Will, with some prompting from his adult daughters. He expresses his views on the use of life support:

“If I had it, I wouldn’t want it for any long, long length of time. I don’t think I would want them to hold me for months and months, especially if the doctor doesn’t think I would get any better.”

The Experience of Pain and Suffering

Respondents’ attitudes and treatment preferences were significantly influenced by their experiences with pain and suffering and the desire to avoid such an experience at the end-of-life. What’s more there was a strong desire to avoid having their families or loved ones experience the excruciating emotional and psychological trauma that is associated with physical pain and suffering:

Mrs. E recalled having experienced her father’s pain and suffering as he fought a losing battle with a formidable foe, colon cancer. She would never want her family to have a similar experience. While she has not completed advance directives, she has given their execution serious consideration. Also, she has given her two adult sons specific verbal instructions in the event of serious or terminal illness before she commits her wishes to writing.

“And I’ve told my sons this. If I were ill and the doctor said your mom is terminal, there’s nothing that we can do, but we can put her on the life support
system to keep her longer—I would want… I would not want to put them through the pain and the suffering, because I experienced that with my father. My father had colon cancer, and I saw my dad in seven days go from two hundred and something to a hundred and fifty. And I stayed at his side those seven days, and I heard and saw the kind of pain and suffering that he went through. I would not want that for my sons. Now on the fifth day that my dad was in the hospital, I never will forget it, the nurse on that floor had gone to high school with me and she came in the room and she said, ‘your dad is in severe pain, excruciating pain.’ And she said, ‘I’m going to talk to the doctor about his pain.’ And the doctor came in there with her, and they gave my dad a shot and I don’t think he had any more pain after that… But I would not want to experience that type of pain.”

Mrs. H, as an LPN, witnessed and cared for those dying and suffering. She emphasized that she had given minimal thought to preparing advance directives and has spent very little time concentrating on death. However, she responded to the interviewer’s inquiry concerning how she gives meaning to physical pain and suffering at life’s end:

“I don’t… Pain, I can’t stand pain. And like I said, I don’t want to suffer. You know, I mean, I’ve seen so much of it. And I don’t want to go through some of the things that I’ve seen some of my patients go through…. No, I don’t want that [pain and suffering] myself. I don’t want that myself. But if it’s something that… that has to be, because I feel that God has all our lives mapped out for us. And if it’s something that I have to go through, He said He’d give me the strength to bear it. I may not even know it, but He’ll take the suffering and pain away. That’s the way I feel.”

Mrs. D recalls the experience, the painful experience, of seeing a loved one, her father, a good man, die from a mean disease:

**Interviewer:** “Do you give any meaning to physical suffering and pain? When you think about physical suffering and pain, and we talk about quality of life, there are some who…give spiritual meaning to physical suffering and pain…”

**Mrs. D:** “No, not really, except that I don’t want to suffer.”

**Interviewer:** “You don’t want to suffer.”
Mrs. D: “Yeah, not… as… so far as having people um… say this is because of some sin that I’ve done or something like that. I don’t see that.”

Interviewer: “You don’t see it as… they’re reaping what they have sown. You don’t see it that way?”

Mrs. D: “No, because my dad was a good person, and he died with cancer, and that’s a mean disease. And he was a good person; so I can’t say that.”

Likewise, Mrs. B voiced very strong beliefs concerning pain and suffering. However, as a minister, she leaned heavily on her spiritual and religious connectedness as a means of understanding and overcoming pain and suffering:

“I tell people and I even tell my own family, sometimes it [pain and suffering] comes upon you from your own thoughts and your own self. Bible says, ‘So a man thinks, so is he.’ So, if you think you are hurting, if you name the parts what’s hurting, if you concentrate on that and put emphasis on that, its’ going to start to hurt because you can speak things into existence…. You know, just say, ‘This is not going to happen to me.’ And if it does, rebuke it…. And I say—sometimes a pain’ll hit your body and I said, ‘Lord, this is your body. Lord, have mercy. Lord, you know, move it. I know you can move it…. And just give me the grace to stand while you’re moving it.’”

Mr. W, who has advance directives, shared his views and the meaning that he gives to pain and suffering. He sees nothing noble about pain and suffering:

“…I just hate to see people suffer. Now, my parents did not suffer. My mother had a stroke and never recovered from the stroke. She was… she couldn’t talk and like that. I think she understood when you tried to talk with her and things like that, but I don’t think she was suffering. Well, she had suffered before, because she had… diabetes and she lost a leg… Anyways, she lost… lost everything in that leg and they had to cut it off… and she had to get an artificial limb… There wasn’t much she could do at that stage of life; she had the stroke. She was helpless.”

Mr. T noted relief when his father finally sent word to his church to cease praying for his healing. The interviewer inquired: “When he sent word to the church to stop
praying, what were your thoughts? What did you feel”? Mr. T, like Mrs. D, reflected on a loving man who was dealt a bitter blow by a mean disease:

“I don’t know that I wasn’t somewhat relieved or glad for him because he was a man that knew what he wanted and I felt like dad was in a position to make a good judgment call. I loved my dad. My dad was very good. He was kind. He was one of the most loving persons that I ever knew. I don’t know a man that was more loving and kind than my dad…. I was his masseuse, to try and give him some relief from that pain. And I would massage his legs because, you know, the weight loss caused his body to just, you know, become stiff. And being in bed too long, for long periods of time, not being able to roll over or get up or walk around. And I would just go and minister to him, or, just sit. I didn’t always talk. Sometimes I would just be there…”

On Being a Burden

Respondents expressed themselves with total certainty as they speak of the strong desire to avoid being a caregiving or financial burden to their families. Whether they had completed advance directives, or not, and regardless of demographics they held fast to the hope and desire to avoid being dependent on others for their day-to-day care.

Mr. W, a married lawyer with two daughters to whom he is close, having executed advance directives, yearned to “go quickly and quietly” so that he is not a burden for loved ones.

“… Although I am proud, like some people are, I’d hate to get in the position where someone is going to have to take care of me. My ambition, like any one else’s, if I’m going to go, I want to go quickly and quietly, and I want to have all of my faculties when I go. In other words I don’t want to be a cripple that someone’s going to have to take care of, have to dress, to wash, to take baths, to carry around, and need things, or things like that. I don’t want to be like that. I don’t want to be all crippled up like that… I hope that someday I just have a heart attack or God calls me with a stroke or something like that. Now, that’s my ambition….”
Mrs. H, a retired LPN, and a childless widow, who had not completed advance directives--and insisted she had no plans to do so, had given very precise instructions to family members to whom she is close, in a preemptive effort to avoid being a caregiving burden:

“And I would say... and I tell my family, if I get to the place that I can’t take care of myself, I don’t want to be a burden to them. I tell them to get one of the nicest nursing homes that you know, where they are going to give a person good care and put me in a nursing home... I don’t want to be a burden on them. My niece and my nephew... My nephew just got married over two years ago and he and his wife would take care of me, I don’t want them to take care of me. I mean, because they have their own life to live. My niece is the same way. They have their own families to look after, and I don’t want to be a burden to them... Put me in a nursing home somewhere, a good one, and come and visit me, you know. And if you have Alzheimer’s and things like that, you’re not going to know that they’re there anyhow. But, that’s just the way I feel.”

Mr. R, who is married, with two adult children, noted plans to prepare advance directives in the near future. He, too, wanted to circumvent being a burden on family. He explained what being a burden meant to him and what his options might be should he become physically dependent:

“And I wouldn’t want someone to have to come in and check on you everyday or have to depend on someone to always be doing something for you... Probably if you didn’t want to be a burden on someone, the only thing left to do is go to a nursing facility... I wouldn’t want to go, but if that’s the best, you know, what else are you going to do?”

Mrs. E, as a widowed, retired educator, whose retirement dreams have been significantly impacted by her decision to be caregiver to her elderly mother, had given her two sons very detailed oral instructions. While she had not completed advance directives, she was giving the idea serious consideration. She shared her verbal instructions:

“And I’ve already said to my sons, one of the things when I get older... I want to stay in my present home as long as I can. Okay? And that was the mistake we
made with my mother. Because she and dad were so close, and my mother was always… she was the always frightened to stay by herself and I’m not… I’ve already said to them, ‘when I get older, you won’t be hurting me, I want to go first to an assisted living—a very nice assisted living community with people my age, people who want to do stuff I like to do. And then you guys will not have to worry about, you know, how I’m being taken care of. I’ll have somebody there if they need you… when they need you, they’ll call you.’ And then from there, I’d like to be in the same community that would move to their terminal care… skilled care.”

Cognitive Dissonance

When thinking and planning for end-of-life, respondents and their families’ way of understanding seemed conflicted and contradictory. Magical thinking, an infantile way of reasoning, and an avoidance of the subject or action characterized the cognitive dissonance that ensued. There existed a “tug-of-war” which is fueled by fear or anxiety and uncertainty that is associated with death.

Indicative of cognitive dissonance was the fact that seven of ten respondents spoke at length about their families’ strong resistance to discussing care at the end of their lives. Such dissonance or avoidance was also present in the language that was repeatedly used by respondents as they related their stories. Language functioned as a means of softening what was considered a hard and harsh topic.

“Fear: That Old Phobia”

There appeared to be a negligible difference between the experience of those who had completed advance directives and those who had not in regard to the stories they share concerning hesitancy and resistance on the part of their families and the “phobia” that is described by Mr. W.

For example, Mrs. E had given serious consideration to completing advance directives, and despite being an accomplished and well-educated retired high school
principal, she is reluctant due to certain beliefs and fear. Speaking of the reasons for being reluctant to complete advance directives, she gave a very telling and potent account of the extent to which cognition is over-shadowed by fear:

**Interviewer:** “When you say, ‘when you sit down to do it, it’s harder than what you think’… tell me what…could you just tell me a little bit about what goes through your mind? What is it that makes it so difficult to actually reduce it to paper”?

**Mrs. E:** “I think what makes it sort of difficult for me to go on and do it [execute a living will] is the fact that I say… is that if I do this, then what I am doing is saying to myself and accepting—and I know that this is an inevitable thing that will happen to all of us, but I feel like I’m saying ‘yes’ to it, and it may happen and become a part of reality quicker than I would want it to. Because I sort of feel like… the tongue is powerful and things you say about yourself, to yourself have a way of becoming reality. And that brings a sort of fear in me that I’m just not ready to go there yet.”

**Interviewer:** “And so when you think about that, putting it on paper, what you’re saying is that it could… or you’re feeling in your mind that it would hasten things”?

**Mrs. E:** “Yes, in my mind I feel like this will hasten this to a reality, in my mind. Bus, yes, realistically, I know that’s not true. I know that’s not true.”

Mr. W relates his experiences as an attorney and the hesitation of individuals to plan for the inevitability of the end of their lives. As in the case of Mrs. E, he identified “fear” and “that old phobia” as major factors associated with individuals’ failure to complete end-of-life directives:

“So that’s the reason toward my… in my last few years I’ve been urging people and insisting that they think about these things. Some people didn’t want to do it [advance directives]. In fact, some people felt, they say, ‘if I do something like that, I’m getting ready to die. That scares me. I don’t want to do it’… Fear… that old phobia. But I tell them, you’re a Christian. You know that tomorrow isn’t promised to anyone—just like the minister trying to get people to get up and join the church. Join it now because you don’t know what’s going to happen tomorrow. So I do the same thing with this here because you don’t know what’s going to happen tomorrow…”
Mrs. D had a living will and durable power of attorney for health care; even so, she expressed discomfort with the idea of her physician initiating discussion regarding the completion of advance directives. Her uneasiness was fueled by factors identified by both Mrs. E and Mr. W:

Interviewer: “Given the option of your physician approaching you and saying, ‘Mrs. D, we really need to talk about what you would want if you couldn’t make decisions for yourself’… given that choice, or you approaching the physician say, ‘I have this Living Will’…. Do you have a preference as to who approaches the subject, whether the physician should approach you… or you should approach him?”

Mrs. D: “I think I’d be more comfortable approaching him.

Interviewer: “You’d be more comfortable approaching him”? 

