THE ROLE OF SPIRITUALITY IN THE SELF-MANAGEMENT OF CHRONIC ILLNESS AMONG
OLDER ADULTS

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Many older adults perceive spirituality as an important resource in their lives and

spiritual practices as crucial to their health and well-being. Unfortunately, there is limited

knowledge of how spirituality is defined by African American and Caucasian American men and

women aged 65 years and older. In addition, less understanding on the role spirituality played in

the self-management of chronic illness among this population. The purpose of this qualitative

study was to define, explore, and describe spirituality in the life of chronically ill elders and to

examine its relationship to self-management of chronic illness in terms of gender and race.

The grounded theory approach guided the study design and analysis. This study used

both comparative method and thematic content analysis in a sample of eighty-eight older adults

in the "Self-Care Study," a NIA-funded study on the process of self-care among older adults.

The analytic technique of comparative method defined spirituality while thematic content

analysis identified patterns of spirituality and self-management. Each in-depth interview was

audiotaped and transcribed verbatim.

Results identified three types of spirituality: transpersonal transcendence, interpersonal

transcendence, and intrapersonal transcendence. In describing the spiritual/self-management

connection nine themes emerged: 1) God: the healer, 2) God: the enabler through doctors, 3)

faith in God, 4) prayer as a mediator, 5) spirituality as a coping mechanism, 6) combining

traditional medicine and spiritual practices, 7) selected spiritual practices of self-care, 8) empowering respondents to practice health-promoting activities, and 9) personal responsibilities in the self-management of illness.

These findings suggest a new direction for public health practice, education, and research. Spirituality is a pervasive factor in this population and may help to ensure positive health-promoting behaviors. The public health significance of this study is great because it is important for public health educators to understand the role spirituality plays in the self-management of chronic illness among the elderly. The implications for public health educators and researchers are the possible collaboration with faith-based institutions to assess, plan, develop, and evaluate interventions within the context of older adults.

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1.   CHAPTER 1

1.1.   INTRODUCTION

The population of older Americans, those 65 years and older, is rapidly increasing. In

fact, the percentage of older adults in the United States has more than tripled from 4% (3 million)

to 12.3% (35.6 million) since 1900 (US Administration on Aging, 2003). It is estimated that

older adults will represent approximately 20% of the United States population by the year 2030

(US Administration on Aging, 2003). These individuals are more likely to have at least one

chronic health condition. Chronic diseases are long-termed illnesses, such as arthritis, heart

disease, and diabetes that are not curable and that negatively affect the daily living of activities.

Stoller and colleagues (1993) explore the issue of self-care among chronically ill older adults.

According to their research, older adults were more likely to carry out self-management activities

if they had a chronic health condition (Stoller et al., 1993). The goal of self-management is to

complement conventional medical care. In fact, self-management is the ability to manage a

medical problem by treating the ailment (Vickery & Levinson, 1993). Most of the self-care

literature concentrates on preventing, treating, or coping with chronic illness but plays little

attention to understanding complementary or alternative self-care practices among older adults

(Coulton, Milligan, Chow, & Haug, 1990; Ory & DeFriese, 1998; Quandt, Arcury & Bell, 1998).

Complementary or alternative self-care practices refer to activities that focus on the

holistic connection of body, mind, and spirit. These activities include, but are not limited to,

yoga, herbal medicine, massage therapy, change in lifestyle, exercise, dietary changes, and

spiritual practices (Barrett, 1993). Older adults with chronic illness reported that spirituality was

an important resource in their lives (Arcury et al., 1996; Koenig, 2002; Landis, 1996; Leetun,

1996; Meisenhelder & Chandler, 2002; Quinn et al., 2001). For example, Arcury and colleagues

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(1996) revealed that rural arthritic adults listed prayer, church services, and inner self/positive thinking as complementary or alternative self-care practices for their arthritis, suggesting a noteworthy influence of spirituality on self-care practices. Furthermore, 92 % of the participants in the study used prayer as an alternative remedy in the treatment of their arthritis (Arcury et al., 1996). The purpose for the following study is to increase our knowledge about the meaning of spirituality and to understand the influence of spirituality on self-management behaviors among older adults with chronic illness.

1.1.1.   Purpose of Study

To address the challenges to defining spirituality and interpreting the role spirituality plays in self-management of chronic illness, this study uses a descriptive, qualitative research design. As this is a relatively new area of inquiry, I used grounded theory to explore the meaning of spirituality and to understand the influence of spirituality on self-management. The ground theory approach guided the study design and analysis. This design involved soliciting information about the process of self-management among older adults who were enrolled in the "Self-Care Responses of Older African Americans and Whites[1]," a study funded by the National Institute on Aging (#R01-AG18308-03), hereafter referred to as the parent study. The parent study examined the process of self-care among 1128 individuals with either osteoarthritis of the hip or knee, or ischemic heart disease as well as compared African and Caucasian Americans who resided in Allegheny County, Pennsylvania over a 4-year time period (2000 to 2004). This study engaged a sample of participants in further conversation using a semi-structured questionnaire to explore the unfamiliar area of spirituality and self-care. As stated previously, the primary purpose of this study was to define spirituality and to examine the relationship between spirituality and the self-management of chronic illness among older adults.

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[1] Unlike the parent study, the author identified whites as Caucasian Americans in this study.

1.1.2.   Significance

Empirical research and surveys on spirituality have exploded during the past 25 years.

For example, national surveys such as the Gallup polls (1994), the General Social Survey (1998,

2002), and the National Survey of Religious Identification (1990) indicate that older adults report

a higher reliance on spirituality or religious beliefs in their lives compared to their younger

counterparts. Despite the documented evidence of spiritual practices (i.e. prayer, mediation)

among older adults, studies conducted in the social sciences (i.e. gerontology, psychology, and

sociology) have restricted their research to religious practices (i.e. frequency of attendance,

religious affiliation) (Ainley & Smith, 1984; Heisel & Faulkner, 1982). Religious practices or

religion has been defined as a systematic set of beliefs or rituals associated with an

institutionalized group designed to generate intimacy to the sacred or transcendent - God or a

higher being (Koenig, McCullough, & Larson, 2001). In contrast, spirituality goes beyond the

traditional boundaries of religion and is more personal. Empirical literature on spirituality and

health has habitually focused on traditional religious practices (George, et al., 2000; Matthews, et

al., 1998; Musick, et al., 2000; Wink & Dillon, 2002; Zinnbauer et al., 1997). These studies

defined spirituality as a religious activity such as the frequency of prayer, the frequency of

church attendance, and religious affiliation. However, people express their spirituality in a

myriad of ways outside the religious arena. Therefore, it is not sufficient to inquire what church,

temple, or synagogue a person attends. As a result, empirical research began to distinguish

spirituality from religiosity, the extrinsic organized faith system grounded in institutional

practices. Recent empirical literature suggests spirituality is positively related to the quality of

life in individuals with HIV (Sowell et al., 2000; Tuck, McCain, &Elswick, 2001), with cancer

(Brady et al., 1999; Fernsler, Klemm, & Miller, 1999; Tate & Forchheimer, 2002), and with

diabetes (Tull et al., 1998). Others researchers demonstrate a decrease in depression among

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Latinas who report high levels of spirituality (Simoni & Ortiz, 2003) and an increase in well-being among individuals suffering from rheumatoid arthritis (Bartlett et al., 2001) and sickle cell anemia (Cooper-Effa et al., 2001).

In the same way, qualitative research is demonstrating the positive relationship between spirituality and health among cancer patients (Taylor & Outlaw, 2002) and diabetics (Daalemen, Cobb & Frey, 2000). Unfortunately, this research does not extend to spirituality and self-management. I identified three publications on spirituality and self-care: an article in *Diabetes Care* (Samuel-Hodge et al., 2000) and two publicized abstracts from the American Diabetes Association scientific sessions (Tull et al., 1998; Tull, Taylor, & Hatcher, 2001). The article and abstracts discussed the influences of spirituality on self-management among diabetics. From these studies, the authors determined that spirituality does influence self-care practices among people of color. For instance, 70 southern African American diabetic women in Samuel-Hodge and colleagues (2000) study articulated that spirituality was an important factor in the self-management of their diabetes. Likewise, Tull and colleagues (1998, 2001) concluded that spiritual orientation acts as a buffer against complications for kidney disease and may influence self-care behavior and metabolic control among African Americans. These findings may have implications in the management of chronic illness among diverse groups of people. However, as stated previously, research exploring the relationship between spirituality and self-care among older adults living with chronic illness has yet to be addressed.

This study aims to fill this gap in the body of knowledge by (1) understanding how older adults with chronic illness define spirituality, and (2) by gaining an understanding of the use of spirituality for self-care in chronic illness. To address these aims, I synthesized the conceptual frameworks from the disciplines of social gerontology and psychology, namely,

Gerotranscendence and Humanistic Phenomenological Spirituality. These two perspectives are

presented in Chapter 2.

2. CHAPTER 2

2.1. STATEMENT OF THE PROBLEM

Recent evidence suggests that older adults are using spirituality to manage the challenges associated with living with their chronic illness (Ramsey & Blieszner, 1999). However, as previously stated, there is limited understanding regarding the definition of spirituality by chronically ill older adults and the influence of spirituality as a resource in managing their chronic illness. Consequently, the issue guiding the development of this study is that early works suggest that chronically ill older adults are using spirituality as a resource, but the available literature does not offer a clear description of how this process occurs. The literature discusses the importance of spirituality in the lives of older adults (Atchley, 1997; Stoll 1989). With the reported benefits of spirituality on an individual's health and general well-being and the increased importance of spirituality among older adults, it is imperative that researchers explore the role and the influence of spirituality within older adults living with chronic illness. This presents an ideal opportunity to add knowledge to the current literature regarding spirituality.

The purpose of this qualitative study was to define, explore, and describe spirituality in the life of chronically ill elders and to examine its relationship to self-management of illness in terms of gender and race. Qualitative methods are best used when attempting to uncover the nature of individuals' life experiences with a phenomenon-like illness (Strauss & Corbin, 1990). For this study, the experts on this phenomenon are those who are participating in the parent study. Spirituality is a broad, multidimensional, construct that lends itself to an individual definition according to his own lived experience. From this standpoint, the aim of this exploratory research is to derive rich, conceptual analyses from the experiences of chronically ill older adults. This research may begin to provide valuable information about differences in

spirituality based on ethnicity, gender, and illness, and it can assist with a deeper understanding of spirituality from the participants' perspective.

2.1.1.   Research Questions and Specific Aims

The qualitative theory-driven research questions explore the relationship between spirituality and self-care among a sample of older adults enrolled in the parent study, which is a four-year longitudinal study funded by the National Institute on Aging. The two specific research questions guiding this study are:

- How do older adults living with chronic illness define spirituality?

- How does the study population use their spiritual practices in the self-management of their chronic illness?

The specific aims are:

- To define spirituality as understood by older African and Caucasian adults with chronic illness.

- To determine whether or not spirituality is a form of self-care among this population.

- To document and describe the differences in spiritual practices in self-care use by race, and gender.

2.2.   CONCEPTUAL FRAMEWORK

Cognitive and emotional theories support the theory that spirituality increases with one's age. It is therefore suggested that cognitive changes, such as wisdom in the elderly, are linked to spirituality and that spiritual growth is often a part of the aging process (McFadden, 1996a; ; Sinnott, 1994). The framework for spiritual development involves spiritual growth as the maturation process. Jung (1964) stated that around midlife (age range, 40-59 years) individuals typically begin to turn inward to explore the more spiritual aspect of the self. Spirituality is the product of the maturational process that occurs during the course of adult life (Alexander et al., 1990; Sinnott, 1994). The connection between spirituality and older age occurs due to adversity.

Atchley (1997) found age discrimination and physical limitations push older adults toward becoming more spiritual. Burke (1999) also suggests that adverse social conditions and discontinuities experienced by African Americans may explain why the African American women were more spiritual than the Caucasian American women in her study. McFadden (1996) posits that spirituality may be more meaningful in older adults because of personal losses and the difficulties they often encounter.

Gerontological research has failed to have a cross-disciplinary approach to aging research. Research can be enhanced by integrating related theories from various social and behavioral disciplines. This integration is important especially in the research of spirituality, which often interconnects the behavioral and social sciences. Based on the aforementioned studies, the conceptual frameworks of this study incorporate elements of two theoretical perspectives from different disciplines: 1) The Theory of Gerotranscendence (Tornstam, 1989; Tornstam, 1994; Tornstam, 1997) and 2) The Humanistic-Phenomenological Spirituality (Elkins et al., 1988).