Mrs. D: “Um-hum.”

Interviewer: “Why do you think so”? 

Mrs. D: “I don’t know. I think he might think I’m going to die.” 
(She laughed.)

Mr. R also felt that it’s more prudent for patients to initiate conversations concerning care preferences at the end-of-life:

“I would think that the patient would be better off talking to the doctor, because that may be a little uneasy for the doctor, maybe to talk to you about something like that. He would probably… I would probably start the conversation and maybe he would finish it, we’ll say. But he may not start the conversation…”

“They Don’t Want to Talk About It”

Participants’ stories concerning the involvement of families and their attitudes toward end-of-life decision making and planning bore striking similarities. Seven of the ten respondents related stories of their families’ resistance and reluctance to discuss what Mrs. E refers to as future “inevitabilities.” This was particularly true of adult children of
the respondents. However, in spite of their stories, these older individuals’ voiced a favorable opinion of advance care planning.

Mrs. A had not completed advance directives, responded to the interviewer’s question of why, or if, African Americans may seem less inclined to discuss issues surrounding death and dying, as suggested by Mrs. J. She responded quickly and definitively concerning the attitudes of her two adult daughters:

“Fear. I think it is fear. Even with my family, they do not want to talk about dying. They’re so afraid that Mamma is going to die. So they don’t… they don’t want to…. Oh, I talk about it…. They [family] simply ignore it.”

Likewise, Mr. W related his experience with the reluctance of his two daughters to discuss advance care planning in regard to him and his wife who suffers from Alzheimer’s:

“Well, both of my daughters have been very close to us, especially to my wife, because she primarily raised them, because I was always busy working…. So I have talked with both of them and both of my children, they understand. And they’re both very bright, very intelligent, so they understand what’s what, and they know… of course they don’t like to talk about death and things like that, especially the older daughter, she doesn’t, ‘Oh, don’t mention that to me.’ She doesn’t want to talk about us dying. But I tell her, ‘you’ve got to face it. It’s going to happen…. Anyway, she has never wanted to talk about death. Even when young and coming along, and I said, ‘Now, we aren’t going to be around’…” Oh, don’t talk about… don’t talk like that Daddy. I don’t want to hear that.’ She just doesn’t want to discuss what’s going to happen to us.”

Mrs. D told a similar story regarding her adult son and daughter’s lack of enthusiasm about having her share with them the details of her wishes as outlined in the advance directives that she completed. The interviewer inquired if her children were given a copy of her advance directives, or if they know how to access them:
“No, I have a copy and the attorney has a copy…. They don’t want to talk about it…. ‘Oh, let’s don’t talk about that, Mom.’ But I say, ‘you know, you need to know that I have made these kinds of decisions.’ That’s all they know.”

The interviewer inquired: “And when they say, ‘Let’s not talk about it, Mom,’ what does that mean to you? How do you make meaning of that?” Mrs. D responded with a response that was so reminiscent of other participants:

“I say, ‘Well, I’m not going to be with you always. You need to realize that fact.’ And then I go on. I don’t get into it that much.”

Mrs. E, although she had not put end-of-life plans in writing, wanted to be certain that her adult sons were aware of her wishes in the event “that I will pass on suddenly” before she formalized plans:

“…My youngest is the one that I said…’I want you to make these decisions for me, and I’ve told him what I want him to do in the event that I will pass on suddenly or before I had everything down in writing. My oldest son doesn’t want to talk about those kinds of things and that’s why… what I have done, pass the responsibility on to my younger son.”

Mrs. H had no children, but related failed attempts to share her desires and plans with her nieces and nephews, with whom she had a close relationship. The interviewer asked if she’d discussed her desires with family, in the event she became incapacitated and was unable to make medical decisions for herself. She replied very pointedly and with a sense of frustration:

“My family won’t discuss it with me…. I try to because… I tried where even my obituary picture and things like that, and they say, ‘Aunt [H], we don’t want to hear it.’ So they won’t discuss it with me because they say, ‘you don’t need to worry about it now because you’re going to live to be 100.’ And so, sometimes they don’t want to hear.”
Later, Mrs. H responds to the interviewer’s inquiry of how she makes sense of her relatives’ response:

“Well, I tell them a lot of times, ‘Let’s get real.’ You know, let’s get real about it. I mean, I may be healthy now and maybe I will live to be 100, but who knows. And they still slough it off. So I… what else is there for me to do? So I just go ahead and don’t think about it too much…. Yeah, but when I talk to them and tell them where my things are if anything should happen, where they would find the things and, like I say they don’t… they just sort of slough it off.”

Mrs. B, who had not completed an advance directive, reflected on her experience and observations as a minister and the reluctance of people in general to find any degree of comfort in discussing end-of-life planning. Similarly, she anticipated reluctance on the part of her six daughters, one of whom is a lawyer, as she prepared to discuss her wishes with them in the near future:

“Oh, yeah, a lot of them say, ‘I hate to talk about it.’ But, I know it’s going to come time for me to talk about it and they will not answer. You know, ‘Well, I’ll deal with that later, I’ll talk about that later.’ So, you just leave them alone, you know.”

Mrs. C completed a Living Will and gave copies to her children and spouse. In the event of her husband’s incapacity, a daughter was designated to carry out her wishes. Initially, she noted her daughter’s trepidation:

“…I sent everybody a copy of it so that when the one daughter makes a decision…well first my husband, but if he’s not here to make the decision or incapable, maybe a stroke or can’t speak or something, then my daughter’s to make the decision. And the others have agreed that they would go along with that. Because in my family, my daughter, the one that I designated said, ‘Oh, no, I would never do this.’ But now that she knows it’s my wish to withdraw all this extra life support…”
While Mr. R had not experienced similar problems talking to his children or spouse about advance care planning, he shared the opinion of other respondents—that the discussion of death, for many, is a very uncomfortable and troubling subject:

“And I think her father [referring to his spouse]… you start talking about funeral arrangements and burial plots and he didn’t want to talk about it. I think a lot of the older people are that way, black and white, just don’t want to talk about death.”

Although neither Mr. T nor Mr. R had completed advance directives, both were considering doing so, with promptings from their daughters, and in Mr. R’s case, from his wife as well. Mr. T’s recent remarriage appeared to be a precipitant to his daughters’ initiation of the conversation concerning end-of-life planning. On the other hand, Mr. R’s daughter’s experience with burial plans for a member of her husband’s family served as a motivating factor in the discussion and consideration of completing advance directives.

The Language of Death

Respondents labeled, defined, and characterized death in multiple ways, using words that captured how they have come to reconcile death’s meanings. The language served to temper their fears, discomfort, and anxiety, but by the same token, reaffirmed their religious beliefs and spiritual groundedness.

Seldom was the word death used in any of its forms. Rather, words that appeared to soften the blow of death’s mighty sting were the chosen vocabulary when speaking of what Mrs. D termed the “unfamiliar.”
What is death?

In their discussion about their experiences with death—how they came to know it, the experience of the death of a loved one, and how they planned for their own death, respondents’ words and language captured how they made sense and defined this little understood phenomenon. Their language was not intended to define death as a condition but rather as a spiritual state.

Their language was a language of opposites—death was understood with certainty and uncertainty, confidence and fear, transition and finality. Each respondent chose language, more often than not, that reflected a culture where avoidance of words such as death or die spoke to a multitude of emotions and beliefs.

Mrs. C explained in a detailed fashion her philosophy of death. She emphasized her freedom from the fear of death and the very certain nature of death: “And I am not a person who’s afraid of dying. You know, I think it’s inevitable, so why not be prepared? That’s kind of my attitude.”

Likewise, Mrs. E spoke of death’s certainty, also using the term inevitable as she disclosed the cognitive contradiction with which she wrestled in regard to executing written advance directives: “And I know that this is an inevitable thing that will happen to all of us, but I feel like I’m saying “yes” to it and it may happen and become a part of reality quicker than I would want it to…”

Mrs. E also used another label for death that suggested its very clear and definitive nature. On several occasions she referred to planning for the end of her life as an eventuality. Speaking of her family and her desire to make end-of-life decisions for herself, she commented: “I have two sons…. And I talk to them often about the
eventuality of when I’m not here…” Using the term again, she discussed the value of preparation for death: “Well, I’ve always been a person who, as I said, tried to prepare for what I thought eventualities would be…. When I reached 50, I decided to look at how I would want to be treated if I suddenly became impaired and was not able to make decisions for myself. And I started to make plans for that eventuality along those lines.”

Speaking of death as an eventuality, Mr. T expressed the equal opportunity nature of death. Speaking of death, he commented: “… It’s something that happens. It’s something that just happens. We all experience it. We can’t live here in this world and not have the experience eventually.

Mrs. H summed up succinctly the certainty of death and the comfort that she finds in the way that she understands and has come to make meaning of death: “Well, I feel about death… I think death’s a part of living. You know, we’re going to live and we’re going to die.” She continued, “I’m not afraid of death because to the Christian, death is just a sleep.” However, she added another dimension to her philosophy of death when she declared, “As I say, death is part of living, but I really don’t give it [death] too much thought.”

Similarly, Mr. W noted an acceptance of death as God’s will. He explained that it’s with emotional maturity and an enlightened spiritual understanding that he currently believes as he does. Speaking of the loss of loved ones to death, he explained: “It’s a blow for the first time when they first pass away—maybe a week or two you just… you know, you think, ‘Oh Lord, why did they take so and so?’ But pretty soon you outgrow it and you realize this [death] is God’s will.”
How They Talked About Death and Loss

As respondents discussed death and loss, their language was often one of metaphor and avoidance that is rooted in a history and culture that “tip toes” gingerly around the taboo topic of death. Words are carefully constructed, providing comfort and safety when talking about this most definite and unavoidable eventuality or inevitability called death. The language was not only intended to make a sometimes unapproachable and most difficult subject more palatable and a bitter cup less so. In addition, the selected language served the dual purpose of giving comfort and hope, while stressing the reality of mortality to themselves and to their loved ones.

Mrs. D, during her efforts to discuss advance directives with her two adult children, attempted to encourage and help them understand the reality of her mortality. She warned and implored: “Well, I’m not going to be with you always. You need to realize that fact.” Explaining how she gave meaning to their reluctance to discuss the unavoidability of her death, she stated: “It’s because they don’t want to face the fact that I’m going to leave them sometime or the other.”

In a similar vein, Mr. W shared how he tried to help his older daughter come to grips with the inevitability of death, his death: “…But I just tell her, you’ve got to face it. It’s going to happen…” Still not using the word that is so often and so easily not spoken, his comments reflected a kinship to his daughter’s fear and apprehension: “She just doesn’t want to discuss what’s going to happen to us.”

Likewise, Mrs. R related words that served as an antidote to the bitter, bitter cup called death. Discussing the end-of-life circumstances and death of his former employer
as decisions were made to remove her life support, he reflected: “And her daughter told her that they were going to take the life support off of her and she said, ‘you know what that means?’ And she shook her head, ‘yes.’

Measured Trust

Families and Medical Providers

Given the reluctance of most of their loved ones to discuss end-of-life concerns of the respondents, how did this impact issues of trust in regard to participants’ confidence and comfort in family decision-making and surrogacy?

Seven of the ten participants discussed situations that documented their concern regarding the reluctance or unwillingness of family members, especially their children, to discuss issues related to verbal or written end-of-life care preferences. Nonetheless, there was overall trust that family members would honor and carry out their wishes. In essence, this cohort of respondents valued family-centered decision-making. However, in some instances they questioned whether certain of their relatives have the strength to cope with the emotional turmoil of their death or the dying process.