2.2.1. Theory of Gerotranscendence

Lars Tornstam, a gerontological sociologist at the University of Uppsala in Sweden, developed the theory of gerotranscendence. Tornstam (1989) questioned the prevailing paradigms within research in social and psychological aging, such as the disengagement theory (Cummings & Newell, 1960). The disengagement theory assumed that the aged gradually withdrew from social activities. Once this process started, it was irreversible. The aging person increased his preoccupation with self and decreased participation with others. As the individual prepared for death, that person gradually removed himself from society. At the same time, society started to reject the aged. The theory does not address whether or not the aged or society initiates the disengagement process.

Tornstam (1989, 1994, 1997, & 1999) presented an alternative theory on gerotranscendence which stated that the general process toward gerotranscendence characterizes human aging. This process is the shift from a materialistic and pragmatic view of the world to a more cosmic and transcendent one, which is normally accompanied by an increase in life satisfaction (Tornstam, 1997). The individual with a transcendent perspective spends more time in meditation and less time in superficial social relationships. The spiritual world becomes more important than the material world. This new concept of life implies a change in the perception of life. Tornstam (1999) maintained that the process toward a transcendent form of life is one that is instinctive and transcultural. He further assumed that this development is essentially continuous, but it may be accelerated or retarded by external factors. The process may be accelerated through meditation or brought on by life crises or severe illness. It may be retarded due to aspects of our culture, which is characterized by the dominance of rationalism (Tornstam, 1999).

The shift in metaperspective is normal for all individuals according to Tornstam (1994), since it is conditioned by genetics. Gerotranscendence is the result of a natural process toward maturation and wisdom in which reality is defined differently than in midlife. Since this is a natural process for all elderly people, the shift in metaperspective leads to an increased satisfaction with life. The progression toward gerotranscendence may be obstructed or modified by cultural characteristics (Tornstam 1997).

As in Jung's theory of the individuation process (1964), gerotranscendence is regarded as the final stage in a natural progression toward maturation and wisdom. According to the theory, the individual moving toward gerotranscendence may experience a series of changes. The gerotranscendent individual typically experiences a redefinition of self and of relationships to others and a new understanding of fundamental existential questions. The individual becomes

less self-occupied and at the same time more selective in the choice of social and other activities. There is an increased feeling of affinity with past generations and a decrease in interest in superfluous social interaction. The individual might also experience a decrease in interest in material possessions and a greater need for solitary "meditation." Positive solitude becomes more important. There is also often a feeling of cosmic communion with the spirit of the universe and a redefinition of time, space, life, and death. Elements in cultures and subcultures, as well as experiences in the individual life, can facilitate or impede the gerotranscendental process.

Several researchers regard transcendence as a fundamental component of spirituality (Dawson, 1997; Hickson & Phelps, 1997; Fry, 1998; Ley & Corless, 1998). Spirituality based on transcendence provides an opportunity for individuals to share a connectedness with a higher power or God (Cole, 2001). Cognitive and emotional theories support the theory that spirituality increases with one's age. These theories include: an increase in reflection about the meaning and purpose of one's life (Erikson, 1950); an increase of physical ailments possibly elicting an increase in spiritual development (Furlong, 1998); and an increase in confronting issues related to death and dying (Roe, 1998). Cognitive changes, such as wisdom in the elderly, may be linked to spirituality and spiritual growth may be often a part of the aging process (McFadden, 1996; Sinnott, 1994).

Empirical data support the framework of spiritual development. In a retrospective study, Tornstam (1994, 1999) found that older adults tended to move away from a pragmatic worldview toward a gerotranscendent one. Fowler (1981) reported a positive relation between age and higher stages of faith development characterized by a sense of unity and personal transcendence.

The shift toward gerotranscendence can include the following feelings:

- An increased feeling of a cosmic communion with the spirit of the universe

- A redefinition of the perception of time, space, and objects

- A redefinition of the perception of life and death and a decrease in the fear of death

- An increased feeling of affinity with past and future generations

- A decrease in interest in superfluous social interaction

- A decrease in the interest of material things

- A decrease in self-centeredness

- An increase in time spent in "meditation" (Tornstam 1989, 1994, 1997)

Tornstam (1999) employs several concepts to describe the theory of gerotranscendence. The main concept of gerotranscendence introduces concepts, such as meta-perspective, cosmic communion, spirit of the universe, affinity, and meditation. These concepts based gerotranscendence on a set of philosophic and religious ideas. Eisenhandler (1994) theorized that spirituality transforms an individual's relationship with God or a divine force, and it intensifies the person's devotion regarding life. Implicit in this concept is the notion that spirituality or the exploration of spirituality heightens and changes a person's awareness regarding self and others (Eisenhandler, 1994). Another aspect of spirituality is the transcendent sense of connection with other people that conveys a sense of life's meaning and purpose. People experience spiritual connections with the world at large, whether it is in a natural setting or in human interaction. Older adults' sense of connection to spirituality occurs in their home, garden, or nature (Eisenhandler, 1994). Tornstam (1989) proposed that aging implies a process during which the level of transcendence increases within an individual. Gerotranscendence is

generated on a daily basis, modified by specific cultural patterns, and is a lifelong, continuous

process. Several researchers (Dawson, 1997; Hickson & Phelps, 1997; Fry, 1998; Ley &

Corless, 1998) regard transcendence as a fundamental component of spirituality. Spirituality

based on transcendence provides an opportunity for individuals to share a connectedness with a

higher power or God (Cole, 2001).

2.2.2. Humanistic-Phenomenological Spirituality

Elkins et al.'s (1988) objective in developing an empirical scale was to define

spirituality. This spirituality would promote a clearer understanding and be sensitive to those

who are not affiliated with a religious organization. They identified four basic assumptions in

the conceptual foundation for humanistic-phenomenological spirituality:

- Spirituality is a human phenomenon and exists, at least potentially, in all persons.

- Spirituality is not the same as religiosity.

- There is a dimension of human experience, which includes certain values, attitudes, perspectives, beliefs, emotions that can be described as spirituality.

- By means of phenomenological approaches, spirituality can be defined and described.

The two main components of spirituality within the phenomenological perspective are: 1)

transcendent dimension and 2) meaning and purpose in life. Transcendent dimension is "simply

a natural extension of the conscious self into the religions of the unconscious or Greater Self"

(Elkins et al., 1988). The spiritual person believes in the unseen world. Fry (1998) described

transcendence as intrapersonal and transpersonal. Intrapersonal transcendence considers the

inner self as a source to turn to during a crisis. Transpersonal transcendence describes a

connectedness with God or a higher power. In addition, transpersonal transcendence is

associated with developing a sense of meaning and purpose in one's life and finding meaning in

suffering (Halsted & Mickley, 1997). Fowler (1997) contends that connectedness with God or a

higher power produces optimism and enhances adaptive capacities among older adults with chronic conditions.

In the second component of spirituality, the spiritual person acknowledges that life has meaning and purpose. An example of this component was also seen in the Abrums's (2000) study. The African American women study participants indicated they had to learn to trust God's wisdom. Their faith gave meaning to life as they suffered through their health crisis. This approach may help those with chronic conditions cope with the uncertainty of their diagnosis and issues relating to spirituality and health among chronically ill elders (Abrums, 2000; Idler et al., 2003), as shown in Figure 1.

Figure 1. CONCEPTUAL FRAMEWORK OF SPIRITUALITY AND SELF-MANAGEMENT
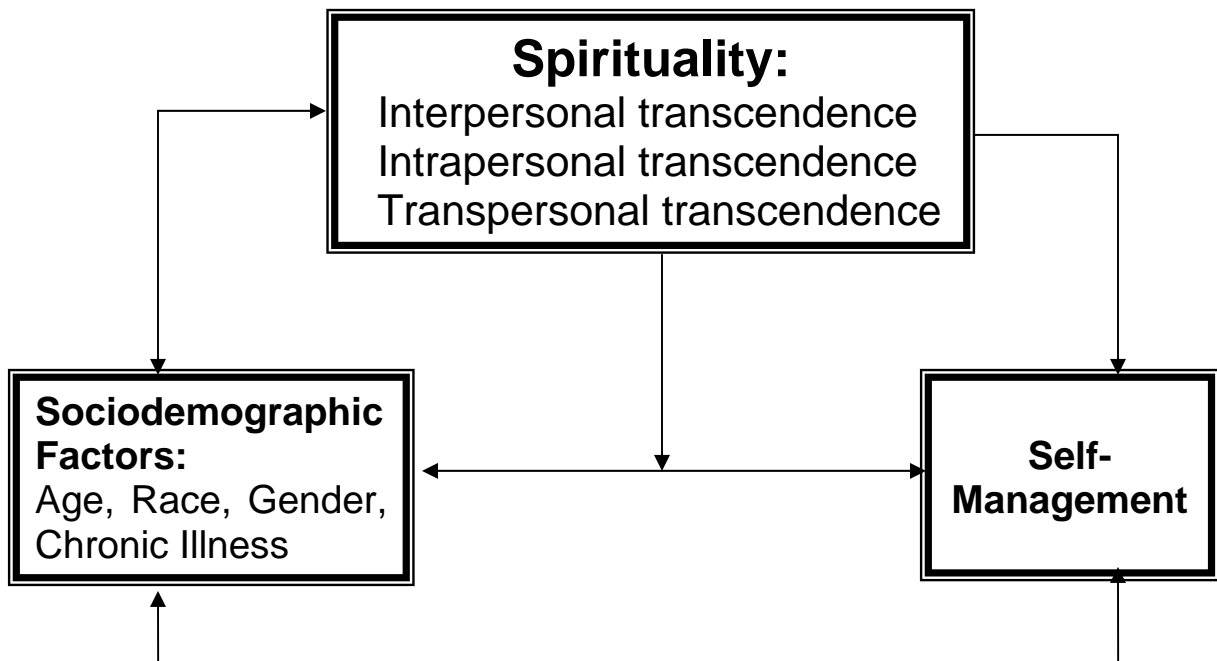
2.2.3.   Summary

It is important to acknowledge the divergence between religion and spirituality. Because spirituality overlaps religion and is distinctive from religion, it needs to be operationalized.

Some definitions of spirituality center on components that encompass God-related or divine phenomena (i.e., substantive). Others are functional, focusing upon what spirituality does, and how it subjectively and existentially affects individuals (Moberg, 2002).

Elkins et al., (1988) defined spirituality as "a way of being and experiencing that comes about through awareness of a transcendent dimension and that is characterized by certain identifiable values in regard to self, others, nature, life, and whatever one considers to be the Ultimate." In spite of the problems associated with the operational definitions of spirituality, qualitative studies combined with quantitative psychometric scales can add clarity to the terminology and usage of spirituality (Wimberly, 1997).

Spirituality is an important factor for those living with chronic health conditions. Measures of spirituality often vary from study to study and among the studies' participants, who vary by gender, age, and ethnicity. This variability of measures and participants ultimately fails to answer the question posed by this study: How do older adults use their spiritual practices in the self-management of their chronic illnesses?

Chapter 3 presents a detailed discussion regarding the different views of spirituality and previous research on self-care. Chapter 4 describes the design of the parent study, and the methodology and the analytic framework used in the pilot study and current study.

3.   CHAPTER 3

3.1.   LITERATURE REVIEW

Prior to the 20th century, religion and spirituality were viewed as single constructs. The split

between religion and spirituality occurred because of the dissatisfaction many people had with

organized religious institutions (Roof, 1993; Turner, Lukoff, Barnhouse, & Lu, 1995). Ross

(1993) attributes the increased interest in spirituality to the baby boomer generation's (those born

between 1946 and 1964) quest for personal and transpersonal meaning outside the confines of

organized religion. During the latter half of the 20th century, research and discussion have

proliferated regarding spirituality. In 1998, a Gallup Poll reported that 8 out of 10 Americans

believed that they needed to experience spiritual growth (Gallup & Lindsay, 1999). Wink and

Dillon (2002) postulated that individuals tended to become more concerned with spiritual matters

as they aged. The elderly population offers a unique framework in considering the role of

spirituality. The spiritual dimension of life does not necessarily succumb to the degenerative

aging process--even in the presence of debilitating physical and mental illness (Leetun, 1996).

3.1.1.   Defining Spirituality

Early gerontological research studies included spirituality as a component of the religious

variables, which also included church attendance and other religious activities (Moberg, 1982;

Paloutzian & Ellison, 1982). Defining the construct of spirituality has been a difficult task taken

on by researchers (Zinnbauer et al., 1997). The definitions of spirituality have both implicit and

explicit connotations and remain perplexing and extensive. The definition problem lies in its

interconnection with religiosity in that spirituality is viewed as the essence of religiosity

(Moberg, 1967).