Attitudes Towards Family Surrogacy

Mr. W had completed both a living will and durable power of attorney for health care. In spite of the reluctance of his eldest daughter to discuss issues surrounding death, he gave her his vote of confidence as he noted trust in her ability to honor his wishes. Mr. W responded as the interviewer reflected on his comments about his observation of his daughter’s reluctance or unwillingness to discuss the topic:
“No she doesn’t. She doesn’t like it at all…. I don’t think we’ll have any problem with her on that. It’s just my opinion because she is very intelligent. She’s been through school and she’s very knowledgeable and we’re a very close-knit family. We love each other deeply and so I feel she’ll get along all right… The daughter here works with Senior Options. And so she is very good at that…but I think the two of them could get together and take care of things if something would happen…”

Mrs. B, likewise, while contemplating completing advance directives, seemed to feel quite confident that her two daughters would implement her end-of-life wishes despite their lack of comfort in discussing the issue:

“I want two people, you know, to take charge of this… I believe they would follow my footsteps, my oldest daughter and the one that’s an attorney. I said, ‘I want you to supervise this, for you and me gonna sign that you will do it equally, you know…I want two people, you know, to take charge of this, and I said the oldest daughter and the one that’s an attorney…This is the way Momma wanted it, and this is the way it’s gonna be…. I can hear them saying to one another, ‘Now, this is what Momma said and this is the Bible…”

On the other hand, Mrs. A voiced strong reservations concerning what she could expect from her two daughters in regard to surrogacy: “The family and people you think can handle it—because that would be my problem… I have two girls and I don’t think either one of them could handle it.” (Laughter)

Mrs. J felt that a discussion concerning end-of-life treatment preferences is important and valued. Nonetheless, she stated that she had not entered into discussions with family members concerning what she would or would not want to happen in case of decisional incapacity. To the question of whether she had talked to her family about these issues, Mrs. J commented: “No, and I should because I have one daughter, she’s a nurse, so…. So I think that she would talk about it.” Like Mr. W, she suggested that her daughter’s profession as a nurse would enhance her daughter’s comfort level in discussing end-of-life planning.
Mr. R expressed considerable confidence in his son and daughter in carrying out his wishes, as he considered plans in the very near future to execute advance directives:

Interviewer: “Have you discussed… Is it your daughter that you would want to take care of things if you couldn’t…”?

Mr. R: “Yeah, our son and daughter.”

Interviewer: “Both of them?”

Mr. R: “Girls always seem to be closer than boys. So they’ll do it together. They’ve never had any kind of a problem with each other as far as making decisions, and they’ll do it together.”

Consistent with Mr. R’s preferences, Mrs. D appointed her son and daughter as joint surrogate decision-makers as outlined in her durable power of attorney for health care. She responded affirmatively to the question of whether she was confident that her children would abide by the wishes laid out in her living will.

Regarding surrogate decision-making, Mrs. C suggested, “it is for the physician to say what your state of health is.” However, she further commented on the importance of family surrogacy:

“But I think the making of the final decision, whether or not you should be on the machinery, or whether or not you should be removed, I think should certainly be a family decision, and if you’ve already told your family what you like, then they can follow that.”

Mrs. E recalled the experience of being a surrogate decision maker for her father, who had not executed advance directives. She based her decisions on what she would have wanted under similar circumstances, feeling a significant degree of comfort in this position, as she and her father were so very close in their relationship:

“If he had made plans himself, I would have honored his plans, whatever they had been…. If this were me, and this is basically what I think about—if this were me,
how would I want this carried out? And I treated it just like I would want to have someone do it for me… because the two of us were so close and talked so much, I felt like I was carrying out what he would have wanted.”

Discussions of surrogacy typically centered on the respondents’ children as surrogate decision-makers, even for those participants who were married. This could be attributed, at least in part, to the fact that the majority of respondents were elderly women, and given that women have a longer life span than men, it was anticipated that this responsibility would fall to their children. Or, as in the case of Mrs. E, it was understood that her mother, due to significant medical problems, was unable to take on surrogate responsibility. Mr. W’s wife suffered from Alzheimer’s rendering her unable to act in the proxy role. Finally, Mrs. C, who has a living will, suggested that her children would act in the surrogate role in the event of her husband’s inability to do so.

Measured Trust of the Medical Establishment

There was measured trust of the medical establishment and medical providers in that respondents considered the quality of medical care to be contingent on whether one has sufficient medical insurance coverage or the financial means to access proper and adequate care. Moreover, they expressed deep concern for those lacking these resources. Nevertheless, there is generally the attitude and belief in the physician as the expert, in whom they can feel confident.

In a related vein, the issue of trust is a much written about and researched area in the end-of-life literature. It is suggested that African Americans are often more mistrustful of the health care system and medical providers than whites because of a history of racism and inequality in many areas of their everyday lives, with health care being a part of this inequity (Crawley et al., 2000; Mouton, et al., 1995). Increasingly,
there are studies concerning health care equity and access in which the findings raise unsettling concerns and many unanswered questions relative to disparities in health care for African Americans (Institute of Medicine, 2002). However, in this cohort, the nature of their concerns regarding health care disparities appeared to stem from socio-economic considerations rather than race or ethnicity.

For example, Mrs. A was a retired social worker that had not completed advance directives. She expressed strong reservations about the quality and availability of medical care for those who don’t have adequate insurance or financial means. She reflected concerning her situation:

“I’ve worked in the welfare system and, of course, I have my personal opinion about that system and people…. I could be sick, but I’m fearful of going to the doctor because I don’t have enough money to pay for it. And I think a lot of time, we do not seek out medical care because we don’t have finances. Now, you have insurance but you still have to pay the twenty or thirty percent co-payment. And so, if the… well, just for me… I don’t have anyone else. If I’m sick, then I don’t want to add another bill. So, I just don’t go to the doctor.”

Likewise, Mr. W saw socioeconomic status as a leading culprit that results in a lesser quality of care for those who have limited economic resources.

“Well, I think those who can afford it, the health care, there’s no problem there. I think we have equal opportunities, those of us who have the knowledge and the funds with which to get good health care; there’s no problem for us. But I feel sorry for those who don’t have, those people who’ve been on welfare for a number of years, those who don’t have any… didn’t even finish high school, those with no education…. I think it’s a tragedy and something ought to be done for them…. I’ve talked to some of them to see what kind of health care they get and I don’t think they get the proper health care. Our government… the people that talk about it all the time… and they don’t do anything about it…. Just like in education, the education is very poor for some in the ghetto areas and things of that type. It’s really a tragedy!”
Likewise, Mrs. H, as a retired LPN, was concerned about what she viewed as regrettable changes that have occurred in the medical profession within the past 20 years, changes that suggest a callous attitude on the part of medical personnel. Her words suggested a lack of confidence and trust in the medical establishment. She responded to the interviewer’s question: “How is it [the medical profession] different”?

“I mean, it… the nurses, sometimes, and the doctors seem like they have a ‘don’t care’ attitude. You know, here’s a senior and here’s an older person, and they’re going to die, so just make them comfortable, you know, instead of trying to give them some therapy of some kind. Show some tender loving care to them. You know, it’s so much different. It is so different. The medical profession is so different than it was 20 years ago when I got out of it.”

Mr. T expresses similar reservations as those expressed by Mrs. H regarding doctors and his level of comfort with his medical care.

**Interviewer:** “Do you feel comfortable with the medical care you receive? Do you feel comfortable with your doctor”?

**Mr. T:** “Some of it. Some of it. A little bit uncomfortable.”

**Interviewer:** “You feel a little bit uncomfortable at times?”

**Mr. T:** Un-huh, because I don’t think the doctors are as conscientious as I would like to see them be.”

**Interviewer:** “Do you see any differences in race?”

**Mr. T:** “No, I don’t think…. No, it’s just that when they [doctors] get to know you, they relax and they take you for granted.”

Mr. T noted, however, that he is generally comfortable with approaching his physician relative to his health care concerns.

While Mrs. C felt fortunate to have good medical coverage, she, like other respondents, was concerned about those who are less fortunate. She also responded to
the interviewer’s inquiry concerning whether she felt she received proper and adequate medical care from health care providers. Her reply suggested measured trust:

Mrs. C: “I’m trustful to a certain degree.”

Interviewer: “You’re trustful to a certain degree?”

Mrs. C: “Uh-huh. I just happen to be fortunate, you know, to have good medical care.”

Interviewer: “So you think you’ve had good…”

Mrs. C: “Right, but there’re so many people that don’t have it [good medical care]. “I’ve been blessed that way.”

Physician as Expert

Though their trust of the medical profession is guarded, the participants generally spoke favorably about the physician as an expert and thus the need to be attentive to medical advice. Nevertheless, there were circumstances where the very strong feeling that physicians had either overstepped certain boundaries or been less than sensitive was evident.

Mr. W, a semi-retired lawyer, expressed a very pointed philosophy regarding the role of the physician.

“Well, I always tell people that if your doctor tells you something, you’re supposed to do… you should do it. That’s his field; that’s his specialty. There’s no point in paying a doctor and the doctor giving you advice, and you not accepting it. But I find so many people will not listen to the doctor.”

Mr. W responded to the question of whether he would trust his physician to make the best decision concerning the withholding or withdrawal of life support technology.

“…I’m satisfied because I think these, with the situation that’s done now… I think in the forms [advance directives]—it tells you there that you don’t take the word of just one physician. You should have a second opinion. So people who are on those machines should have a second opinion. But I read just recently
where somebody was taken off of the machine without any, with no one giving advice on it, and that person died. And had they had a second opinion, they might have had a different story on it.”

Mrs. D had never discussed or given copies of her advance directives (living will and durable power of attorney for health care) documents to her physician. “No, just my attorney,” she responded when the interviewer asked if she has discussed or given copies of the documents to her physician. During further inquiry of whether this is something that she would want to discuss with her physician, she responded: “I don’t… I don’t know. I guess I could. I just feel that he would do what’s best for me… But I’ve never discussed it with him.”

Mrs. A noted her view of the role of physicians when an individual looses decision-making capacity: “I think it’s for a physician to say what your state of health is.” However, she agrees the family should be involved in the decision-making process.

Contrary to the support for the role of the physician, both Mrs. E and Mrs. B relate some negative encounters with physicians relative to end-of-life decision-making and treatment for a life-threatening illness.

Mrs. E recalled the experience of making end-of-life decisions for her father as he suffered with terminal colon cancer:

“… I was there [at the hospital] and he went into cardiac arrest, and they wanted to put him on a life system, and what have you. And nothing had been done about who would make that decision. My mother was there; but of course, she did not want to make the decision—and then the physician said, ‘well, you don’t have a legal right to make that decision for your dad, and your mom doesn’t want to do it. So, we’ll just have to act in his best interest in the hospital to say what we’ll do.’ And I said, ‘I don’t believe that’s true. So, I’m going to say what we’ll do.’ So we came together as a very small nuclear family… My mom and my two sons and I—and we decided.”
Mrs. H tells of an encounter with her physician when she was faced with colon cancer and the prospects of undergoing chemotherapy. In her typical divinely driven defiant style, she celebrates having opted for divine healing.

“And I told the doctor, ‘No, I’m not going to take chemo because God is gonna heal me. And I believe that and I stand on it.’ And he said, ‘Alright, I’ll make my money someplace else.’ He let me know it was all about money too, you know. And I let him know it was all about Jesus with me.”

Race as a Constant Companion

Because this study is being explored from a life course perspective, the nature of historical influences and lived experiences of the respondents, in this culture, is considered central to their attitudes and beliefs concerning end-of-life care and medical treatment preferences. Consequently, included in the content analysis was an examination of issues that related to race in the narratives of the respondents. Moreover, much research and scholarly emphasis has been placed on the impact of race and ethnicity relative to end-of-life planning.

In completing the analysis on racial content, careful attention was given to the place in the interview where race was mentioned and whether such comments were prompted by the interviewer or seemingly spontaneous on the part of the respondents. Most often, racial comments by the participants were not directly related to the topic of advance care planning. Nevertheless, given the frame of reference for the study, such comments were viewed as key to understanding the lived experiences of study participants and how these experiences impacted their attitudes, beliefs, and feeling about the topic under investigation.
Responding to the very open-ended directive from the interviewer: “Tell me about your life and growing up”, a question positioned at the beginning of the interview, issues that concerned race were frequently a part of the participants’ stories. Eight of the ten respondents, in many ways and at varying points, discussed race during the interview process—mostly spontaneous, occasionally prompted by the interviewer’s line of inquiry. Much of what they said about race related to issues surrounding racism and discrimination, racial pride, race and suffering, regret, and overcoming race-related challenges.

For example, Mr. W, a semi-retired lawyer, talked extensively about race during the interview. His first mention of race was unprompted by the interviewer; however, it was reasonable to assume that the interviewer’s race, African American, potentially created a degree of comfort for respondents to discuss racial matters.

Approximately 15 minutes into the interview, while still responding to the initial open-ended question, uninterrupted by the interviewer, Mr. W reflected on his contributions to civil rights:

“Oh, I’ve been in… haven’t been too active in… say, civil rights matters and things of that type. I guess I should have been, but I haven’t. The only thing I did do was—I did open up a lot of opportunities for people in the community through my work in the legal profession. We had a law club and we opened up the courts because at that time they were discriminating against black attorneys, and the courts looked down upon us… At that time, we didn’t have any black officials anywhere, so I think through our work—was a part of the work in making openings for a lot of the people coming up now in politics, such as the… such as judges and city councilmen, and the mayor, of course…”

Mr. W also discussed the racial prejudice in the south as he repeatedly expressed regret concerning his lack of activism in the civil rights struggle:

“Well, in those days, of course, when I was coming along, I knew that down in the south…how they were being treated down there. They were second-class
citizens down there in the south. And I was afraid… my mother’s from Virginia, so I went down to Virginia to visit with her… saw some of the signs ‘for colored only’ to the restrooms, ‘colored only restaurants and things like that… and I’d heard about the beatings and lynchings and all those things.”

Less than five minutes into the interview, Mrs. D responded to the open ended directive to tell about her “childhood and growing up.” A follow-up question, the interviewer asked, “How large was the community in which you grew up”? She responded:

“Well, it was a coal mining camp. And there were over thirty different camps. You don’t know about up the holler, down the holler, around the holler until you go to West Virginia. I lived up the holler. I was born around the holler, and at the age of four we moved… moved up the holler.” (Smiling) So, and we walked back and forth to school, and we passed by this other school for the White students, this brick, you know, schoolhouse to get to our little two-room school. And we did a little fighting on the way back and forth with the other kids.”

Responding to the question of whether she attended racially segregated schools, Mrs. D answered:

“Right. As far as the school was concerned, but in the neighborhood where I lived—well we had a lot of Hungarians and Italians and we were all living in the same community, but we didn’t… couldn’t go to school together. We didn’t go to church together.”

Later in the interview, Mrs. D recalled her early experiences as a young music teacher and racial barriers to employment in her chosen field.

“I graduated from West Virginia and I taught thirteen years there. We moved, left there because my husband was looking for work. And so we came here, and then I taught for three years for the Franklin County Retarded Children’s program, because they told me down in the Board office…education office…they didn’t have any place in Columbus Public system for a black music teacher… That was in… it had to be in ’60.”

Mr. R, like Mr. W and Mrs. D, mentioned race in the very early portion of the interview, as he tells about his “life and growing up.” He responded to the interviewer’s inquiry, “What was it like growing up in Plain City”? He reflected:
“Not too many blacks. There were only probably five… yeah, about five blacks in the high school. Had a lot of fun. There wasn’t anybody prejudiced or anything like that. Now, you take West Jefferson or London, Ohio, and they were prejudiced over there. But Plain City never had a problem.”

He recalled some of his experiences with prejudice as a young person growing up, in response to the interviewer’s question concerning the topic:

“Well, you know, I wasn’t around West Jefferson too much. I would play in the band and we would go over there, maybe for a parade or an ox roast… But you just knew from the older people—they passed down the word that it was prejudiced there… Now London was the same way, because I remember when London opened their public swimming pool. They didn’t want blacks to swim there, but it was public and they had to let them in. After that was over with, there wasn’t any problem.”

Mrs. C reflected on “abuses” that cause health problems for African Americans, particularly “alcohol and cigarettes.” She stated:

“I think these are two of the major abuses that I see African Americans suffering from. And many times I think it’s because of disappointments in life and depression that’s untreated, and so they self-medicate with alcohol or with drugs.”

Mrs. C, as she discussed issues surrounding raising her great granddaughter, emphasized the importance of knowledge of one’s history and heritage:

“I make quilts and things and I’m also teaching her Underground Railroad history our story… Whenever I do lectures, I tell them, talk to the senior citizens in your family. Write down what they say… and share that knowledge with other family members that are around. And then I also tell them that our ancestors had a very impossible dream, that one day they could be free. And the Lord did deliver them like he did the children of Israel…”

Mrs. A observed concerning the feasibility of completing advance directives:

“Well, I think this is very good for the black person. And this [referring to education] should be taken to groups, churches… different organizations where blacks are gathered because we just don’t think about it [advance care planning].”

In summary, race was discussed in a variety of ways—in relation to health care status, racial discrimination, historical changes in race relations, pride in racial heritage
and struggle and survival. Other comments in their narratives, relating to race, are interspersed throughout this chapter. For example, Mr. T’s experience with racial discrimination during his military time was previously cited.

Race was ever-present in how they defined and related their experiences of how they grew up, where they grew up, and who they are. Where health care access and quality are concerned, they do not appear to be of the opinion that race or ethnicity is the culprit that results in poor or inadequate health care, but they believe that one’s economic status is a central and determining factor in health care access and quality. Likewise, they generally don’t have a preference that their medical provider is of a particular race; instead, they expressed an emphasis on the physician’s qualifications to practice.
CHAPTER 5

DISCUSSION AND IMPLICATIONS

Introduction

The purpose of this study was to explore and describe how the lived experiences of ten older (age 65 and over) African American, male and female respondents informed their beliefs and attitudes concerning end-of-life or advance care planning. According to Pearlman (2001), advance care planning is a three-stage process that entails first, thinking of the relevant values related to end-of-life planning; second, communicating the values and preferences to involved family members and health care providers; and third, documenting the values and preferences in an advance directives document. Concerning beliefs, Fishbein and Ajzen (1975) suggest that during the course of individuals’ lives, their personal experiences lead to the formation of different ways of thinking about objects and issues. These beliefs in turn guide or impact their attitudes, intentions, and behaviors concerning certain actions or events. In a related vein, Fishbein and Ajzen indicate that attitude locates the person on a bipolar evaluative or affective dimension, linking the object to some attribute, and a pro or con disposition toward the action or object.
This suggests that attitudes are not formed in a vacuum (Rajecki, 1982), including attitudes concerning death and dying. Morgan (1997) notes that death attitudes are shaped by (1) our philosophy, (2) our view of the world, and (3) our place in it. Attitude, as it is specific to this study, is viewed as the way study participants thought, felt, or behaved in favorable or unfavorable ways (Kalish, 1985) relative to advance care planning.

The study proceeded by exploring the lives of the participants across the life course, while examining the interaction of contextual issues, the impact of historical time, and the intersection of demographic, social, and cultural factors. Research (Garrett et al., 1993; Kalish, 1976) suggests that the most significant differences surrounding ideologies about death are associated with differences in culture, not differences in demographic factors, such as sex, age, or education. Thus, it was important to understand how the lived experiences of the respondents inform the way they think, believe, and make decisions in the area of advance care planning. Thus, the research question that was explored was: “How do the lived experiences of older African Americans, over the life course, inform their attitudes and beliefs concerning end-of-life planning”?

Erikson (1982) notes that to understand how a life ends, one must gain an understanding of how it begins. Thus, in order to gain useful insights into how individuals’ perceive planning for death and dying, one must explore an understanding of how they give meaning to their lived experiences, and how they come to give meaning and purpose to their existence and to the inevitability of death. Consequently, the interview guide contained questions that were intentionally positioned to be broad initially, then becoming more specific concerning experiences.
The rationale and imperative for this study are aptly captured within the Last Acts (a national coalition to improve care and caring near the end of life) Statement on Diversity and End-of-Life Care (2001, Fall):

[The Diversity] Committee believes that all individuals’ life experiences contribute greatly to the complexity and uniqueness of the end-of-life that we all face. These experiences, as much as anything, shape our desires and beliefs about health, illness death and dying (p. 1).

As such, the provision of optimal care at the end-of-life requires that all providers—whether physicians, nurses, clergy, social workers, or other disciplines—respect, acknowledge, and understand how attitudes, beliefs, and values concerning end-of-life care and planning are impacted by factors such as race, culture, ethnicity, gender, and spirituality. Of equal importance is an understanding on the part of practitioners of the diversity or variation that exists within various racial, cultural, ethnic or religious groups. Thus, a presumption that a given group is monolithic in its beliefs, attitudes, or desires relative to advance care planning has the potential to be no less counterproductive than a lack of awareness of such factors.

Given that advance care planning occurs within the context of the human experience, a phenomenological perspective was chosen as a framework for the participants to define and give meaning to their experiences. A phenomenological perspective was well suited as it provided a useful and effective framework for examining and exploring how multiple factors in the participants’ lives, over the life course, interacted to inform their current attitudes and beliefs concerning end-of-life treatment preferences. In addition, this approach is particularly useful in exploring past
events and influences while clarifying events that have led to present attitudes and beliefs of the participants.

In the remaining pages of this chapter I will discuss and highlight the theoretical framework that framed the study and topics related to the dominant themes. The chapter ends with a discussion of study implications, methodological limitations, and recommendations for future research.

The Bioecological Model from a Life Course Perspective

The conceptual framework for the study was that of the bioecological model in a life course framework (Bronfenbrenner, 1995; Bronfenbrenner & Morris, 1998; Bronfenbrenner, 2000). From this perspective, development refers to “stability and change in the biopsychosocial characteristics of human beings over the life course and across generations” (Bronfenbrenner & Morris, 1998 p. 995). This framework explores how beliefs and attitudes about death and dying, and ultimately beliefs and attitudes concerning end-of-life planning, develop over the life course, coupled with the impact and interplay of historical influences across generations and within individuals’ lives. According to Elder (1999), “human development in life course theory represents a process of organism-environment transactions over time, in which the organism plays an active role in shaping its own development…The developing individual is viewed as a dynamic whole, not as separate strands, facets, or domain…” (p. 952). It is from this perspective that the study was conducted and the following findings were noted.

Summary of Study Findings
Consistent with findings from prior studies (Emanuel et al., 1991; Gamble, McDonald & Lichstein, 1991), respondents were generally favorable towards advance health care directives or instructions in the event of incapacity. However, of the ten respondents interviewed, three had actually put their wishes in writing, two having completed both a living will and durable power of attorney for health care, and one a living will. At least three indicated a definite intent to execute formal directives in the future.

Nine of the ten respondents reported good health in general, although some lived with chronic conditions such as arthritis and hypertension. However, one female respondent had experienced two medical conditions that were potentially life threatening, colon cancer and heart disease. Nevertheless, she expressed optimism and was positive in her attitude concerning her health status. Moreover, she felt victorious in overcoming the challenges posed by the diseases. It is important to note that although respondents viewed their health as reasonably good, they did not hesitate to point out the physical and mental changes that they have experienced over time and with increased years.

The respondents noted an overall positive attitude and hopefulness about life and the quality of their lives in their older years. For participants, a quality life included personal independence—both financial and health-related. The participants emphasized being productive and contributing through service to others. Likewise, the desire for longevity was strongly associated with having a good quality of life, being independent in activities of daily living and contributing, being productive.

Given this strong need to be independent and active, respondents consistently expressed the desire that they never present a caregiving, financial, or emotional burden
on their families. They noted a genuine willingness to be placed in assisted living or other long-term care facilities in an effort to spare their loved ones this caregiving burden. At least three persons had given detailed instructions to their families concerning the types of settings they wished to be placed should the need for alternative care arise. In all cases, except one, likely caregivers of whom the participants spoke were adult children. Although they seemed determined to spare their families of caregiving burdens, several participants had been caregivers to family members, one currently. The participants expressed a positive view toward caring for loved ones. However, Mrs. E, a retired principal, acknowledged that being a caregiver to her elderly mother had been a source of disappointment due to her inability to pursue long awaited post-retirement plans. Nonetheless, respondents, including Mrs. E, viewed caregiving as an obligation and responsibility, an attitude and philosophy that is most likely a function of cohort influence.