Religion is defined as a system of beliefs or rituals that are associated with an institutionalized group designed to generate intimacy to the scared or transcendent--God or a higher being (Koenig, McCullough, & Larson, 2001). Spirituality, on the other hand, is more personal and is defined as a unifying force that cultivates a relationship with the sacred or transcendent. Therefore, public prayer, church attendance, or participation in religious activities is categorized as variables for religion, but spirituality includes praying privately, meditating, using positive affirmations, or watching or listening to religious programs (Benson, 1997; Koenig, McCullough, & Larson, 2001).

The definition variation of spirituality is based on scholarly, scientific, or clinical disciplines: medicine (Kass, Friedman, Leserman, Zuttermeister, & Benson, 1991; Luskin, 2000; Mills, 2002; Moadel et al., 1991); nursing (Heriot, 1992; McSherry, Draper, & Kendrick, 2002; Reed, 1987; Walton, 2002); psychology (Miller, & Thoresen, 2003; Wink & Dillon, 2002; Zinnbauer et al., 1997); psychiatry (Turner et al., , 1995); theology (Jernigan, 2001); sociology (Moberg, 2002); and public health (Samuel-Hodge et al., 2000).

Theology

In Judeo-Christian religious practices, spirituality is defined as a human response to God's gracious call to have a relationship with Him (Benner, 1989). Much of the literature regarding spirituality in the United States is based on some of the basic Biblical principles and teachings derived from the teachings of the New Testament in the Bible. Vaughan (1991), however, describes spirituality as "a subjective experience of the sacred," while Tart (1983) suggests it is a "vast realm of human potential dealing with ultimate purposes, with higher entities, with God, with love, with compassion, with purpose." These definitions imply that spirituality centers on

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an individual's collective life, which involves a loving relationship with God, self, and others (Jernigan, 2001).

In today's society, spirituality is associated with the human capacity to experience a transcendental sense of wholeness within the self, with other persons, with the world, and with God (McFadden & Geri, 1990). Spirituality denotes one's existential search for the ultimate meaning through an individualized understanding of the sacred (Atchley, 1997) even though it often merges with religious concepts (Zinnbauer et al., 1997). Atchley argues that spirituality involves the integration of intrinsic and extrinsic experiences through systematic practice, which demands commitment, depth, and focus.

Psychology

Past psychologists have explored ways to define spirituality (Clark, 1958; Coe, 1900; McReady & Greeley, 1976). Zinnbauer et al. (1997) sought to identify how individuals define spirituality. They surveyed 346 individuals residing in Pennsylvania and Ohio. The respondents came from vastly different religious organizations (i.e., Presbyterian, Catholic, Lutheran, Unitarian, Episcopal, and New Age) and age groups (15 to 85 years of age). According to the survey, 95% of the participants were Caucasian Americans and 68% were female. When the category of "being spiritual but not religious" among the study participants was examined, the survey found that these individuals fell into the group categorized as "active seekers" by Roof (1993). The study concluded that the participants' spirituality described either having a relationship with God or a higher power, or having a personal belief system in God or a higher power (Zinnbauer et al., 1997).

Modern psychology researchers, such as Jung (1964) and Frankl (1984), have historically acknowledged that spirituality occurred through the maturational process of aging. Spirituality is

therefore the personal quest for understanding answers to the ultimate questions about life, meaning, and the relationship to the sacred or transcendent. Spirituality may or may not lead to or arise from the development of religious rituals (Zinnbauer et al., 1997). The concept of spirituality is subjective, personal, and expands the concept of religion. It refers to a person's interpretation of life, whereas religion denotes a formal system of beliefs. In contrast, religion is an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent (e.g., God, a higher power, or the ultimate truth). Zinnbauer, Pargament, and Scott (1999) present three polarizations that differentiate religiosity from spirituality: 1) organized religion versus personal spirituality; 2) substantive religion versus functional spirituality; and 3) negative religiousness versus positive spirituality. Organized religion fell under the purview of religious beliefs and practices while transcendence were qualities of personal spirituality (Zinnbauer, Pargament, & Scott 1999). A content analysis by Emblen (1992) found two key constructs associated with religion and spirituality. Faith, organized beliefs, and practices that cultivate a connection with a supreme being were associated with religion while spirituality was linked to a personal transcendent relationship with God and others (Emblen, 1992). Functional spirituality represents a sense of connectedness with others, meaning in life and purpose, while religion is constantly linked with religious institutions (Zinnbauer, Pargament, & Scott 1999). Finally, spirituality is credited for reaching the pinnacle of humanity while religion is considered a hindrance to this potential.

Nursing

Research in spirituality has been well documented in the field of nursing (McSherry & Draper, 1998; Nagai-Jacobson & Burkhardt, 1989; Stoll, 1979). Nursing's intervention strategies recognized the patient's spiritual concerns, spiritual distress, and spiritual despair, which is

incorporated in the diagnosis and treatment plan of the patient (Kim, McFarland, & McLane, 1982). According to Lemiesz (1999), nursing is described as the ministry of healing that treats the whole person. Researchers such as Heriot (1992) described spirituality as the "manifestation of the spirit, just as physiology is one manifestation of the body, and emotions are one manifestation of the mind." It is the core of the patient's existence, which integrates and transcends the physical, emotional, intellectual, and social dimensions of the individual (Landrum, Beck, Rawlins, Williams, & Culpan, 1984). Gress and Bahr (1984) acknowledged that spiritual aging develops across the life span simultaneously as an individual's philosophy of life evolves.

Spirituality is a major component in a patient's treatment plan. Geriatric nursing is currently producing guidelines to assess the spiritual needs of hospitalized older patients (Hermann, 2000). The treatment plan is divided into three stages: intervention, rationale, and evaluation. The intervention phase entails a comprehensive spiritual needs assessment that evaluates the patient's desire for spiritual help. This allows the nurse to recognize the patient's need for spiritual comfort through familiar means. The nurse collects subjective data (e.g., articulating a relationship with God or a higher power), as well as objective data (e.g., presence of religious or inspirational books or jewelry) in order to design an individualized intervention plan for the patient (Hermann, 2000; Lemiesz, 1999). Spiritual assessments are question-based, focusing on aspects of a client's spirituality or religion. These assessments also focus on the hope and framework of meaning through which the nurse can develop a strategy to meet the patient's individual needs (Stoll, 1979; Stolley & Koenig, 1997). The rationale stage is devoted to behavioral change activities. These activities allow patients to engage more deeply in their spiritual beliefs while participating in activities designed to promote physical healing. Finally,

evaluation determines whether the patient's goal was obtained while hospitalized (Lemiesz, 1999).

Patients voiced that their spiritual faith and their trust in the nursing profession contributed to their healing (Narayanasamy & Owens 2001). Camp's (1996) grounded-theory study with patients, who underwent coronary artery bypass grafts, corroborates these findings. The purpose in spiritual assessment is not to solve the patient's spiritual problems, but to create an environment with resources that promote spiritual expression by the patient and family (Treloar, 2000).

Medicine

Spirituality and health have become one of the debatable topics in medicine with researchers trying to determine whether spirituality had either a positive or a negative effect on health. The interest in spirituality exhibited by the medical community occurred because of a growing interest in the field of complementary and alternative medicine (Mills, 2002). In a study by McBride, Arthur, Brooks, and Pilkington (1998), patients seen in a family practice clinic, who claimed to be either highly or moderately spiritual, reported less physical pain and better health than those who reported having lower levels of spirituality. Despite these and other findings, clinicians have generally ignored spiritual variables, as they tend to be too controversial to be included in clinical care or research studies. Sloan et al. (2000) have raised the ethical issues surrounding the patient's autonomy in matters of religion. These researchers believed that the medical profession is treading on perilous ground if the advice about religious matters has the same impact as the recommendation for antibiotic treatment (Sloan, Bagiella, & Powell, 1999; Sloan et al., 2000). Physicians also lack the necessary training that is required in obtaining a

client's spiritual history, as well as time constraints during physical examinations (Ellis, Vinson, & Ewigman, 1999).

Regardless of the variant definitions within the medical and psychosocial disciplines, the consensus is that spirituality--when broadly defined--is the inner resource of people and the personal interpretation of life rather than religious activities (Heriot, 1992).

3.1.2. Spirituality and Health Outcomes

During the past 30 years, the interests in spirituality and its connection to health outcomes have increased. Burkhardt (1993) identified characteristics of spirituality as a belief in a higher power, prayer, a sense of inner strength, and a relationship with others and nature. Social scientists are currently examining spirituality and well being and their impact on health outcomes (Meisenhelder & Chandler, 2002; Moadel et al., 1991; Tuck et al., 2001; Tull et al., 1998). Research has shown that spirituality enhances mental and physical well being (Burton, 1998; Courtenay, Poon, Martin, Clayton, & Johnson, 1992; Fehring, Miller, & Shaw, 1997; Koenig, 1995; Koenig, Kvale, & Ferrel, 1988; Matthews et al., 1998). Positive associations were found regarding: spirituality/religious activities and improvement in subjective states of well being (Ellison, 1991); reduction in depression (Williams, Larson, Buckler, Heckman, & Pyle, 1991); and reduction in disease morbidity and an increase in longevity (Levin, 1996).

Ai, Dunkle, Peterson, and Boiling (1998) examined the role of prayer in middle-aged and older adults recovering from coronary artery bypass graft (CABG). From this sample of 151 patients, 67.5% cited prayer as the most frequently practiced non-medical behavior. Patients who prayed had better psychological outcomes 1 year post-surgery with significantly lower levels of depression.

Prayer is a spiritual practice, as well as a religious one (Taylor & Outlaw, 2002). People who describe themselves as "spiritual," but not necessarily as being "religious," use private

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prayer (Zinnbauer et al., 1997). Researchers acknowledge that prayer is commonly used as a

mode of communication between an individual and a higher power or God (Bearon & Koenig,

1990; Close, 2001; Dossey, 1993; Finney & Malony, 1985; Poloma & Pendleton, 1998; Taylor

& Outlaw, 2002). Several studies documented prayer as a coping strategy for physical

symptoms among older adults (Bearon & Koenig, 1990; Manfredi & Pickett, 1987; Mull, Cox, &

Sullivan, 1987). For instance, Ai et al. (1998) determined that prayer acts as a coping

mechanism for post-operative CAGB patients.

    Two separate prospective, randomized-controlled, double-blind studies demonstrated the

effect of intercessory prayer among cardiac patients. Intercessory prayer studies are comprised

of participants praying for another group with outcome measures being studied in the second

group. In the first study, Byrd (1988) investigated the effects of intercessory prayer on patients

in a coronary care unit. Results from the study revealed that a significant difference existed

between the prayer and control group. Byrd found that patients who were not informed that they

were being prayed for had fewer cardiac complications (congestive heart failure,

cardiopulmonary arrest, and pneumonia). These patients required less diuretics, ventilatory

assistance, and antibiotics than the control group (i.e., patients who were not on the prayer list).

In the second study, Harris et al. (1999) replicated the Byrd study. In the Harris study, 1,013

cardiac patients were randomly assigned to either the remote, intercessory prayer arm or the non-

intercessory prayer arm of the study. Harris et al. (1999) found that patients in the intercessory

prayer group had fewer adverse outcomes. These patients needed fewer prescriptions and

therapeutic procedures than those CCU patients in the non-intercessory prayer group who

received a lower mean cardiac care unit score. This score represents the level of comorbidities

experienced after being discharged from the hospital.

3.1.3.   Self-Care

There are several domains within self-care, which range from maintaining one's health to managing chronic illness. The discipline of self-care is comprehensive and includes physical, social, psychological, and spiritual factors. Self-care is an essential component to the management of chronic illness. The concept of self-care encompasses a variety of health- and disease-related behaviors. It is important to understand the patient's needs, especially when different cultural contexts can lead to different responses to similar illnesses. For example, with a study of cultural differences in self-care among arthritic Caucasian, Hispanic, and African Americans four types of self-care were identified: 1) psychological and spiritual; 2) food and drinks 3) physical actions; and 4) folk remedies. The psychological and spiritual categories included meditation, prayer, and traditional spiritual healings. Food and drinks involved herbal teas, alcohol, and certain foods. Exercise, rest, massage, and heat or cold application were categorized as physical actions. Folk remedies focused on homemade oils and liniments and the wearing of copper bracelets, as well as the use of over-the-counter painkillers such as aspirin (Coulton, et al., 1990). Caucasian Americans were more likely to use dry heat, wear copper bracelets, and change their routine. Hispanics utilized more treatment by herbal teas and other home remedies. African Americans were least likely to rest or use aspirin (Coulton et al., 1990).