An emphasis on their “spiritual walk” was a most significant and integral part of the respondents’ stories. I am reminded of a recent conference concerning end-of-life care in the African American community in which the speaker noted: “Death is a spiritual experience with medical implications” (Crawley, 2004). This statement goes to the very core of how this cohort of older individuals gives meaning and makes sense of their mortality and the eventuality of their deaths. Their spirituality guides how they think about preparation for death’s inevitability. In this regard, they expressed a strong and consistent belief in an omnipotent, all-knowing God who holds life and death ‘in His hands.” Central to their beliefs was the belief and view of life and death as integration, a cycle, a continuum, with an afterlife, or “transitioning to the other side” following death,
(Barrett & Heller, 2002). From a pragmatic perspective, they understood death as an inevitability requiring careful preparation not only in the spiritual realm but also in the area of getting ones business affairs in order—business affairs included proper burial insurance, the completion of an estate will, and the completion of advance care planning. Of the ten participants, twice as many, six, had executed estate wills as had completed advance directives. Three respondents had completed estate wills and had executed advance directives. Three of the four individuals who had not completed estates wills noted plans to do so. One participant noted no plans to complete these documents, explaining that her circumstances did not necessitate such planning.

Seven respondents were female and three were male. There were no significant differences in their attitudes concerning aging, death and dying, pain and suffering, or the value of advance care planning. In regard to gender differences, researchers suggest that women are less favorable toward life-sustaining care across ethnic groups (Blackhall, et al., 1999; Garrett et al., 1993). Some researchers attribute women’s disproportionate status as caregivers as a rationale for this finding (Blackhall et al., 1999; Eleazer et al., 1996). However, three male participants had served in a caregiving capacity on some level. In addition, they had been involved in end-of-life decision-making for their parents. Mrs. E was the only individual acting in a caregiver role during the study. She cared for her mother in her home.

In a related vein, research suggests that those respondents with personal experience with illness are more inclined to execute an advance directive (Blackhall et al., 1999; Murphy et al., 1996). Each respondent, not surprisingly given their ages, related multiple experiences with the deaths of loved ones or acquaintances, and had been
intimately involved in the dying process and the dying event. Only three of the ten respondents had executed written advance directives; thus, personal experience with death had not prompted them to complete the documents at the point of the interviews. However, based on their narratives, it seemed quite evident that for those participants who had completed advance directives, their experiences with illnesses and deaths over time were a precipitant to the completion of the documents. For the remaining six participants who were considering, contemplating, or who verbalized positive feelings about completing advance directives, their experiences with death and the dying process—including chronic debilitating illness, impacted their interest in completing advance directives.

Much has been written and researched concerning the historical presence of violence, injustice, poverty, and discrimination and its linkage to African Americans’ mistrust or distrust of the health care system (Blackhall, et al., 1999; McKinley et al., 1994; Mouton, et al., 1995; Waters, 2000). Overall, the respondents trusted their medical providers and had confidence in the medical system to provide them with quality care, as long as they had sufficient medical insurance or financial means to access such care. In addition, they related that the race of the medical provider took a back seat to the level of providers’ qualifications and skills. However, respondents expressed minimal confidence and an enormous sense of concern and doubt about the quality of medical care for vulnerable populations, void of advocates or financial means.

The respondents in this study were generally well-educated; three had graduate degrees and two had bachelor’s degrees. Three had some college; one was a high school graduate and the other completed tenth grade. The three who had completed advance
directives included a 73-year-old female, widowed, retired school teacher with a bachelor’s degree; an 80-year-old, married, male semi-retired lawyer, and a 69-year-old, married, female, retired school teacher. Researchers have found that individuals’ completing advance directives tend to be female, white, and better educated (Miles, et al., 1996; Galambos, 1998).

Respondents across the board expressed an appreciation and desire for family centered decision-making, although they agreed that medical providers have a role to play, largely as experts or in consultative roles, as support to the family’s decision-making process. Furthermore, participants, across the board, indicated a desire to discuss their end-of-life preferences with family members, primarily adult children. Three of the ten (Mr. T, Mrs. J, and Mr. R) suggested a willingness on the part of their adult children to discuss the topic with them. The remaining participants noted reluctance of their adult children (except in the case of Mrs. H, who identified nieces and nephews as potential surrogates) to discuss end-of-life planning. Regardless of such reluctance, the respondents were confident that their families would honor their wishes if and when the circumstances require their involvement as surrogate decision makers.

According to Barrett and Heller (2002), “for many blacks, there’s almost an acceptance, if not the glorification, of suffering as a good thing, that suffering is somehow noble. If Christian, they identify with Christ’s suffering on the cross as being the most noble of experiences” (p. 796). However, the respondents in this study were unequivocal in their beliefs and desires concerning pain and suffering, and stated convincingly and repeatedly their desire not to endure pain or suffering at the end of their lives. Pain and suffering were not viewed in a noble sense, but as a state that they wished
to avoid. However, given their strong Christian convictions, they explained that if pain and suffering should be their plight, then God would give them the strength to endure. In addition, there was not a desire for aggressive medical treatment interventions regardless of the expected state or the futility of the effort, a finding that differs from prior studies (Caralis et al., 1993; Garrett et al., 1993; Mebane, et al., 1999).

Cohort Influences

A life course framework guided this study of ten older African American respondents. Central and fundamental to this framework were the concepts of historical time and place, timing in life, and linked lives (Elder, 1998, Hareven 1978). In this context, and within this framework, a discussion follows using the stated concepts to gain insight and understanding into the lived experiences of the respondents, while highlighting how the experiences impact their attitudes and beliefs about advance care planning, death, and life.

Historical Influences

The older African American individuals who participated in this study were born between the years 1921 and 1937 and ranged from ages 66 to 82. The average age was 72.7 years. Passuth and Bengston (1988) note “a birth cohort is a group of people born at the same time in history who age together” (p. 338). According to Hareven (1996), “a cohort is defined by its interaction with the historical events that affect the subsequent life course development of that group” (p. 16). Elder suggests (1999) that birth year positions or locates people in specific birth cohorts and according to particular social changes.
Historical time is examined through a succession of social, political, economic, and environmental events that occur during one’s lifetime (Cavanaugh, 1997).

A core principle of life course theory posits that the individual’s developmental life course is embedded in and powerfully shaped by conditions and events occurring during the historical period through which the person lives (Elder, 1998). Thus, it is appropriate and important to examine how historical events and contexts in the lifetime of the cohort guide and inform their beliefs concerning issues that include the meaning they assign to life, death, and planning for the end of their lives. Most notably, during their childhood and young adulthood years, the respondents lived through The Great Depression and WW II. They experienced the turbulent Civil Rights Era of the 50’s and 60’s in which the struggle for equal rights for African Americans was fought on numerous fronts and regions of the country. In addition, they experienced the widely publicized and scandalous Tuskegee Syphilis Study in which African American males went intentionally untreated for syphilis by an agency of the federal government, and were allowed to succumb to the ravages of this very treatable, yet left untreated, devastating disease (Reverby, 2000). Moreover, this cohort was subject to the influence of an era that saw unequaled advances in medicine and medical technology—an age of advances in organ transplantation, life sustaining support systems and treatments, and new and powerful medications. During recent decades they witnessed an era when the right to live or die, with well-publicized and much debated cases like Nancy Cruzan and Karen Ann Quinlan, (Annas, 1992; Gostin, 1997) challenged the ethics and efficacy of life sustaining technology and the conditions under which it should be applied. It was an
era that brought to the forefront the issue of patient autonomy and patients’ rights. Ushered in was an era of debate, litigation, and legislation concerning the right to live and the right to die.

The respondents’ stories included comments and experiences that relate to events and situations that occurred at various stages of their lives. Mr. W, age 80, as a non-combat veteran of WWII recalled the loss of two young adult friends to war. This historical event of war exposed him to the loss of two young friends who died “early.” Were it not for war, such an experience may not have come so soon.

Likewise, the participants experienced the harshness of Jim Crow, racial prejudice and discrimination. Without prompting, the issue of race, in some form, was ever-present in their stories and was significant in their response to telling the interviewer “about their lives and growing up.” Indeed, their lives and the lives of their parents and grandparents had been lives of struggle and survival during periods in history that significantly impact who they are today, giving significant meaning to their identities. In their narratives, they voiced determination and a refusal to give in to infirmity and adversity. In this regard, Mrs. C spoke of the “ancestors” and their having overcome “impossible” odds.

**Timing in Life**

From a life course perspective, the principle of timing in life suggests that the developmental impact of a succession of life transitions or events is contingent on when they occur in individuals’ lives (Elder, 1998). According to Elder (1999), an aspect of timing is explained in the concept of age grading in which social roles and events are organized across the life course. Hagestad and Neugarten (1985) suggest that age-related
expectations create a sense of what lies ahead as life progresses, but the scheduled transition has the potential to be upset when the event is off-time. In addition, this off-time event has the potential to have an enduring influence on the individual’s attitudes and beliefs concerning the direction of their future lives. Thus, it is important to examine such off-time events in the lives of respondents and its impact on their attitudes and beliefs and how they give meaning to life and death.

Several respondents in the study experienced off-time events in their lives, at various stages of development. For example, Mrs. D experienced widowhood in her mid-forties, having been left to raise two dependent children. She described being thrust into a new role that required her to provide sole support and nurturing for her family. It was during this period that she began to view life through a different lens, pondering the meaning and purpose of her life, having experienced the untimely death of her spouse. She referred to the realization of the “innocence of life and that God didn’t take me, that he had something else for me to do.” In assigning further meaning to this statement, she explained that she came to the realization that life—“It’s not here always, and we have to prepare for eternal life… that God puts us here for a purpose, and I realized that I wasn’t fulfilling my purpose.” Similarly, when Mrs. E was widowed unexpectedly in her fifties, she, too, pondered life’s meaning, considered its brevity, and determined that she had to “make every moment count.” Both Mrs. E’s and Mrs. D’s responses to the loss of their spouses in mid-life are consistent with the concept that Kalish (1985) labeled as “death as an organizer of time.” The experience and awareness of death highlights the finite nature of life and alters the meaning of the way in which one uses time, or the way one sets priorities.
At a time when Mrs. C assumed she would be focused on transitioning into post-retirement at age 69, she was instead focused on raising a 6-year-old great granddaughter, a non-normative role assigned in late life that is a consequence of the off-time death of her granddaughter. She that she and her spouse had applied to adopt the child “so we can help prepare her life for education and so forth…” Hagestad and Neugarten (1985) refer to Mrs. C’s circumstance as an event that upsets the “expected sequence and rhythm” (p. 41) of one’s role or life transition. Despite having assumed this new and off-time role, Mrs. C had moved ahead with end-of-life planning, having executed a living will.

Events that occur at various stages of life have the potential to have an enduring quality. Mrs. B, at the age of seven or eight, experienced the loss of a cousin whom she described as being “like my mother.” Her mother’s response to her question of “Jesus, why you take my cousin?” remained with her over the years: “Well, you know, we didn’t come here to stay.” Mrs. B explained that as she “grew older” she came to “accept” such losses, “cause the way my mother sat and talked with us, it let us know that we got to leave here. We got to go.” Her mother’s response to this very event very early in her life, and with reinforcement throughout her developmental years, significantly informed the way she had come to understand death in late life.

Similarly, Mr. T’s experience as a pre-teen, in the loss of his developmentally disabled brother, had a far reaching impact on his attitude toward death and dying later in life. He related that as he matured, he understood his mother having “treated” his brother’s death as an answer to her prayer. He reflected: “I felt like it was an answer to her prayer as well. And as a matter of fact, I thought it was kind of great that the Lord
would answer her prayer and take brother before He took her.” He recounted that he understood that no one would have cared for his brother as his mother had cared for him. Later in life, when his father neared the end-of-life, having experienced significant physical suffering, he accepted his father’s petition to his church congregation to cease praying for “healing.” Again, he felt a certain relief because his father was a man “that knew what he wanted… I felt like Dad was in a position to make a good judgment call.” and he was suffering mightily. These very significant death experiences were instrumental in shaping Mr. T’s views of death as a relief from suffering, as experienced by his father, and a source of protection and assurance for his disabled brother.

Such experiences in the formative years, like the loss of a loved one, may have a stronger and more enduring impact on our choices in future life experiences (Barrett and Heller, 2002) and the meaning that is applied to an event, or how one makes sense of life and death. The respondents experienced death in mid-life and during their youth. Their narratives captured the enduring impact of these experiences at differing developmental stages of life.

Linked Lives

According to Elder (1999), “linked lives refer to the embeddedness of the life course, intertwined with the lives of others” (p. 963). Central to linked lives is social interaction, intergenerational ties, and kinship networks. From a life course perspective, there is interdependence in the living of lives, and historical and social influences are expressed through this network of shared relationships (Elder, 1998). Hareven (1994) views the concept of linked lives as a synchronization of individual life transitions with
collective family transitions. It is within the framework of intergenerational ties, familial interdependence, and synchronization of individual life transitions that the concept of linked lives is addressed.

The strong presence of intergenerational ties is evident from a bi-directional interactive process when we, again, consider Mrs. E. After many years as a high school principal, she looked forward to the opportunity to enjoy retirement and to do those long awaited leisurely activities that seemed impossible given her demanding and rigorous schedule. However, her plans were side tracked due to the illness of her 84-year-old mother for whom she was caring in her home. Mrs. E’s postretirement experience was consistent with the assumption of Szinovacz and Ekerdt (1996) which posits that “retirement plans, decisions, adaptation, and postretirement activities are contingent on the accumulation and timing of other life events, including events pertaining to family members” (p. 376). While Mrs. E seemed firmly entrenched and accepting of familial caregiving responsibilities for her mother, she expressed a strong desire that her two sons should not feel obligated to provide similar caregiving responsibilities for her, under similar circumstances. While she hedged and expressed ambivalence regarding completing written advance directives, she gave her sons very specific instructions concerning her treatment wishes in the event of future illness or disability that would lead to physical dependency. She noted: “I’ve already said to them, when I get older, and you won’t be hurting me, I want to go first to an assisted living—a very nice assisted living with people my age…” Regarding the idea of placing her mother in a nursing home, Mrs. E. stated: “I have a problem, now I have a problem with… putting my mother in a home and my commitment to her and to my dad is that I will take care of her as long as my
health permits it.” Concerning end-of-life care, Mrs. E discussed a conversation she held with her sons: “If I were ill and the doctor said your mom is terminal, there’s nothing that we can do… I would not want to put them through the pain and the suffering. Because I experienced that with my father.”

Consistent with Mrs. E’s wishes to avoid having her sons become caregivers in the future, this cohort of respondents expressed a strong desire to avoid becoming a caregiver burden for their families--financial, emotional, or physical. Therefore, the concept of caregiver burden is germane to the discussion of linked lives or familial and intergenerational dependence and interdependence.

**On Being a Burden**

Emanuel (1993) suggests that not being a burden, and other less clinical features of life are important to individuals in making certain clinical decisions about treatment at the end of their lives. This cohort of elderly individuals is part of a generation in which the extended family, specifically the African American extended family, is valued and kindred ties and responsibilities to care for family members across generations and all stages of the life cycle are well established (Johnson, 1995; Sussman, 1985). However, in spite of the strong family ties that seemed evident for each of the respondents, they generally took a fairly strong stance concerning their willingness to accept institutional care in an assisted living facility or in a nursing home should they no longer have the ability to adequately attend to their activities of daily living. Their loss of independence was a much-dreaded condition, and it is evident that a generation that has given so much in the way of caregiving, for the very young and the very old, feels a sense of obligation.
to spare their families this duty and responsibility. For example, Mrs. H had no children, but has a very close and loving relationship with a niece and nephew but doesn’t want to be a burden because, she explained: “My niece and my nephew… my nephew just got married over two years ago, and he and his wife would take care of me; I don’t want them to take care of me… because they have their own life to live.” While there is no eagerness to find residence in an institutional setting, respondents felt that there are limited options. For example, Mr. R explained when asked if he had considered what he would do should he lose the ability to care for himself. He responded: “Probably, if you didn’t want to be a burden on someone, the only thing left to do is go to a nursing facility… I wouldn’t want to go, but if that’s the best, you know, what else are you going to do?”

In spite of the bonds within the African American extended family structure (Johnson, 1995; Sussman, 1985) there is evidence that African American older persons are more prone than whites to express preference for non-family care alternatives, conserving family resources until other resources are depleted (Kalish, 1976; Sussman, 1985). In addition, African Americans, historically, have relied heavily upon their community churches, not only for spiritual support but as a source of emotional and economic assistance as well (Kart, 1996). In spite of this reliance on community-based support systems, the African American family values making use of the extended family in providing care to older family members (Johnson, 1995). However, the participants were hopeful of continued independence as they pondered and sought meaning and purpose in life and continued to strive for a productive and independent existence.
Personal Meaning in Life

The way this cohort of elderly respondents understood and experienced death and dying was significantly guided by the way in which they have found and continue to seek purpose and meaning in life, a defining feature of their lives and its quality. Recker, Peacock, and Wong (1987) define meaning as, “…making sense, order, or coherence out of one’s existence. Purpose refers to intention, some function to be fulfilled, or goals to be achieved” (p. 44). Thus, Reker and Wong (1988) sum up personal meaning as being “the cognizance of order, coherence, and purpose in ones’ existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfillment” (p. 221). In addition, Moore, Metcalf, and Schow (2000) argue that the question of meaning in old age has implications for the quality of life, as one grows older.

In the discussion of how study participants’ find and assign personal meaning in life, an interpretation of their view of the sanctity of life or The Sanctity of Life Principle (SLP) is germane to the discussion. The SLP suggests the belief that a person’s life must be prolonged even if maintaining life is of no identifiable benefit to the individual (Kuhse, 1987). In this regard, Barrett and Keller (2000) argue:

Blacks as a group generally believe in the sanctity of life. They generally operate with the traditional belief that life is to be preserved at all costs. This belief in the sanctity of life would suggest that, in general, blacks would not be inclined to discontinue life-sustaining treatment, once it was started, if they perceive that decision as causing death (p. 795).

Such conclusions are supported by various studies (Blackhall et al., 1999; Caralis et al., 1993; Garrett et al., 1993; Mebane et al., 1999) in which findings suggest that African Americans’ express a desire for heroic end-of-life care even in the face of futility. Conversely, other studies’ (Dupree, 1998; Waters, 2000) findings are counter to
the notion that African Americans’ desire unconditional aggressive end-of-life treatment. Furthermore, findings from the present study suggest that meaning and purpose in life far outweigh the respondents’ adherence to or strong identification with the sanctity of life philosophy and a desire for care at all costs. Neither the idea that African Americans resist death, as they are metaphorically not prone “to go gently into that good night”, or conversely that they view death as a “welcomed friend,” was evident in the respondents’ narratives. Such metaphors describe African Americans’ beliefs and attitudes as extremes on a continuum—strongly resisting death on one hand and welcoming death on the other. Instead, there was a more moderate view and attitude toward death that impacted how, and to what extent, respondents wanted medical intervention at the end of their lives. Their attitudes and beliefs were largely spiritually and experientially driven, and also based on an acceptance of the reality and inevitability of their mortality.

For example, Mr. T’s reflection of his philosophy about death appeared to be significantly influenced by his mother’s prayer that “the Lord would answer her prayer and take brother before he took her.” He explained that he “never looked on death as being something that was necessarily awful. It didn’t have to be all that good, and yet, it wasn’t all that awful to me. It was something that happens. It’s something that just happens.” Similarly, Mrs. H explained her views on death: “Well, I feel about death… I think death’s a part of living. You know, we are going to live and we are going to die.”

That participants’ views about sustaining life were far more moderate than findings in extant research is not cause to conclude that they place a lesser value on life as they ponder and consider end-of-life decision making. As Glaser and Strauss (1965) so poignantly note: “American perspectives on death seem strangely paradoxical” (p. 3).
As an example of this phenomenon, Glaser and Strauss highlight the contradiction associated with the way in which newspaper headlines confront the brutal facts of deaths, while funeral announcements are buried in less prominent sections of the daily news. An observation that was made almost four decades ago; it still holds true in the new Millennium.

Given such paradox, herein lies the value of hearing respondents’ narratives in an effort to shed light on contradiction that is often apparent in research or discourse related to the topic of death and dying or end-of-life planning. In this regard, McAdams (1993) writes: “If you want to know me, then you must know my story, for my story defines who I am…” (p. 11). Embedded within the respondents’ stories was a very rich narrative that detailed a strong and enduring appreciation for life, and a desire to live life fully, however, with meaning and purpose.

Finding or fulfilling meaning and purpose in life for the respondents’ was central to happiness and contentment in late life. Staying alive at all cost and regardless of the condition was not apparent relative to their desires for themselves, or for loved ones. If medical care was determined futile, following proper and adequate input from medical providers, they reported a preference for discontinuing or not engaging life supporting efforts, and opting for effective comfort care.

According to Levinson (1979) a basic developmental task of late life is to find a new balance of involvement with society and with the self. Furthermore, Levinson suggests, “the developmental task is to overcome the splitting of youth and age, and find in each season an appropriate balance of the two” (p. 35). The respondents demonstrated, in their narratives, their efforts to find appropriate balance in late
adulthood by staying active, engaging in new challenges, assisting loved ones, and contributing to their communities. For example, Mr. W, at age 80, emphasized the maintenance of an active schedule and valued the help he extended to members of his church: “At my church, for example now, I try to give legal counseling, anyone needs legal counseling... But if I can be of help to people, I’ll try to do it…” Likewise, Mrs. H spoke of the value of being productive and active, suggesting there is absolutely no reason for inactivity simply because one is “older.” She challenged her older acquaintances to become involved: “Go to some of the places where… nursing homes and places where, you know… They can use you as a volunteer.” In this context, “meaning is created in commitments, achievements, and relationships” (Reker and Wong, 1988, p.223).

Reker and Wong (1988) suggest that as one searches for meaning in life, key questions are, “What is worth living for? What is the purpose of life” (p. 220)? This existential search is evident in Mrs. D’s narrative concerning a turning point in her life in response to her husband’s death in her mid-forties. She pondered her purpose, as it was divinely intended. Having “realized” that she wasn’t fulfilling her purpose and that “God had placed” her “here,” she recognized the need “to get busy” fulfilling her purpose in life. Finally, she proclaimed: “My purpose is to help other people get to Him.” Her role in her church as minister of music has given her the opportunity to work diligently at fulfilling the purpose that she had identified. As a matter of fact, the interview with Mrs. D was conducted at her church after she finished working on one of her many projects there.
Similar to Mrs. D, Mrs. B related her search for meaning and purpose some twenty years ago, as she struggled with the idea of becoming a protestant minister. She reflected on her “calling”: “… I just had a deep burning in my life… that I had a calling that I couldn’t even express.” Like Mrs. D, she explained: “I knew there was a feeling there that I wasn’t doing enough. And then one day I sat down quiet enough, doing my busy schedule… and the Lord let me know that it was a ministry that He wanted me to do, and He sat me down one day and I got quiet, and in my spirit He was speaking… That’s when my heart opened up and said, “yes” to His will.”

In addition, for these elderly participants, there was a striving for financial and physical independence and security. Consequently, the conditions under which they experience meaning and purpose in their lives and desire longevity were inextricably tied to whether they remain self-sufficient and do not present a burden to loved ones—financial, physical, or emotional.

Reker, et al. (1987), studying various dimensions of life attitudes found an increased level of life purpose and satisfaction associated with late life when compared to young and middle-aged participants. Such findings are suggestive of a process of integration—the elderly individual having mastered a sense of integrity, or an appreciation for how he or she has lived (Erikson, 1963). In a related vein, Bolling (1995), commenting concerning the African American funeral ritual for the older individual, states: “When a person has led a full and productive life, the sentiment tends to be more of a celebration of their passing than a mournful state of depression” (p. 156). Furthermore, an understanding of how the respondents’ experienced meaning and purpose in life also provides one with some understanding of how they had come to find
meaning and purpose in death and suffering and how their loved ones give meaning to their lives and to their deaths.