Defining Self-Care

The definition of self-care has been defined in several ways. Initially, Levin, Katz, and Hoist (1976) defined self-care as the activities a layperson performs on his own behalf to promote health or detect, prevent, and treat disease. The definition for self-care was modified even further to include a wide range of activities that enhance health, evaluate symptoms, and restore health (Dean, 1986; Dean & Kickbusch, 1995). DeFriese and Woomert (1992) described self-care in terms of "self-care practices." These practices relate to mobility and instrumental

activities of daily living that occur during recurrent health problems, such as chronic illness among older adults. Stoller et al. (1993) used diaries to identify the self-care practices among older adults in the management of their disease. The study consisting of 526 respondents reported that approximately 20% used self-care practices exclusively, 19% used self-care before seeking any consultation, and 17% used self-care before turning to professional care.

DeFriese, Konard, Woomert, Norburn, and Bernard (1994) emphasized three domains in self-care: 1) medical self-care which includes lay interpretation and management of symptoms of acute and chronic conditions; 2) lifestyle practices to enhance or prevent disease; and 3) self-care practices related to functional capacity or activities of daily living (ADL). This study will focus on the self-care practices as they relate to activities of daily living or physical functioning. Riegel, Carlson, and Glaser (2000) added the practice of an active cognitive process undertaken by a patient managing his illness to the definition of self-care.

Self-Care and Older Adults

Several studies have investigated self-care behaviors among older adults. In a sample of primarily Caucasian American women living with chronic conditions, Haug, Wykle, and Namazi (1989) found that the type of self-care varied among age groups. The oldest age group (75 years and older) was more likely to use home remedies, and the younger age groups (45-59 and 60-74 years) were more likely to use over-the-counter drugs for symptoms, such as exhaustion, cold symptoms with fever, sneezing, ear problems, dizziness, and tiredness. The study concluded that the type of self-care used among the age groups was symptom-specific.

McDonald-Miszczak, Wister, and Gutman (2001) hypothesized that certain chronic conditions can prompt the adoption of self-care behaviors among older adults diagnosed with arthritis, heart problems, or hypertension. In a sample of 794 married, elderly Canadian women,

McDonald-Miszczak et al. found that individuals with arthritis were more likely to use self-care practices than individuals with heart problems or hypertension. Within the arthritis groups, women and individuals between the age of 50 and 64 years reported a higher usage of self-care practices.

Researchers (Charmaz, 1991; Padula, 1990; Silverman, Musa, Kirsch, & Siminoff, 1999) acknowledge that self-care is a major component in the care of chronic illness. Researchers are also addressing the impact of self-care on the health of older populations (Mockenhaupt, 1993). Several studies assessed self-care practices among individuals with chronic illness, such as arthritis, diabetes, and heart disease. The studies demonstrated that self-care had a positive effect on the management of disease based on duration (Carlson, Riegel, & Moser, 2001; Clark et al. (1991); (Dean, 1986). In a descriptive, cross-sectional study, which was conducted primarily with elderly men, Carlson et al. (2001) compared self-care management behaviors between post-one-year individuals diagnosed with a one-year diagnosis of heart failure with those who were newly diagnosed with heart failure. Individuals in the one-year post-diagnosis heart failure group were more likely to practice disease-specific self-care management behaviors than the newly diagnosed group. The impact of self-care practices is evident in the patient's specific actions (i.e., reduce sodium intake with sudden weight gain or rest) with the experienced heart failure patient group.

Alternative Self-care Practices

There seems to be an increase in alternative self-care practices, which include relaxation techniques, massage, exercise, biofeedback, folk remedies, spiritual healing, and prayer (Arcury

et al., 1996; Ibrahim, Siminoff, Burant, & Kwoh, 2001; Kaboli, Doebbeling, Saag, & Rosenthal, 2001; Yoon & Horne, 2000). Ibrahim et al. recently studied the extent to which older African Americans and non-Hispanic whites with osteoarthritis use self-care practices in their perceptions of treatment in a cross-sectional study. The sample consisted of arthritic male patients from a veteran's hospital. The African American patients were more likely to rely on self-care practices (i.e., herbal medicine, massage, prayer, cooper bracelets, and medicinal salves) than their white counterparts were likely to rely on them. Unfortunately, these studies did not evaluate the role of spirituality and its impact on chronic illness or self-care practices (Haug et al., 1989; McDonald-Miszczak et al., 2001).

3.1.4. Summary

This chapter began with an overview regarding to the phenomenon of spirituality as it relates to health. The findings of this review indicate that spirituality is an important factor for individuals living with a chronic illness. The field of self-care includes several components such as physical, social, psychological, and spiritual factors (Berman & Iris, 1998). The definition of self-care broadly includes the "range of health and disease behavior undertaken by individuals on behalf of their own health" (Dean 1992). The beliefs surrounding self-care are formed within several frameworks (e.g., personal, social, and cultural). These activities derived either from knowledge and skills undertaken by individuals on "their own behalf," independently, or in collaboration with health care providers (World Health Organization, 1983).

After reviewing much of the spirituality-self-care literature, it appears that research pertaining to spirituality and self-care practices among older adults with chronic illness is lacking. The sparse literature, though instructive, fails to answer the questions posed by this study: How do older adults with chronic illness define spirituality and how does spirituality influence their self-care practices? This study fills a gap in the literature on both spirituality and

self-care by examining the influences of spirituality on self-care among this older population.

Chapter 4 describes the design of the parent study, and the methodology and the analytic

framework used in the pilot study and current study.

4. CHAPTER 4

4.1. RESEARCH DESIGN AND METHODOLOGY

This chapter outlines the methodological procedures that guide this study. This study explores the relationship between spirituality and self-care behaviors among older adults with chronic disease. The purpose of this predominately-qualitative study is to define, explore, and describe spirituality in the life of chronically ill elders and to examine its relationship to self-management of illness in terms of gender and race. The sparse literature falls short of integrating spirituality and self-management for chronic illness. The lack of research indicates that an exploratory and rigorous qualitative research design (i.e., the grounded theory) is an appropriate method to guide the study design and analysis. In order to provide a context for the research study, this chapter introduces the parent study "Self-Care Responses of Older African Americans and Whites (R01-AG18308-03)." After the discussion of the parent study, I will discuss the rationale of the research design, grounded theory approach in sampling, data collection, data management, and analysis as well as the pilot study and the protection of human subjects.

4.2. THE PROCESS OF SELF-CARE BEHAVIORS: PARENT STUDY

A four-year study funded by the National Institute of Aging (R01-AG 18308-03) examined the process of self-care for osteoarthritis (OA) or ischemic heart disease (IHD), comparing African and Caucasian Americans who reside in Allegheny County, located in western Pennsylvania. Dr. Myrna Silverman, a professor in the Behavioral and Community Health Sciences in the Graduate School of Public Health, is the Principal Investigator of this study. The overall objective of the study is to describe the process by which self-care behaviors are adopted, maintained, or changed using a longitudinal design (30 months). The study

centered on the stability and change in self-care behaviors among older adults. The study was designed to examine the effects of self-care decisions based on the chronic illness, the living environment, disease, and characteristics of an individual.

The sample frame was randomly drawn from individuals 65 years of age and older in the Medicare enrollment file for Allegheny County, as of April 2001, and screened by telephone for study eligibility. The national Medicare enrollment file includes more than 96% of adults 65 and over and thus is broadly representative of all older adults. Telephone numbers were obtained from a third party vendor. People without telephones or who reside in nursing homes or other dependent living situations were not eligible for the study and were therefore excluded. The sample was stratified by gender, race (African American or Caucasian) and type of disease (IHD or OA) to ensure that comparisons between groups would be possible.

The telephone recruitment survey was conducted between June 2001 and June 2002. Persons who were enrolled in the study had an in-home interview shortly after being recruited. The response rate for the telephone recruitment survey was 40%. About 50% of the individuals who completed the recruitment survey and were eligible for the study agreed to enroll. Eligible non-participants were older and had lower levels of education than participants. Eligible African Americans were more likely to agree to participate than eligible Caucasian Americans; females were more likely to agree to participate than males for both racial groups. Eligible non-participants did not differ from participants in health status.

4.2.1.   Sample

The parent study recruited 1,128 individuals into the study (523 African Americans and 605 non-African Americans). The parent study is a four-year longitudinal study that examined changes in self-care behaviors among community dwelling individuals aged 65 and older diagnosed with either ischemic heart disease or osteoarthritis of the hip or knee. Nine-hundred

and fifty-nine participants completed Time 3 in the parent study. The Time 3 interview began on May 12, 2003, and ended on February 15, 2004.

For the study on spirituality, I focused on a subset of persons (n=414) who were enrolled in the parent study during Time 3. Using the quota sampling technique, 40 African Americans (both male and female) and 40 Caucasian American (both male and female) were selected during Time 3 of the parent study to receive additional questions regarding their spirituality and self-care practices. Excluded from the study were individuals who did not identify himself or herself as African or Caucasian American. The spirituality interviews occurred as part of the Time 3 parent interview.

4.2.2.   Subject sociodemographics

Respondents participating in the Time 3 study were interviewed either in their home or at an agreed-upon location. The in-depth interview incorporated both quantitative measures and qualitative questions to assess spirituality (see Appendices A, D). The sociodemographic characteristics of the participants included age, gender, race/ethnicity, marital status, education, and income. With the exception of education, sociodemographic variables were collected throughout the study. During Time 3, the sample consisted of approximately 43% African Americans and 57% Caucasian Americans[2]. The average age in Time 3 was 74 years with a standard deviation of 5.706 and a range from 65 to 96 years. Education was a category variable measured as 1 (less than a high school degree) to 8 (doctorate/professional degree). More than half of the sample (55%) had completed high school. Self-reported income collected during Time 3 included 10 categories: from 1 (less than $5,000) to 10 (more than $100,000); 55%   of the sample reported a yearly income less than $25,000 (see Table 1).

Table 1. CHARACTERISTICS OF PARENT STUDY RESPONDENTS (N=959)

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[2] Unlike the parent study, the author identified whites as Caucasian Americans in this study.

Variables	N	%	Mean	S.D.
Race:				
African American	392	42.9		
Caucasian American	521	57.1		
Gender:				
Male	466	48.6		
Female	493	51.4		
Age:			73.76^{3}	5.71
65 to 74	582	60.7		
75 and older	377	39.3		
Marital Status:				
Single, never married	41	4.3		
Married	522	54.4		
Widowed	288	30.0		
Separated	29	3.0		
Divorced	75	7.8		
Living with someone	4	0.4		
Education:				
< High School degree	194	20.2		
High School/GED	334	34.8		
Vocational School Degree	65	6.5		
Some College	166	17.3		
Associate, # 2-year, Jr. College	45	4.5		
Bachelor's Degree	89	9.3		
Master's Degree	47	4.9		
Doctorate/Professional Degree	19	2.0		
Income:			5.04^{4}	2.06
Under $5,000	16	1.8		
$5,000 - $9,999	102	11.8		
$10,000 - $14,999	115	13.2		
$15,000 - $19,999	121	13.9		
$20,000 - $24,999	128	14.7		
$25,000 - $ 34,999	163	18.8		
$35,000 - $49,999	127	14.6		
$50,000 - $74,999	62	7.1		
$75,000 - $99,999	18	2.1		
Over $100,000	16	1.8		

4.3.   GROUNDED THEORY

Grounded theory is a qualitative methodology, which derived its name from the practice

of generating theory from research, which is "grounded" in data. Introduced by sociologists,

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[1] Mean value is based on a continuous scale.
[2] Mean value is based on 10 categories.

Barney Glaser and Anselm Strauss in *The Discovery of Grounded Theory* (1967), this

methodology emerged as an alternative strategy to quantitative analysis, which relied heavily on

hypothesis testing and verification techniques. Whereas, Glaser was committed to principles and

practices in the qualitative paradigm, Strauss added positivistic assumptions such as replicability,

generalizability, precision, significance, verification and interpretation of qualitative results,

which placed him closer to the quantitative paradigm. Using this methodology, Anselm Strauss

and Juliet Corbin published *Basics of Qualitative Research: Grounded Theory Procedures and

Techniques* (1990). They believed that the verification of data occurred through systematic data

collection and analysis.

The grounded theory approach guided the qualitative interviewing technique and research

analysis in this study. The researcher sought to define, explore, and describe spirituality in the

lives of chronically ill elders and to examine the relationship of spirituality to self-management

of chronic illness. Theoretical sensitivity and symbolic interaction were the two primary

characteristics of this design. Strauss and Corbin (1990) described theoretical sensitivity as the

researcher's ability to generate concepts from data. It represented the researcher's ability to draw

upon his or her personal and professional experience. My personal life as well as my

professional experience provided the awareness needed to delineate the subtleties of spirituality

and self-management.

Symbolic interaction focuses on the meaning of events to people in everyday settings and

the attachment to interpersonal relationships. It is how people define their reality and how they

act in relation to their beliefs (Glaser & Strauss, 1967). This viewpoint helped me to construct

what the participant saw as their reality as they managed their chronic illness.