Death Anxiety, Acceptance, and Meaning in Life

According to Wong, Reker, and Gesser (1994), death anxiety and death acceptance are related to the pursuit of personal meaning. Likewise, Drolet (1990) notes a negative relationship between death anxiety and purpose in life. Thus, this section addresses the linkage between these constructs, personal meaning in life, death anxiety, and death acceptance.

Death attitude research is concerned with how individuals’ think, feel, and behave in favorable or unfavorable ways concerning death (Kalish, 1985). Thus, death anxiety may be viewed as an unfavorable attitude toward death and conversely death acceptance as a favorable attitude toward death. Kubler-Ross (1969) categorized death acceptance as the last stage of dying, in which the individual was resigned to the inevitability of death after experiencing the prior stages of denial, anger, bargaining, and depression. Wong et al. (1994) view death acceptance in the framework of successful aging and defines death acceptance broadly, “as being psychologically prepared for the final exit” (p. 124). More specifically, Wong et al. (1994) view death acceptance as a two-dimensional construct, a “cognitive awareness of one’s own finitude and a positive (or at least neutral) emotional reaction to this cognizance” (p. 124).

Butler (1975) proposes that people are more afraid of a meaningless existence than of death, and individuals who consider their lives to be fulfilling and meaningful should show more death acceptance and less anxiety or fear surrounding death. In a
similar vein, Kalish (1994) posits that there is relationship between fear of death and personal meaning, and that the fear of death stems from the failure to find meaning for one’s life and death. Similarly, Erikson (1963), in identifying identity crises throughout the various life stages, categorized the polarity in late life as that of integrity versus despair, suggesting that the task of late adulthood is to develop a sense of integrity or an appreciation of how and why one has lived. According to Frankl (1965), finding meaning in life eliminates individuals’ fear of death and increases their well-being.

The respondents in this study generally noted an acceptance of death and freedom from fear of this eventuality or inevitability. They attributed this to their religious and spiritual connectedness, repeated experience with death, time, and maturity. The narratives of several of the respondents were replete with references to their lack of fear of death. For example, Mrs. C recalled her elderly father’s discussion of death as he proclaimed, “I’m not afraid of death or any man. I love God and God loves me.” Mrs. C reasoned: “And so, I guess I grew up with that attitude; and in my family the people prepare for death.” Likewise, Mrs. H noted a spiritual basis for her attitude and feelings toward death. She stated emphatically: “I’m not afraid of death because I think to the Christian, death is just a sleep.”

Because belief in an afterlife is rooted in religiosity, it seems logical to conclude that individuals who profess strong religious beliefs would be prone to have less death anxiety or fear (Wong et al., 1994). However, according to Wong et al., based on prevailing research, the relationship between religiosity and death anxiety remains inconclusive, as research findings are mixed. There is some evidence (Kalish, 1985; McMordie, 1981) however, that fear of death is lowest in individuals who are either very
strong in religious beliefs, or those who profess no faith-based beliefs. Elderly individuals are more likely to believe in life after death than younger cohorts but there is uncertainty as to whether this is attributable to age or a developmental effect (Kalish and Reynolds, 1976). Perhaps the very strong faith-based beliefs of this cohort and a sense of meaning and purpose in life explain the extent to which they expressed less death anxiety and a considerable degree of death acceptance. Each of the ten respondents attended church on a regular basis, and at least three held responsible offices in their churches (Mrs. D, Mr. W, and Mr. T).

 Nonetheless, two respondents expressed ambivalence and anxiety toward death at this stage of their lives, Mrs. E and Mrs. D. Yet, like the other respondents, they too, were significantly involved in faith-based activities and verbalized very strong religious beliefs. Mrs. D was concerned with the idea of what is on “the other side” the “unfamiliar” side of death. Mrs. E wrestled with the thought that to initiate preparation for death, such as the completion of advance directives, could hasten death. She stated: “Yes, in my mind I feel like this will hasten this to a reality, in my mind… but yes, I know that’s not true. I know that’s not true.” However, Wong et al. (1994) posit that, “death acceptance is not the categorical opposite of death fear” (p. 124), and that fear and acceptance may “coexist in an uneasy truce” (p. 124). This suggests that even those individuals—as in the case of Mrs. E and Mrs. D—who may accept death on a cognitive level, still have the potential to experience ambivalence and uneasiness about their mortality and preparing for its eventuality.

 Wong et al. (1994) sum up death acceptance in a three-component model. *Neutral* acceptance is defined as the acceptance and understanding that death is an
integral part of life. The mere fact of one’s life is to live with the knowledge of death and
dying. One neither fears death nor welcomes it; rather, it’s viewed as an unchangeable
fact of life. Mrs. B’s memories of her mother’s reminder concerning death: “We didn’t
come here to stay, you know,” was an example of such neutral acceptance. Or similarly,
Mrs. H’s pronouncement that, “death is a part of living, but I really don’t give it too much
thought,” spoke to this dimension. Approach acceptance implies belief in a happy
afterlife, which is strongly associated with religiosity. This component was evident in
Mrs. B’s bidding her daughters not to place her on life support. She stated: “I believe
that the life God gives us… We should live it; and when He calls us in, we should be
ready and not try to preserve it against His will… I believe that he’s got a particular time
to come, and when that time comes I believe we should be willing to go.” Finally, escape
acceptance denotes that death may be considered a welcomed alternative when one is
overwhelmed by suffering and pain and there is little likelihood of relief. The desire for
escape, perhaps, was more closely associated with the “badness” of living than with the
“goodness” of death. This dimension was demonstrated in Mrs. E’s and Mr. T’s
supporting decisions to “let” their fathers “go”—that pain and suffering rendered the state
of life to be less acceptable than the state of death. Furthermore, it was for this same
reason, that respondents stated a preference not to have life maintaining treatment in the
face of futility, but to be kept free from pain and suffering.

According to Kalish (1985), a conceptual problem in studies of death attitudes is
the implicit assumption that people say what they mean. “It is assumed that a person who
states he or she is unafraid of death, thereby, is unafraid of death” (Kalish, p. 152). A
second conceptual problem is the blurring of terminology—for example, the blurring of
boundaries between such terms as fear and anxiety. Conversely, in regard to the issue of blurring of terminology, Neimeyer (1988) suggests that as persuasive as the conceptual arguments may be, they are not compelling on either conceptual or practical grounds. For this discussion, the terms death anxiety and fear of death were used interchangeably. 

**Familial Anxiety**

Death anxiety or discomfort experienced by family members, as reported in the narratives of respondents, appeared to be significantly more pronounced than that of the respondents. As such, this anxiety adversely impacted the level of comfort with which respondents approached the subject of end-of-life planning. Because this older cohort of individuals placed a high value on family centered decision-making and discussion, it is important to gain insights into their families’ responses.

While the concept of death anxiety or death fear contributes to such insight, cognitive dissonance theory provides additional understanding concerning this phenomenon and is thereby briefly discussed for its contribution to added insight.

According to Harmon-Jones and Mills (1999), cognitive dissonance theory provides a means of understanding how two cognitions or elements of knowledge, consonant and dissonant, can be relevant or irrelevant to one another. Harmon-Jones and Mills suggest further:

The existence of dissonance, being psychologically uncomfortable, motivates the person to reduce the dissonance and leads to avoidance of information likely to increase the dissonance. The greater the magnitude of the dissonance, the greater is the pressure to reduce the dissonance (p. 3).

This concept fits well with the observations of respondents concerning family members and their reluctance or avoidance where discussing advance care planning is concerned.
It was demonstrated in Mrs. H’s niece, who told her aunt that she will live to be 100, thus avoiding any discussion of death or end-of-life planning, with the goal of reducing the dissonance and resultant discomfort. These stories were repeated by at least seven of the ten respondents. Participants’ feelings of frustration and bewilderment were apparent in their narratives.

Because older individuals’ strongly desire family centered decision making, the discomfort associated with family members’ reluctance to discuss the topic, particularly adult children, has significant implications for practitioners in all professional disciplines that engage in assisting older persons with end-of-life planning. In the following pages further implications and recommendations address these critical issues.

**Implications and Conclusions**

This study has implications in multiple areas when considering the task of improving end-of-life care in general and for older African Americans in particular. These implications extend to social work practice and education, social policy, and theory. The following pages outline these important and critical areas.

**Social Work Practice**

The role of social work in end-of-life care extends to multiple and varied settings and circumstances, including hospice care, intensive and critical care units, nursing homes, community based clinics, and community-level traumatic events. Likewise, social workers provide end-of-life intervention to individuals across the life span, ranging from infancy to late life. Furthermore, the profession’s domain of services reaches across the socio-economic spectrum, connecting with diverse cultural and ethnic groups.
Similar to other disciplines that are engaged in providing end-of-life care, including physicians, pharmacists, nurses, and psychologists—research findings repeatedly document that social work educational curricula and training do not adequately or properly prepare social workers for this vital and increasingly complex demands of this role (Kramer, et al., 2003). For social workers to be more effective in their role, critical conceptual issues must be more adequately and comprehensively addressed, and social work curricula at institutions of higher learning must respond to this most pressing mandate and task. In the practice realm there must be expanded emphasis on the nature of social work practice in end-of-life care, recognizing that it is process oriented, complex, and holistic.

**End-of-Life Care and Its Process Orientation**

Effective end-of-life planning and care require looking beyond the act of completing advance directives. Furthermore, end-of-life planning and care is a process that includes the patient, family, and significant others over time. Therefore, it must be viewed and carried out as a process, not as a one-time event. In this framework, the execution or writing of advance directives may not be the central or the defining feature of the process. Rather, it is ideally the outcome of a painstaking effort on the part of multiple disciplines to address the unique needs and perspectives of the individual served.

The concept of advance care planning, as identified by Pearlman (2001), suggests that the completion of advance directives is one part that goes into comprising the whole of advance care planning. The organizational or discipline specific emphasis on aggressive implementation of advance directives (High, 1993; Kirmse, 1998) fails to pay
adequate attention to the process that is involved and the complex and sensitive nature of advance care planning. Such organizational goals aimed at increased completion rates are likely to continue to remain unmet unless we step back, rethink, and reevaluate the social process. This is especially true of African American older persons who value family ties and the input and consultation from and with their families, particularly their children.

Key to sound and effective social work practice in end-of-life care is effective social work education. The health care concentration comprises the third largest group of students in graduate social work programs (Lennon, 1992). Yet, insufficient training and education of social workers in this area is a frequently cited and major barrier to effective practice (Christ and Sormanti, 1999; Csikai 2004; Foster, et al, 1993). Kramer, Pacourek, and Hovland-Scafe (2003), in a content analysis of social work textbooks found that a major limitation of content was the placing of emphasis on the act of completing advance directives forms, with minimal attention to dialogue and discussion among family members. Central to bringing about needed changes and improved social work education is the development of an educational curriculum, including a continuing education curriculum (Csikai & Raymer, 2002) that seeks to fill in the identified competency gaps and deficits. Key also to the problem solving effort is rigorous research.

The Complexity of Advance Care Planning

In this very complex and diverse society, one thing is certain, there is much diversity between ethnic groups, and similarly variation within the same groups. Regarding African Americans, such complexity is astutely captured in the words of
W. E. B. Dubois, commenting on the duality of the belief systems within African American culture—“two souls trapped in one dark body often warring against each other” (Bolling, 1995, p. 145).

Key to understanding such complexity in the advance care planning effort is an understanding of the role of multiple factors, including culture. A culturally competent health care system and practice extends beyond cultural sensitivity to cultural competence (Chinn, 2000). According to Chinn, cultural competence implies “a set of behaviors, attitudes, and policies that enable a system, agency, or group of professionals to work effectively in cross-cultural situations” (p. 26). Such competence requires the incorporation of the importance of culture, cross-cultural relations, vigilance towards the dynamics that result in cultural differences, the expansion of cultural knowledge, and the adaptation of services to culturally unique needs and perspectives. Cultural insights also add to one’s ability to unravel what often appears to be paradox and contradiction in the language and behavior of the individual or family members.