4.3.1.   Sampling

Grounded theory uses purposive sampling. Based on this reasoning, I used purposive sampling.

Purposive sampling gathers information-rich data. This approach builds off the principle of

other grounded theory studies: the Charmaz (1990) study in understanding chronic illness; the

Leenerts and Magilvy (2000) study of the self-care practices among HIV+ women; the

Backman and Hentinen (1999) study in the self-care model for home-dwelling elders;   and the

Walton (2002) study in identifying the meaning of spirituality in hemodialysis patients. In

grounded theory, the hypotheses generate and test the study population throughout the length of

the research project.

One type of purposive sampling is quota sampling. Quota sampling focuses on obtaining a

certain number of designated types of participants (Aday, 1996). It involves dividing

intentionally selected target populations into strata with the goal of discovering elements that are

similar or different across the subgroups (Kemper, Springfield, & Teddlie, 2003). Because

potential participants in the parent study may be unwilling to undergo additional questions

regarding their spirituality and self-care practices, quota sampling was deemed the appropriate

sampling procedure for this study.

In qualitative research, there is no analytical formula used to calculate sample size. Sampling

usually relied on a smaller number of participants who were chosen to inform in detail about

their personal meaning and experiences. Decisions can be made prior to the research study based

on sampling theory. Strauss and Corbin (1990) stated that certain variables such as age and

gender were important when considering sample size. Qualitative research in aging used sample

sizes consisting of individuals from 10 to 100 (Gubrium, 1992). Morse (1994) recommended a

sample size that ranges from 30 to 50 interviews if grounded theory is the mode of analysis.

Based on the Morse, Strauss, and Corbin recommendations and my desire to learn in detail and

in-depth about the live experiences of chronically ill older adults, my sampling strategy included

20 older adults from each of the two groups (gender and race). The total sample size consisted

of 80 individuals (20 older African American men, 20 older African American women, 20 older

Caucasian American men, and 20 older Caucasian American women).

4.3.2. Data Collection and Data Management

Qualitative methods are well suited for the study of patterns and meaning (Rubenstein,

1994). In this study, an in-depth qualitative interview explored the definition of spirituality and

the patterns of spirituality and self-care practices among older adults with chronic illness. This

open-ended questionnaire defined, explored, and described spirituality in the life of chronically

ill elders and examined its relationship to self-management of chronic illness. The questions

were exploratory in nature and aimed to guide the interviewers through the interviewing process.

Although in-depth interviewing is time-consuming, it is a flexible and adaptable method

of seeking answers to difficult questions. The rapport that can occur between the interviewee

and the interviewer is invaluable. As previously stated, the parent study was a longitudinal study

in the process of self-care. Prior to Time 3, the interviewers in this study already interviewed the

participants twice in their home or at a mutually agreed upon location. They had an ongoing

with relationship with the participants. This relationship allowed the interviewers to ask the

participants the delicate questions in regards to the use of spirituality in the self-management of

their chronic illness. The questions about spirituality offered a unique opportunity for the

participants to elaborate their definition of spirituality and the self-management of their illness

by using probes to expand on their responses in an attempt to uncover underlying reasons for the

use of spirituality in the self-management of chronic illness. The interviews were conducted in a

very open manner allowing for greater richness and depth in the data collected. In-depth

interviewing is the best way to achieve subjective understanding and "a data-gathering

technique" used to collect detailed information from participants (Kaufman, 1994). The strength

of the in-depth interviews is the opportunity to obtain explanatory responses to probing

questions. The goal is to obtain richer and more complete data, as opposed to a self-administered

questionnaire (Kaufman, 1994). Often self-administered questionnaires are criticized for

generating superficial data because the opportunity to reveal why the participants responded in a

particular way is not always forthcoming. Respondents are often forced to answer questions in

the form of pre-determined categories, which may or may not be appropriate. It was for this

reason that the in-depth interviews were subsequently carried out.

Four other experienced interviewers in addition to the author conducted the spiritual

interviews. During the face-to-face interview, we asked the participants questions regarding

their spiritual beliefs and self-care behaviors. The interviews took place in either the

participant's home or an agreed-upon location. The spirituality questionnaire occurred at the end

of the parent study's Time 3 questions and took an extra 40 minutes to complete (see Appendix

D). With permission from the participants, the interviews were audio taped. In addition to the

audiotape, the interviewers took field notes to describe any important idiosyncrasies, such as

group dynamics or home environment.

In the spirituality interview, we made every effort to encourage candid responses by the

participants. The interviewers asked the respondents the following question to ascertain their

overall self-perceptions of spirituality on a 4-point Likert scale ranging from 1 (very spiritual, 2

(moderately spiritual), 3 (slightly spiritual), or 4 (not at all spiritual): "To what extent do you

consider yourself a spiritual person?" This question was later used to introduce the qualitative

questionnaire on spirituality and self-management among the participants.

The spiritual questionnaire opened with a general question that set the framework for our discussion (Bowers, 1988). We initially asked the following question: "You said you were (very, moderately, slightly, or not at all) spiritual. There are many ways that people define spirituality. It can mean different things to different people. We would like to know, what does being spiritual mean to you?"

We then focused on the participant's experience with spirituality, the personal meaning of spirituality, and the role of spirituality in his self-care practice. Throughout the interview, we followed the participant's lead. For instance, if the respondent used words such as "prayer" or "God" to describe the usage of spirituality, we then incorporated that word into the remaining questions. We used our own judgment to determine the length of the interview based upon the unique situation of each interaction. The spirituality interviews took an additional 40 minutes after the parent study. I conducted 26 of the 88 spirituality interviews. The study data collection began on November 10, 2003, and ended on February 15, 2004.

The professional transcriptionist transcribed verbatim each spirituality interview. We labeled each audiotape with the day of the interview, time of the study, and participant identification number. The participant identification number was the only identifying characteristic provided to the transcriptionist. The transcriptionist emailed and mailed the transcriptions to me. I randomly selected and reviewed 10% of the transcriptions to check for accuracy. I imported the transcriptions into ATLAS/ti Version 4.2, which is a computerized qualitative analysis program. The length of the transcribed interviews ranged from 8 pages to 75 pages. I used ATLAS/ti to store and to analyze the collected data. Once all the transcripts were coded, ATLAS/ti enabled easy retrieval of the data according to various categories or combination of categories.

4.3.3. Data Analysis

This section outlines the procedures use in analyzing the research data. The analysis allowed the participants to "speak for themselves." Therefore, I used two different approaches in analyzing the data. In defining spirituality, I used a comparative method of analysis as described in the next section. Because of the difficulty of pertaining information on spirituality and self-management from any specific question, I relied on thematic content analysis. Often, the respondents could not differentiate their use of spirituality from its connection to the self-management of chronic illness. The author, therefore, had to interpret from their responses using the entire set of the spirituality questions to assess what role spirituality played in the self-management of their chronic illness by using the technique of thematic analysis.

In the first analytic technique, I employed the constant comparative method of analysis to categorize data (Strauss & Corbin, 1990). I accomplished this method of analysis by constantly comparing the participants' narratives based on similarities and differences. Grounded theory uses a specific analytic technique that includes the reduction, categorization, and integration of the data into codes (Strauss & Corbin, 1990). Open coding begins with a line-by-line review of the data that is open coding. I examined each line to develop the open codes. With each new idea, I created a new code and attached it to the corresponding lines of text in ATLAS/ti. I identified and defined each code using the codebook feature in ATLAS/ti. Afterwards, I created axial codes from the open codes. Axial coding occurs when concepts are clustered into categories. It is the process "of relating subcategories into categories . . . the coding is more focused and geared toward discovering and relating categories in terms of the paradigm model" (Strauss & Corbin, 1990, p. 114). I placed each axial code into categories. In the final stage of coding, I created selective codes. Selective coding systematically places each category parsimoniously into codes that will eventually become core codes (Strauss & Corbin, 1990). The

core codes help to shape the data and strengthen the ideas that developed within the study, which is discussed in Chapter 5.

In the second analytic technique, I used thematic content analysis to evaluate data that focus on the role of spirituality in the self-management of chronic illness. I chose this form of analysis because I wanted to preserve the richness of details within the transcripts and because of the issue stated above. While coding the interview data, I utilized the coding scheme that conceptualized data from an emic perspective (i.e., from the informant's perspective). I used the following coding technique: transcribed interview ⟶ informant's words or phrases ⟶ themes/ classifications.

Thematic content analysis is the evaluation of data that categorizes recurrent themes. Themes are the generalized statements by participants about beliefs, attitudes, or values (Luborsky, 1994). I identified themes by discovering the central meaning of spirituality in the participant's ability to manage his illness. I accomplished this method using the "pen and paper" approach; therefore, I did not use ATLAS/ti to analyze these data. This method allowed me to compare and contrast my categories. I began with a line-by-line analysis that focused on themes. In the margin of each transcript, I categorized key themes. I consulted with the chair of my dissertation committee as I developed the themes. Tentative themes were formed based on prior research findings and the theoretical framework of the study. After undergoing several revisions of the coding schemes, themes were finalized into major categories of themes, which are discussed in Chapter 6.

Grounded theorists are often engrossed in the continuous process of literature review, question generation, data collection, and analysis. To insure qualitative reliability, three techniques are suggested: coding reliability, triangulation, and auditing and log trials (Richards,

2002). Coding reliability consists of ways in which the researcher establishes reliability through coding with a team of researchers analyzing the same data over time. Triangulation is the combination of different methods that leads to the same conclusion with the same phenomenon (Denzin & Lincoln, 2000). Auditing and log trails are written protocols of the analysis process that is reproducible (Lincoln & Guba, 1985; Richards, 2002). I incorporated the triangulation technique into my analysis to ensure reliability.

To insure maximize verification in qualitative research, I recommend that three different sources be utilized (Richards, 2002). These may include comparing data with existing empirical literature, comparing notes with colleagues, and gathering additional information from participants, triangulation, or increasing the sample size. I incorporated the existing literature in my data analysis. Another technique I used to verify my study was to obtain an independent reviewer who randomly selected and coded 10% of my study respondents. We met several times to discuss any discrepancy in the interpretation of the data. After several meetings, we were able to agree upon a set of codes, which I used in defining spirituality. To further enhance the verification of the data as they relate to the role of spirituality in the self-management of chronic illness, the chair of my dissertation committee and I met regularly to review the classification of responses.

4.4.   PILOT STUDY

The pilot study was conducted with 10 older adults, aged 69 to 79. This sample consisted of individuals currently enrolled in the parent study. The pilot study utilized quota sampling in the selection of the participants. The pilot questionnaire consists of open-ended questions that served as a guide during the interviewing process. The goal of the questionnaire was to attain rich contextual data that explored the definition of spirituality and the role spirituality played in

the self-management of their chronic illness (see Appendix C). The results from the pilot study helped determine which questions were appropriate to use in the research study. The University of Pittsburgh - Institutional Review Board (IRB) approved the pilot study on September 3, 2003.

Another trained interviewer and I asked the participants in the parent study if they were willing them to respond to additional questions that focused on the definition of spirituality and the way spirituality acts as a form of self-care in managing their chronic illness. We introduced the qualitative questions at the end of the Time 3 parent study. Refusal to take part in the pilot study did not prevent the respondent from continuing in the parent study. Only those who agreed to participate in the pilot study were asked to sign the informed consent to participate for the one-time, in-person pilot interview (see Appendix B). This in-person interview occurred in the participant's home. The average time to complete the spirituality questions was 40 minutes. All interviews were audio-recorded.

For clarity and cultural appropriateness, I modified the spirituality questionnaire six times. The modification improved the data collection regarding ascertaining information in the definition of spirituality and the role it played in the self-management of chronic illness in this population. After the completion of the pilot test, the spirituality questions were formally integrated into the parent Time 3 interview and approved by the University of Pittsburgh IRB on November 5, 2003.

4.4.1.   Protection of Human Subjects

We advised the participants prior to the interview that their involvement is voluntary and that they could stop the interview at any time without penalty. Confidentiality procedures involve removing all identifying information associated with the participants such as all interview information, study's tapes, and transcripts were in a locked file. To guarantee

anonymity and confidentiality, tapes and transcripts were given an identification number. Only authorized project personnel have access to the information.

4.4.2. Summary

The purpose of this study is to address the challenge of defining spirituality in addition to interpreting the role spirituality plays in self-management. The purpose of this chapter was to produce a framework grounded in data to describe the process of data collection and analysis. To that end, this chapter discussed the following topics: the parent study, the rationale and methodological consideration for qualitative research design, the pilot study, data collection, and analysis procedures. I discussed the sampling procedure, analysis of the data, protection of the participants, and methods to assure the rigor of the study. I also detailed the methods used to guide and analyze the data in defining spirituality and the relationship between spirituality and self-management behaviors. The process of data analysis and findings were created through two distinct processes: the constant-comparative approach and thematic content analysis. Both methods presented data from the perspective of the study population. I described the measures used to enhance the reliability and validity of the data. I will present the results on the definition of spirituality in Chapter 5 and the role of spirituality in the self-management of chronic illness in Chapter 6.

5. CHAPTER 5

5.1. FINDINGS: DEFINING SPIRITUALITY

There is a renewed interest in illness narratives of chronically ill individuals, especially among older adults (Bury, 2001). Illness narratives provide an excellent opportunity to capture the everyday experiences from the vantage point of the chronically ill. The next two chapters' present findings from 88 individuals who represented a subset of respondents from the Time 3 interview in the parent study. The data represent both a quantitative and qualitative data collection on the subset. The quantitative findings correspond to the spirituality scale in the parent study. The qualitative interview embodies the illness narratives of the participants as they relate to the role that spirituality plays in the self-management of their chronic illness.

This chapter describes the demographic characteristics of the 88 participants, and uses qualitative analysis[5] within the framework of grounded theory regarding the definition of spirituality (see Chapter 4). As previously mentioned, this study identified whites as Caucasian Americans. This chapter presents the results of the following research question investigated in this study:

1. How do older adults living with chronic illness define spirituality?

5.1.1. Sample Characteristics

This chapter begins with the description of the participants' demographic characteristics. We collected qualitative data from 88 chronically ill older adults who resided in Allegheny County, Pennsylvania. The respondents participated in the parent study. As part of the Time 3 protocol for the parent study, an in-home, semi-structured questionnaire was administered to all

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[5] NOTE: The following codes are the identifying characteristics of the participants: AAF =African American Female, AAM = African American Male, CAF = Caucasian American Female and CAM = Caucasian American Male. As expected, some participants discussed and elucidated the phenomenon of spirituality more frequently than others did; they are therefore more likely to be quoted. Direct quotations are used whenever appropriate. (See Appendix E for the list of participants' identification numbers, ethnicity, gender, and selected chronic illness.)

participants in the study between November 2003 and February 2004, either in the person's home or at an agreed-upon location. The target population consisted of 21 African American females, 26 African American males, 20 Caucasian American females, and 21 Caucasian America males. This subgroup of 88 older adults suffered from a myriad of chronic illnesses. The reported major health problems included: heart disease and circulatory problems (47.7%); arthritis (15.9%); diabetes and complications due to diabetes (i.e., kidney dialysis) (17%); cancer (6.8%); and various other chronic conditions (12%).

The participants ranged in age from 66 to 86 years old, with a mean of 73.7 years. Forty-eight (54.5%) reported they were married and 26 (29.5%) reported they were widowed. The majority of the sample (33%) had at least a high school education. Twenty-six (34.7%) reported that their household income ranged between $20,000 and $34,999 a year. Regarding religious affiliation, the majority (68.2 %) reported being Protestant, and the next largest religious group reported being Catholic (27.3%). Those who reported being Jewish made up less than 3% of the respondents (see Table 2).

Table 2. DEMOGRAPHIC CHARACTERISTICS OF SPIRITUALITY STUDY POPULATION (N=88)

Variables	Frequency	%
Race		
African American	46	52.3
Caucasian American	42	47.7
Age		
65 to 74 years	54	61.4
75 years and older	34	38.6
Gender		
Male	47	53.4
Female	41	46.6
Marital Status		
Single	4	4.5
Married	48	54.5
Widow	26	29.5
Divorced	8	9.1
Separated	2	2.3
Education		
Less than High School	21	23.9
High School/GED	33	33.0
Some College/Vocational	23	26.1
Bachelor or higher	15	17.0
Income		
$5,000 to $9,999	9	12.0
$10,000 to $19,999	19	25.3
$20,000 to $34,999	26	34.7
$35,999 to $74,999	18	24.0
Over $75,000	3	4.0
Religion		
Protestant	60	68.2
Catholic	24	27.3
Jewish	2	2.3
Other	1	1.1
None	1	1.1

Comparing race/ethnicity, African Americans were more likely to be married (53.2% vs. 51.2%), while Caucasian Americans were more likely to be widowed (41.5% vs. 25.5%). African Americans were more likely to have a high school diploma (25.5%) compared to Caucasian Americans (22%). Almost 92% of the African Americans in this study reported being

Protestant while Caucasian Americans were divided between being Catholic (51.2%) and

Protestant (41.5%) (see Table 3).

Table 3. DEMOGRAPHIC CHARACTERISTICS OF SPIRITUALITY STUDY BY RACE (N=88)

Variables	African American N = 47		Caucasian American N= 41	
	N	%	N	%
Age				
65 to 74 years	22	(46.8)	17	(41.5)
75 years and older	25	(53.2)	24	(58.5)
Gender				
Male	26	(55.3)	21	(51.2)
Female	21	(44.7)	20	(48.8)
Marital Status				
Single	2	(4.3)	2	(4.9)
Married	25	(53.2)	21	(51.2)
Widow	12	(25.5)	17	(41.5)
Divorced	6	(12.8)	1	(2.4)
Separated	2	(4.3)	0	(0.0)
Education				
Less than High School	12	(25.5)	9	(22.0)
High School/GED	17	(36.2)	14	(34.1)
Some College/Vocational	11	(23.4)	10	(24.4)
Bachelor or higher	7	(14.9)	8	(19.5)
Income				
$5,000 to $9,999	6	(12.8)	3	(7.3)
$10,000 to $19,999	15	(31.2)	2	(4.9)
$20,000 to $34,999	14	(29.8)	12	(29.3)
$35,999 to $74,999	8	(17.0)	10	(24.4)
Over $75,000	0	(0.0)	3	(7.3)
Missing	4	(8.5)	9	(22.0)
Religion				
Protestant	43	(91.5)	17	(41.5)
Catholic	3	(6.4)	21	(51.2)
Jewish	0	(0.0)	2	(4.9)
Other	1	(2.1)	0	(0.0)
None	0	(0.0)	1	(2.4)

The majority of the participants classified themselves as "moderately spiritual" (53.4%)

followed by the classification of being "very spiritual" (28.4%); 10.2% classified themselves as

being "slightly spiritual"; and 7.9% classified themselves as being "not at all spiritual" or "don't know" if they were spiritual (see Table 4).

Table 4. SPIRITUALITY SCALE OF SPIRITUALITY STUDY (N=88)

	N	Percent (%)
Very Spiritual	25	28.4
Moderately Spiritual	47	53.4
Slightly Spiritual	9	10.2
Not Spiritual at All	4	4.5
Don't Know	3	3.4

I performed a cross-tabulation to see if there was a significant relationship between perceived spirituality, age, race, and gender (see Table 5). There was not a significant relationship between perceived spirituality and age within this sample. The majority of the participants in both age categories (65 to 74 years (53.6%) and 75 years and older (50.3%)) classified themselves as being "moderately spiritual." There was a slight significant relationship between perceived spirituality and race. Of the African American participants, 87% considered themselves either "very or moderately spiritual" versus 76.2% of Caucasian American participants. Caucasian Americans (19%) in the study were more likely than the African Americans (10.9%) to classify themselves as "slightly spiritual" or "not spiritual at all". There was no significant relationship between spirituality and gender. Both female (53.7%) and male (53.2%) participants classified themselves as "moderately spiritual."

Table 5. OVERALL SELF-PERCEPTION OF SPIRITUALITY

	Very spiritual	Moderately spiritual	Slightly spiritual	Not spiritual at all	p-value
Age: 65 – 74 years 75+ years	16 (26.6%) 9 (25.0%)	26 (53.6%) 4 (50.3%)	6 (14.0%) 3 (20.4%)	4 (5.8%) 0 (4.3%)	.484
Race: African American Caucasian American	20 (43.5%) 5 (11.9%)	20 (43.5%) 27 (64.3%)	4 (8.7%) 5 (11.9%)	1 (2.2%) 3 (7.1%)	.023
Gender: Male Female	13 (27.7%) 12 (29.3%)	25 (53.2%) 22 (53.7%)	5#(10.6%) 4 (9.8%)	3 (6.4%) 1 (2.4%)	.866

5.2.   DEFINING SPIRITUALITY

The following findings were based on interviews with 81 respondents who were participating in the Time 3 interview of the parent longitudinal study. Seven of the 88 participants classified themselves as "not being spiritual at all" or did not rate their spirituality, therefore they were not asked to define spirituality.

This section will discuss the results of research question one: How do older adults living with chronic illness define spirituality? Participants were asked five questions to capture the main themes of spirituality. The questions were:

- How do you define spirituality?

- What does being spiritual mean to you?

- Why do you consider yourself (very, moderately, slightly, or not at all) spiritual?

- What do you do in your life that you think is spiritual?

- What is it about your life that is spiritual?

To provide the participants' definition of spirituality, I coded and categorized the participants' responses using the grounded-theory method, as described in Chapter 4. My goal was to illustrate the definition of spirituality within the context of the respondents' own words and to ground their narratives with the relevant literature. Data collected used several sources to

categorize the definition of spirituality. These were the responses to the level of spirituality and the in-depth interview defining spirituality.

The qualitative analysis of the participants yielded rich data on the definition of spirituality. The themes that emerged from the analysis separated the components of spirituality into the three levels: 1) transpersonal transcendence, 2) interpersonal transcendence, and 3) intrapersonal transcendence (Reed, 1992). Each level has subthemes that emerged, for example, transpersonal transcendence subthemes were transcendent dimensions (i.e., belief and faith), religious resources, a sense of connectedness through a personal relationship with the sacred or with God, and spiritual guidance. The interpersonal transcendence subthemes were religious roles, community of faith, spiritual/religious upbringing and role models, meaning and purpose in life, and mission in life. Finally, the intrapersonal transcendence subthemes were lifestyle and self-potential. I will expand upon each of the themes, striving to capture the various dimensions from the perspective of the study participants.

As I read the participants' transcripts regarding the definition of spirituality, it became apparent that this construct was multidimensional, incorporating several levels of meanings and experiences. For example, in reading the transcripts of the participants, I recognized the following relationships: the vertical relationship that is the connection with God (transpersonal transcendence); the horizontal relationship that is the connection between the participants and others (interpersonal transcendence); and the relationship within self (intrapersonal transcendence).[6] This study highlights the interconnections and interdependence of the myriad levels of transcendence within the psychosocial and physical realms.

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[6] Participants in this study did not proclaim their religious affiliation although the relationships with other church members were mentioned. For example, participants who mentioned their relationship with their priest or pastor did this in the context of a personal crisis or a health crisis. The term "God" was used most frequently when referring to

Transpersonal Transcendence

Stoll (1989) suggested that a person's spirituality features a relationship that is vertical.

The vertical dimension reflects the transcendent relationship with the sacred or with God. As

demonstrated from several of the participants' responses in the study, transpersonal

transcendence is divided into four themes: 1) transcendence dimension; 2) religious resources; 3)

a sense of connectedness through a personal relationship with the transcendent; and 4) spiritual

guidance from the transcendent. The transcendence dimension was defined as the belief and

faith in God or a higher power. According to Reed (1987), spirituality involves the personal

view that there is something greater than oneself. Almost half the sample, 48.1% (39 of 81

respondents) believed or had faith in God, Jesus, Jehovah, or a higher power.

> Spiritual to me means you believe in God and Jesus Christ. To me,
> spirituality means that you have faith. You have the faith to know that
> God is God and that there is no other. And if you have the faith, you
> don't need nothing else except to say thank you Jesus every day. That is
> my spirituality. (AAF)

Religious resources were defined as religious rituals or practices used as an outward

expression of spirituality. Nineteen of the 81 (23.5%) respondents expressed their spirituality

through prayer, and 11 of the 81 respondents (13.6%) expressed their spirituality through reading

the Bible. These religious rituals provide a stabilizing effect in the lives of the chronically ill

elders (Stoll, 1979). When the reality of chronic illness was confronted (i.e., chronic pain),

prayer provided a sense of stability. Participants identified prayer as a common element in their

spirituality. Prayer crossed all religious affiliations and served to seek God's wisdom. It was

viewed as "talking to God." Prayer ultimately brings one into an awareness of the existence of

God. Overall, prayer was a meaningfully defined action:

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the sacred followed by either "a higher power" or "supreme being." Terms specific to Judeo-Christianity, such as
the Holy Spirit, Christ, and Lord, were frequently heard among those who were "very spiritual."