**Holistic Emphasis**

The impact and importance of culture as it informs individuals’ attitudes toward end-of-life treatment preferences are consistent with the social work profession’s historical emphasis on the person-in-environment (Germaine & Gitterman, 1980), the holistic nature of practice, and a strengths-based perspective. A holistic perspective encompasses the physical, spiritual, emotional, and psychosocial aspects of individuals’ lives. Such an emphasis and perspective are vital and germane to effective work with the individual, family members and significant others.
Also, it is important to understand that a holistic framework that draws solely on the cultural practices and uniqueness of older African Americans (Minkler & Estes, 1991) runs the risk of overlooking the influence of structural forces such as race, and class on the health care of older African Americans. A perspective and understanding of these structural barriers is key for those who occupy advocacy roles, as is a key role of the social work practitioner.

Policy Implications

The Patient Self-Determination Act (PSDA) legislation was enacted by the United States Congress with goals of preserving end-of-life autonomy and reducing the costs of unwanted medical treatment. It was enacted as part of the deficit reduction effort of the Omnibus Budget Reconciliation Act (PL 101-508) of 1990 (Galambos, 1998). The cases of Karen Ann Quinlan and Nancy Cruzan served as the impetus to this very public and editorially fueled debate concerning individuals’ rights concerning end-of-life choices. While this was not a new issue leading up to the decade of the ‘90’s, the public nature of such private and personal decisions in the Cruzan and Quinlan cases caught the attention of the American public and lawmakers as never before.

Central to the PSDA, is the Western value and concept of autonomy and self-determination, specifically, the right of a mentally competent adult to make medical decisions for him or herself relative to medical treatment that is wanted or unwanted as one approaches the end-of-life. As a response to advances in medical technology and the high costs that are associated with heroic medical care, the PSDA legislation required all health care organizations receiving Medicare and Medicaid to: (1) provide written
information to adult patients concerning treatment options, and their right to complete
advance directives; (2) provide written information concerning the health care
organization’s implementation of such rights; (3) document in the patient’s medical
record whether an advance directive was executed; (4) ensure compliance with the
applicable State law pursuant to advance directives and (5) provide for the education of
the institution’s staff and the community concerning advance directives (French, 1991;
Link, 1994). The failure of the PSDA to accomplish goals that were the intent of the
legislation requires a multidimensional focus and analysis in order to better understand its
failure.

First, it seems plausible to explore whether the PSDA as a public policy was
conceived using faulty assumptions. The idea of autonomy and self-determination in
end-of-life planning and decision-making suggests that death is a person-oriented event.
However, such an assumption is challenged by research that finds this is counter to the
beliefs, practices, and preferences of older individuals (High, 1993; Miles, et al., 1996;
Singer, et al., 1998).

According to Singer et al., (1993), traditional “academic assumptions” about
advance care planning are based on the premise that: (1) the purpose of advance care
planning is to prepare for incapacity; (2) the ethical principle of autonomy and the
exercise of control drive advance care planning; (3) the focus of advance care planning is
the execution of advance directives; and (4) advance care planning takes place within the
context of the patient-physician relationship. It is important to note Singer et al., findings
following empirical validation revealed the different ways in which patients gave
meaning to these assumptions. For example, key findings suggested that patients’ view
advance planning not solely on the basis of autonomy and personal control, but also on personal relationships and relieving burdens on other. Furthermore, the focus of advance care planning in not only on completing written advance directives but also on the social process, and end-of-life planning is not limited to the context of the patient-physician relationship but also within the context of relationships with close family. These findings are generally consistent with the present study relative to the way in which respondents give meaning to end-of-life planning and highlight the necessary emphasis on process and a family oriented focus to advance care planning.

A second systemic issue is that of procedural barriers. Systemic and procedural barriers add to problems associated with low advance directives completion rates. Correction of this barrier requires clarifying advance directives documents, which includes scenario and treatment specific statements or choices. Current forms, are in some cases quite lengthy, confusing, legalistic and cumbersome to complete, especially for older individuals.

Finally, the timing of discussion of advance directives with patients should be separated from the admission process in order that non-related paperwork that is completed during the admission procedure does not serve to minimize the intent of the PSDA statute, or cause unnecessary confusion for patients and their loved ones. The PSDA requires Medicaid and Medicare reimbursed medical facilities to advise patients of their right to state their treatment preferences upon admission and to complete an advance directive if they desire. However, the effective implementation of this directive requires that health care organizations rethink and restructure their implementation of the
provision to ensure that appropriate and trained personnel provide advance directives counseling during this process.

Theory

The existing structure of advance care planning, largely driven by the core concept of individual autonomy or self-determination requires rethinking and redefining based on the meaning that is assigned by individuals who come from diverse, backgrounds--ethnic, cultural, and social. This approach, reframing and re-examining the concept (Lapine, et al, 2001), encourages and permits the individual to determine the extent and form of his or her autonomy. In a related vein, Bailly and Depoy (1995) argue that as one ages the concept of autonomy takes on a qualitative change in meaning, shifting from the capacity to act directly to have decisions implemented on their behalf due to a loss of function or health in old age. As High (1993) so poignantly argued, self-determination does not preclude the involvement of those whose input and opinions are highly valued by the elderly. This highlights the importance and significance of involving families and significant others in the end-of-life decision-making process, and of equal importance, in the end-of-life educational process.

Second, there is a need to examine and re-examine the structural forces that impact disparities and inequities in health care for vulnerable populations, including African American older persons. Such an examination requires reconceptualizing the very prevalent notion of African Americans’ mistrust of the health care system and its adverse impact on access and preventative health care. Rather, attention to the concept of breach of trust (Crawley et al, 2000) is in order, a perspective that is well-suited for
critical theorizing. The concept of breach of trust posits (Crawley) that the label of mistrust, without supporting data, has the potential for unfairly and inaccurately portraying African Americans as inherently mistrustful toward advance directives and other care-related end-of-life issues. Instead, emphasis should be placed on culturally relevant education as a means of addressing certain barriers to health care access, and addressing systemic barriers to equal access. “Any skepticism of medical care might be better explained as a result of poor experiences rather than poverty” (Minkler and Estes, p. 264).

Limitations of Research

Although the researcher believes that this study helped to reveal areas that explain how older African Americans’ lived experiences, over the life course, inform their attitudes and beliefs about end-of-life planning, study limitations are acknowledged. First, the study consisted of a small purposive sample that was appropriate for this qualitative project. However, because of the nature of the research question and purpose of the study, respondents were limited to older African American men and women who resided in a single geographic area. Therefore, while the findings provide additional insights that have meaning and implications for policy, practice, future research, and theory, they are not generalizable to other populations.

Future Research Implications

The results from this study demonstrate significant areas for further inquiry. Future research that explores the nature of autonomy as it is practiced and understood by African American older persons and other ethnic groups is essential to improved end-of-
life care and more clearly identified end-of-life planning in these groups. Second, the problem of health care access and health care disparities require investigation that is approached from a constructivist framework that illuminates and clarifies issues labeled as African American mistrust and distrust of healthcare establishments. Third, further research is needed that moves in the direction of identifying a model of end-of-life planning that is values driven from the perspective of identified groups, especially older persons and ethnic groups, given the very Western orientation that currently directs formal advance care planning. Finally, further naturalistic research that focuses on the role and impact of the family of older persons in outcomes on advance care planning deserves further investigation.
APPENDIX A

INDIVIDUAL INTERVIEW SCHEDULE
Individual Interview Schedule

Consistent with a qualitative approach, a set of open-ended questions will be used to guide the interview, starting with general questions and moving to more specific inquiry. The following are questions that will be asked during individual interviews:

1. Tell me about your life and growing up.
2. How have you experienced growing older?
3. What does living a “good life” or “quality life” mean to you?
4. How have you come to understand what it means to live a “poor quality” of life?
5. What does living a long life mean to you?
6. What meaning do you give to physical suffering and pain?
7. What are your thoughts and feelings concerning living wills, or appointing someone to make your healthcare decisions for you, if you were too ill to make such decisions for yourself?
APPENDIX B

FOCUS GROUP INTERVIEW SCHEDULE
Focus Group Interview Schedule

Consistent with a qualitative focus, a set of open-ended questions will be used to guide the interview, starting with general questions and moving to more specific questions. The following are questions that will be asked during the focus group session:

1. How have you experienced growing older?
2. What does living a “good life” or “quality life” mean to you?
3. What does living a “poor quality” of life mean to you?
4. What does living a long life mean to you?
5. What meaning do you give to physical suffering and pain?
6. What are your thoughts and feelings concerning living wills or appointing someone to make your healthcare decisions for you, if you were too ill to make such decisions yourself?
APPENDIX C

SOLICITATION LETTER
Solicitation Letter

My name is Evie Bradley, and I am a doctoral candidate in the College of Social Work at The Ohio State University, Columbus, Ohio. I would like to invite you to participate in a research project that I am conducting for my dissertation at The Ohio State University College of Social Work under the direction of Dr. Virginia E. Richardson. The intent of this research is to examine older African Americans’ views about medical treatments they might want if they had a life-threatening or terminal illness. The interview questions focus on your opinions about the medical care you would desire, and who you might want to make decisions if you were unable to make medical decisions for yourself.

My role in this study is that of a researcher, and I am not acting in my capacity as a licensed social work practitioner.

Your participation in the study is strictly voluntary, and you have the right to withdraw from the study at any time. Your responses to the questions asked will be kept in strictest confidence, and your name will not be used in reports compiled concerning the interview.

Your participation requires approximately one to two interview sessions of sixty to ninety minutes each, which will take place within a three to four week timeframe.

The knowledge that is gained from this project will be valuable to those in the health care field in providing sound medical care and treatment options to those with life-threatening or terminal illness.

If you are willing to participate in the interview, please contact me at (614) 253-7970, weekdays between the hours of 8:00 a.m. and 4:30 p.m., or (614) 866-5190, evenings and weekends. Or, you may contact Dr. Virginia Richardson at (614) 292-1507.

Sincerely,

Evie L. Bradley
APPENDIX D

INFORMED CONSENT DOCUMENT
CONSENT FOR PARTICIPATION IN SOCIAL AND BEHAVIORAL RESEARCH

Protocol title: An Exploratory Study of the Attitudes and Beliefs of Older African Americans’ Concerning Advance Care Planning: A Developmental Perspective

Protocol number: 02B0127

Principal Investigator: Virginia E. Richardson, Ph.D.

I consent to my participation in research being conducted by Virginia E. Richardson, Ph.D., of The Ohio State University and her assistants and associates.

The investigator(s) has explained the purpose of the study, the procedures that will be followed, and the amount of time it will take. I understand the possible benefits, if any, of my participation.

I understand that those conducting this study are acting in the role of researchers and not in a clinical capacity, or as service providers.

I know that I can choose not to participate without penalty to me. If I agree to participate, I can withdraw from the study at any time, and there will be no penalty or reprisal.

I consent to the use of audiotaped interviews and the transcribing of the tapes.

Participation in the study requires approximately one to two interview sessions; each will last from sixty to ninety minutes. Duration of contact will be over approximately a three to four week period.

I have been advised that a copy of this signed consent form will be retained on file by the researcher for at least three (3) years beyond the termination date of my participation in the study.

I have had a chance to ask questions and to obtain answers to my questions. I can contact the investigators: Virginia Richardson at (614) 293-5706 and Evie Bradley at (614) 866-5190. If I have questions about my rights as a research participant, I can call the Office of Research Risks Protection at (614) 688-4792.

I have read this form or I have had it read to me. I sign it freely and voluntarily. A copy has been given to me.

Print the name of the participant:

______________________________________________________

Date: _________________________________  Signed:  ___________________________________

Signed:  ________________________________  (Participant)
(Principal Investigator or his/her authorized representative)

Signed:  ___________________________________
(Person authorized to consent for participant, if required)

Witness:  _______________________________
(When required)

HS-027 (Rev. 05/01)  (To be used only in connection with social and behavioral research.)
LIST OF REFERENCES


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