I speak to Him every morning. I speak to the Father and I thank Him for letting me wake up to another day and to be here. Every morning I talk to Him. I know He's there. He's there with me. I talk to him. And when I leave out of that room, I'm relaxed and know what my day is going to bring. (AAF)

I turn to prayer, first, in all situations. Because I've had so many prayers answered. (AAF)

Another African American female participant said, "[I] know that God does answer prayers. He may not always do it when you want it, but he's always on time." As mentioned earlier, transpersonal transcendence spirituality included prayer, which was meaningful in the life of several of the female participants with ischemic heart disease. A Caucasian American female participant stated, "I believe if you pray that He [God] will listen to you." Another Caucasian American female participant said, "I pray a lot for my health and that kind of helps me out." Finally, a Caucasian American female participant said, "I know that God's up there and if you pray to him, you can ask him for things."

As previously mentioned, reading the Bible was the second most religious ritual identified. It was often referred to as the primary source of spiritual information.

Well, I read my Bible. As a matter of fact, I told my husband just last week I think I'm going to try to--I wish I had a Koran to read really, because it's better than the King James version of the Bible. (AAF)

I got a Scoffield Bible. It's so wore out in there, because I read it and study every day. (AAM)

The way you believe in the words of the Bible that God said or Jesus have done. We have to live by that book. That's the most important book there is, is that Bible. And He will let you know what is going on, what's ahead of you, what's going to happen, and all those things. (AAF)

Several researchers defined spirituality as a connection with God (Albaugh, 2003; Elkins et al., 1988; Reed, 1987; Stoll, 1989) or having a personal closeness with God. This relationship goes beyond the transcendent dimension (Elkins et al., 1988) to include a dynamic personal

camaraderie with God (Shelly, 2000). The participants discussed their relationship with God in

an intimate manner, as if they were discussing a relationship with a significant other.

> Well, to me, when you wake up every day, it means the Lord came by
> and woke you up. And most of the time he will take care of
> everything…And He's going to take care of everything…And you really
> don't worry about it too much. (AAM)

> I just get up every morning and look across that window and throw him a
> kiss [indicating a kiss] Thank you, Jesus, for just one more day. And
> with that I walk with him every day, all day long. Sometimes when I'm
> just sitting here, I'll say, thank you, Jesus, for just one more day. (AAF)

> I think that [I] always feel that God's presence is near, that God is a
> dependable force. [I] can always depend on God. [I] can always talk to
> God when [I] can't talk to no one else. And that itself is a comforting
> thought. (AAM)

Finally, this special connection helps guide the participants as they go through the day. God is

constantly and always available to help navigate their lives. This comes to reason because the

participants acknowledged God as being greater than themselves (Reed, 1987).

> I guess I feel that I have spiritual guidance, but I don't know what brings
> this about. Things that happen to me that seem to be out of the ordinary I
> contribute to some spiritual influence somehow. Well, I just feel that I
> don't have control over everything, and some things that happen I
> attribute to spiritual guidance. Something or someone tells me what to
> do. (CAM)

> In everyday living I connect with Him. I don't get up in the morning
> without saying my prayers and say, "Lord, you're the center of my joy.
> You're the center of my joy and I need your guidance. I need your input,
> because I'm the sheep that don't know nothing." And I need guidance in
> everything that I do, and He delivers me to the guidance. And I just
> follow as best I know how to follow. (AAF)

Interpersonal Transcendence

Interpersonal transcendence is defined as a connectedness with others and the natural

environment (Reed, 1992). Spirituality is classified as a social phenomenon regardless of an

individual's religious beliefs or affiliation, and spirituality reflects the horizontal relationship

(Stoll, 1989). The horizontal relationship reflects the importance in the role of a social

support/social network and spiritual beliefs. Interpersonal transcendence is divided into five

themes: 1) religious roles; 2) community of faith; 3) spiritual/religious upbringing and role

models; 4) meaning and purpose in life; and 5) mission in life. The expression of spirituality can

take on a variety of forms (Cohen, 1990), but the religious roles in which an individual

participates was a visual expression of that person's spirituality. Religious roles are defined as

the various church positions in the respondent's life and the respondents often held several roles

in the church.

> I was [the] chaplain's assistant for eight months when I was in the Army
> in Korea. That was some of the best times I ever had in my life. The
> experience of being close to the Lord and seeing the impact He had on
> different people's lives. We had church services for the Koreans. The
> Pocket Testament League sent some evangelists over there, and we had
> our own training. We passed out thousands of pocket testaments to some
> of the Korean people around there. I sang and played the organ with
> them. I had a great time. I felt like I was fulfilling life's purpose.
> (AAM)
>
> I do a lot of things, work at the church. I run the church food bank,
> which I'm going to have to get up pretty soon and go get. I'm the trustee
> in the church. I'm an usher in the church. I'm the head trustee. (AAM)
>
> I'm chairman of the finance committee, secretary, treasurer of the
> trustees. I'm on the nominations committee. So I spend three or four
> days a week in church because of religious nature. (CAM)
>
> I do a lot of work. You know, I'm down at the church. And I like to help
> people, you know, work at the food bank. You know, we donate food,
> you know, to different churches. (CAM)

One-fifth of the sample (16%) mentioned their community of faith. Community of faith is

defined as a relationship that exists within their church.

> Well, I go to church. I help at the church. I help anybody that I can
> help. And I do things that people that's supposed to be spiritual do. I
> pray. And I go over to others and help. So it means a lot to me to feel

this way and to do whatever I can in a spiritual way, participate in things. (AAM)

I just can't miss church. When you do something down at the church and somebody dies in the neighborhood, oh, I'm in the church. And we go down and make their dinner for them and I feel good. (CAF)

Well, basically, just going to Bible study, interacting with the other people that are there, and going to Sunday school and going to church. (AAF)

Research indicated that people often identify family members as spiritual mentors (Sodestrom & Martinson, 1987). Several participants spoke of the significant people in their lives who have influenced the development of their spirituality. The spiritual mentors who assisted them in their spiritual growth were family members.

And I grew up in a Christian home. And my parents didn't make a lot-- they didn't go around blowing their own horn and trumpeting about that I'm a Christian. But they just quietly lived a Christian life. They just quietly did things. And I think one of the great--well, it was a blessing and a curse really, but when we opened my father's safety deposit boxes after his death, it was full of uncollectible IOUs. And I mean, you know, it said a lot about the man. Because he was a banker. And during the Depression, people would come to him who were desperate. They were about to lose everything they had. And they--he knew that they were very poor risks for the bank. So somehow he would scrape together money that obviously had to have been his so the family didn't get it and that's what I mean, we never went hungry and we never went without clothes, but we didn't have a whole lot of money either. Because he had helped these people. And most of them never would pay him back, including some royalties. And I mean, finally, I think my sister said, well, what are you going to do about these? And Mother said, "Obviously nothing because if your father had wanted to collect them, he would have." That was it. So that was his legacy. Do you not see that-- I mean, how anybody could grow up not--I mean, he said just about a week before he died that he asked the good Lord to put him on this earth to help other people. And I just always--I mean, that was the kind of father and mother that I grew up with. And then I married a man who was just exactly like my father. It's just always been there. I mean, I can remember my father taking me to church with him. And I just didn't get a lot out of the sermons, but, I mean, I was too young. But I know there was something there that was important enough to him. He was treasurer of that church for 47 years and it got enormous. I mean, he had

a lot of assistant treasurers. But my gosh, they had about 2,000 members or more. And so, you know, these things were very important to him and religious education in the public schools. He was all for it and went against the minister of their church to whom he was very close because the minister didn't want that. And my father felt that so many people would be exposed to Christianity who would not otherwise get it at home. And he felt it was very important, yes. (CAF)

I was raised up in the church because I had to go to church. It was thing in my family. But I thank God for my father and my mother for it because that's what saved my life was me being forced to go. Because I learned about Jesus when I was a little kid. But all that I learned from a child up until the age that I went back to my father is the seed that was planted when I was a baby, when I was a child, when I was going to Sunday school in junior church, in church when I got baptized, when I was 12 years old--well, 10 or 11 or something like that. (AAF)

Every Sunday my father and mother used to make me go to church. When I was a child they used to make me. Yeah. And we all went--my whole family. My father and mother used to take us to church. (AAM)

Some findings have suggested that mothers are more influential than fathers in the spiritual development of their offspring. Mothers may serve a primary nurturing role in spiritual development since women are acknowledged as being more spiritual (Francis & Wilcox, 1998; Taylor, 1993). For example, mothers may assume primary responsibility for teaching basic spiritual and religious views. A few participants confirmed this viewpoint.

Well, I guess a lot of it was my mother [who] was a very spiritual person, and she taught me, you know, to believe and pray to God to guide us and to accept things you can change and the things you can't change. (CAM)

I'm from the South, and I was raised that way from my grandmother--my great-grandmother besides my mother. And we were taught that what God says, you obey. Together we will stand and we'll make it. That's why I'm going to respect you. And there's nothing wrong with having love and respect. (AAF)

Well, I guess because that would probably stem from my rearing from my mother, my grandmother, you know. (AAM)

Having "meaning and purpose in life" was identified as a critical attribute (Burkhadt, 1993; Elkins et al., 1988). The spiritual person believes that life has meaning and purpose. Although each respondent's meaning was somewhat different, commonalities emerged, especially in the form of "helping others."

> My purpose for being here is to show God's love to be helpful. I believe that God uses me to encourage people. Just like when I go to the store. If I see something there and I know someone's in need, I'll purchase it and give it to them. And I would hope that they would pass it on. And what I do or try to do, I don't do for any personal gain. I do it just because it's me. (AAM)

> Like I said, a lot of things: I help others. I used to take care of an old lady across the street. I used to cook her dinner every day. And, you know, go over and see about her and stuff. And I worked in a lot of church programs and stuff like that. I worked in the kitchen and cooked and all that stuff. (AAF)

> Well, I feel that every day the Lord has me to meet somebody or do something to help somebody. I think that the Lord, if you do every day, like I said, maybe some days nothing happens, but then sometimes you'll meet somebody, and he'll give the words to say and do, if you let the Spirit work with you. It could be in the grocery store or something, and they'll ask you a question, and the answer you give, the Spirit will work with you and give you the words to say. (CAM)

Several of the participants felt that they had a personal mission in life. They felt a sense of responsibility to life--a calling or mission to accomplish. Mission in life is defined as a force that activates a person to act as a guiding principle for living.

> Which means you are a servant and you are a volunteer servant because that's what you want to do. That's what you want to be. (AAF)

> Well, I think my career as a teacher has been fulfillment in the sense of my spiritual obligations. And I think, you know, my concern about the welfare and health and development of family and friends are, you know, like part of my spirituality. What I'm giving back, I'm putting into life. (AAF)

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I help my son's friends at the bowling alley--they're all handicapped. I also help the senior citizens. You will be surprised at some of them that can't read or write, and I help them at the Vintage. (AAF)

Intrapersonal Transcendence

Spirituality or spiritual beliefs were likely to influence the participants' way of living.

Intrapersonal transcendence involves connectedness of one's inner self and resources. For that

reason, intrapersonal transcendence themes are lifestyle and self-potentiality. Lifestyle is

defined as activities that are deeply ingrained into a participant's way of living. An individual

spiritual belief often shapes his lifestyle choices (Dyson, Cobb, & Forman, 1997). The belief

system of an individual influences the lifestyle behaviors in which a person lives.

> That's what I believe. And I believe you have to live Christianity. I mean, now I put God into everything that I do, even in cooking. I learned that a long time ago. I went on a job, and I was making hollandaise sauce, and I had almost messed up a dozen eggs, and it curdled on me. And I said, Lord, please help me, and He did help me. I took a little bit of cream and whipped those eggs together, and it came out the best sauce that I ever had made before. And from then on, before I started cooking anything, I asked the Lord to help me, and He has done it. (AAF)

> Being spiritual means following the dictates of Christianity and following the principles that I read and learn about in the Bible that I study. I use the Bible as a means of guidelines for living. As I read about them in the Bible, I understand that there are specific rules or regulations and things that we are able to do and to look forward to in spite of those situations. (AAF)

Fry (1998) stated that spirituality was the potentiality of self. The spiritual person

acknowledges that the inner strength is within the self. Participants in this study defined

spirituality as a part of them. According to their conversation, self--as it relates to the totality--

undergoes a transformation, which produces self-transcendence.

> I guess everybody has their own, you know, deep opinion. I believe it's all in yourself, you know, what you feel inside. And how you deal with your daily problems and how spirituality helps you. (CAF)

It's your feelings, I think, and your thoughts, plus your past and present, just a part of you. (AAF)

And I think it's you and it's your makeup, your character, you know, how low you want to be in life. (CAM)

5.2.1.   Summary

This chapter presented findings from in-depth interviews with the subgroup of participants from the parent study. The definition for spirituality emerged as being multifaceted in which each component interrelated with one another. Spirituality was an available tool that was used extensively by many of the participants and became the foundation that constructed their lives. The participants described a holistic approach in their relationship with God. They practiced their spirituality through religious rituals, such as conversing with God. Their personal relationship with God was similar to their relationship with significant people in their lives. Participants spoke about God as they would a close friend, someone from whom they sought advice when decisions needed to be made. In essence, God served as both a confidante and a parent. He provided the necessities of life and a loving soundboard when problems arose. The practice of spirituality facilitated their personal spirituality by providing opportunities to talk with God and seek sustenance from Him.

The working definition of spirituality might be the inclination to obtain a meaningful relationship through a sense of relatedness. This relatedness transcends self in a way that empowers the individual. An intimate and individualistic relationship originates from a belief in a supreme being who is considered an intimate "spirit" involved in the day-to-day process of living. This group of older adults with various chronic illnesses defined spirituality in a broad, holistic way that included both a vertical and a horizontal dimension. These dimensions exhibited the interconnections through the relationships, with self, with others, and with the

sacred (i.e., intrapersonal transcendence, interpersonal transcendence, and transpersonal transcendence). The dimensions of spirituality ranged from practical considerations found in everyday life to the philosophical belief that God was intimately involved in all aspects of the participant's life. The three levels of spirituality were intricately intertwined with their self-management practices for their chronic illness. According to the participants in the study, spirituality was one of the key components in managing their illness. They believed that spirituality plays a vital role in the self-management of their illness.

The next chapter, Chapter 6, examines the qualitative results derived from this sample concerning the role spirituality plays in the self-management of chronic illness. Chapter 6 also deals with the second question in this study: How does the study population use spiritual practices in the self-management of their chronic illness?

6.   CHAPTER 6

6.1.   FINDINGS: THE ROLE OF SPIRITUALITY IN THE SELF-MANAGEMENT OF CHRONIC ILLNESS

This chapter examines the role of spirituality in the self-management of chronic illness among the elderly using the thematic content analysis as described in Chapter 4. It answers the research question: How does the study population use spiritual practices in the self-management of their chronic illness? For individuals who are suffering from chronic illness, spiritual beliefs, and spirituality play an integral part in a person's health and well-being (Burkhardt & Nagia-Jacobson, 1994; Young, 1993). Among the chronically ill, the role of spirituality can influence self-care/self-management behaviors. The definition of self-care covers the activities that people do to improve or maintain their health (Mockenhaupt, 1993). In other words, self-management of chronic illness refers to the day-to-day activities that individuals adopt to keep the illness under control, reduce its impact on their physical health status, and cope with the psychosocial consequence of the illness. These activities often include, but are not limited to, medication management, physical activity, and dietary compliance.

Based on the previous chapter, the emerging definition of spirituality involved an intimate relationship that originates from a belief in a supreme being. This definition includes clearly defined spiritual practices. The spiritual practices included praying, reading the Bible, attending church services, volunteering, or helping others. Spirituality played a key and supportive role in the overall management of the participants' chronic illness.[7]

As was evident in defining spirituality, it was difficult to separate the various aspects of spiritual practices in the self-management of chronic illness. However, nine themes emerged in

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[7] Note: None of the participants mentioned delaying medical care or rejecting medical advice based on their spirituality or spiritual beliefs.

the current study 1) God: the healer; 2) God: the enabler through doctors; 3) faith in God; 4)

prayer as a mediator; 5) spirituality as a coping mechanism; 6) combining traditional medicine

and spiritual practices in self-management; 7) selected spiritual practices of self-care; 8)

empowering respondents to practice health-promoting activities; and 9) personal responsibility in

the self-management of illness. The following section describes and articulates--in the

participants own words--how spirituality relates to self-management of their chronic illness.

God: The Healer

The participants' narratives reflected their faith and trust in God. They believed that God

provides the means to get through their illness by either restoring them back to health or

accepting the outcome of their health. They believed that God ultimately could heal them from

their illness if God chose to do so.

> When I get pains and soreness--soreness and pain or aches or whatever, I
> pray to God He relieve it; cast it out of my body…He's the only one that
> can heal it. Because I know that He has the power to heal. He has the
> power to heal, and He's the only one that has the power to heal what my
> problems are within my body, my mind. He's the one that can cleanse
> my mind and can cleanse my body…That's how I feel. I can take all the
> medicine that's in the pharmacy, and if He doesn't want me healed, I
> won't get healed. It's up to Him to make the medication work, to heal
> me…He can just send the Spirit down to heal me. (AAM)

Participants believed that God was in control of their life and trusted God with health outcomes.

> Well, when I first had the heart problem, I knew that God was with
> everything and me. And at first, I had a little fear and all. But as
> medical treatment took place, I began to feel better. And then I realized
> that God is in the plan. He is overseeing everything. And, therefore, I
> didn't panic and when I had the cancer of the prostate, I trusted God that
> everything would be all right. And I went through the procedures and so
> forth, and everything did come out all right. I look to God, and my body
> is under God's control. I think that I have trust in God, and I just don't
> have that fear. I don't have the fear because I believe that everything will
> be all right, you know. And I realize that I'm getting older and things are
> going to happen. But I have faith and trust that everything is going to be

all right. And from a spiritual point of view that means that I'm not
worried about them. (AAM)

God: The Enabler through Doctors

God is a collaborative partner in addressing chronic illness through doctors. Medical care

is the extension of God's involvement in their illness. The participants maintained their dual

working partnership between God and their doctors. The participants believed that God gave the

medical doctors wisdom to treat their illness.

I obey the doctors. When the doctor just wait on me, I take their
medicine like they say…that is spiritual because if God hadn't sent a man
down here with wisdom, where would we have been? God gave them
the wisdom of being a doctor…I had faith in God and the doctors.
(AAM)

The following quotes are representative of the working partnership between God and the

medical profession in providing health care in the lives of the participants.

God put the doctors down here…They work together. God helps put the
doctors so He can help you. So I think God helped me. And He put
these doctors down here to give you medicine and help you in that
direction. So you got two good things going for you. (AAM)

God is going to take care of my hip…The doctor tells you what to do . . .
the Lord and the doctor; they're going to take care of my hip. (AAM)

I think God works through man, I really think it's the way that God
works. If you expect for God to come and I'm sure there has been some
miracles that God come down and removed a cancer, but I think that God
puts you in an area. He guides you through His divine wisdom. He
doesn't talk to you. He just some kind of way moves you by some
spiritual forces. He directed me to a good doctor. Then the doctor was
able to work with the person up at the VA hospital. See this is when you
say God was involved. (AAM)

Faith in God

Faith is the personalized, internalized perspective of the individual's belief, outside of the religious teachings. Participants reported that their faith allowed them to accept the outcome of their illness.

> Well, when I went in for bypass surgery, I was not concerned one bit--what was going to happen because I knew if God wanted me, He'd take me. If He didn't, I'd be all right. So my faith was in God, whatever He said, that's what's going to be. (CAM)
>
> I know that if I do not go to dialysis, I know that if I don't go and get the treatments like I'm supposed to, if I miss them, I'm going to die because the poisons are going to form up in my system, and I won't live. If you don't have faith in God and if you don't trust in it. You have to believe in Him. You have to understand that this is His work along with the doctor that you're going to survive; you're going to get better. (AAF)
>
> That's the only way you can deal with the illness, is through your faith in the Lord and what you know is going to be the outcome of whatever you have. You just trust in the Lord. And He sends you where you need to go and He sends people that you need to see. And He takes care of the situation. (AAF)

Frankl (1955) believes that every experience has meaning to a person of faith. It provides a conceptual framework that someone or something is in ultimate control concerning health.

Prayer as Mediator

Prayer as an expression of spirituality can play a central role in the self-management of chronic illness. Prayer can help people accept their health issues. While remaining extremely intimate, prayer is a broad process of expressiveness that reflects the diversity of culture and religion. Prayer provides the framework that enables a person to connect with God. The categories of prayer include petitioning God to help in the self-management of chronic illness and to heal or alleviate the physical condition. Several participants prayed before taking

prescribed medications, while performing disease-specific self-care practices, and in the middle

of medical treatments.

> I had a friend that asked me, do you pray over your medication that the doctor give you? And I thought about it. I said, yeah. New medicine, especially that they won't make me sick and it would help me. (AAF)

> Q. And when you take your medication, what do you pray for?
> A. Dear God, my Father, guide me to do what I'm supposed to do, like take my medicine and that everything is going to be all right. (AAF)

> Well, I guess just basically because I have seen some difference in, you know, in just my test results. Even with my daily glucose testing, they are so much better than they had been for so long, something that I had prayed for. (AAF)

> I pray a whole lot. I can walk the street and pray. And I ask for God's help. I've had hypertension over the years. I try to keep my blood pressure under control with medication. I think when you pray about something, you can only take it to God one time. So when I pray, I say I'm leaving it in your hands. Either go to the doctor or I pray about it. And I certainly take my medication. And I ask God to give me the strength to do that. (AAF)

> Sometimes I pray while on the dialysis machine.
> Q. And what do you pray about, when you are on the machine?
> A. I ask my Lord and Savoir--I say Dear God, my Father, watch over and protect me from all evil and harm. You are my true Lord and Savior. Giving you all the praise, glory, and honor because I know you're here with me, and I can't change. (AAF)

The following quotes represent those who ask God to heal or alleviate their symptoms.

> You have to have their prayers, and I found that out when I had my aneurysm, you know. And I do believe He brought me through. I had everybody praying for me, prayer partners, and things like that. That I got better, that I was healed. I had a lot of people praying for me and I prayed a lot myself, especially when I had this brain surgery. (AAF)

> Just for the Lord to heal any part that's needs to be healed. (AAM)

> There have been moments when I've had severe palpitations, shortness of breath, and pain. And I have just simply prayed and asked God to alleviate the situation and to change the situation. What makes me

believe in it so much is that I found that the physical ailment just merely went away. It was really, for me, a prayer-answering result. (AAF)

If I was to know that I had some special condition that might be crucial in my health, I would pray for that, for guidance through that. (CAM)

It's helped me a lot when it's getting very difficult for me to breathe. Sometimes I just say a little prayer and just ask for some help. I just ask God to ease my breathing. (AAF)

I have not had a physical heart palpitation within the past year, and I have been more involved with prayer and meditation, and I think that it was a direct result of my prayer life and my spiritual life. (AAF)

Spirituality as Coping Mechanism

The participants offered many approaches they used to cope with stressors of their chronic illness and pain. This category focuses on how the participants cope with being ill. It is clear that managing their illness means using spirituality practices and beliefs as a coping mechanism. Participants within this study repeatedly described the process in which they incorporated spirituality as a coping mechanism. This mechanism alleviated several potential physiology and psychological stressors such as pain and helplessness. The following quotes described how the participants used their spirituality to cope with their illness.

Like I said, if I didn't believe in the Almighty . . . I probably would have ended it all a long time ago…It keeps me together. It keeps my head straight…I ask the good Lord for mercy if it gets bad enough. (AAM)

Well, I ask God in the name of His son, Jesus Christ, to help deal with my health. That feeling of being able to do something instead of being downhearted or feel like things are always against you. It takes that away from me. It gives me inspiration to want to do something and to believe more strongly that it will help you. (AAM)

Well, when you meditate, that kind of lightens your burdens of all what bothers you or your aches and pains, everything is wrong with you. (AAM)

If I feel that I am in a crisis situation physically, it helps me to cope by reminding me that the ultimate choice of whatever the outcome of this

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situation is, is not my own. And, therefore, I give myself over to whatever will there needs to be as far as my belief in God is concerned. And, therefore, whatever is happening to me at the time, I'm able to cope with it easier. And at the same time, it also asserts that what my belief teaches, that we're not given a spirit of fear but of faith. And when I reiterate that or when that comes to mind, for some reason the problem doesn't seem as great. And my coping skills are enhanced. And I calm down and I get quieter. And sometimes it just gives me such a relief from the tensions or whatever the crisis is that I'm just better able to deal with that. If I am nervous, if I am jittery, I just seem to get this sensation of peace and quiet that comes over me, and I know that that's not of me. I know that it isn't. It's truly, I believe, the hand of God and the touch of God and the Holy Spirit that quiets and consumes me. And I am whatever I need to do at that time; it's just given to me. And I can cope. I wouldn't be able to deal with a heartbeat that is so irregular that it, you know, it used to jolt me in the middle of something or take my breath away or make me feel so anxious and aggravated and out of control with this. I wouldn't be able to do that without having the spirituality to help me get through that. (AAF)

Well, it has helped me spiritually to cope with my condition by not having to think about it often. I place everything in faith. If I'm supposed to go that way, that's the way I'm going to go, vice versa. See, I'm at peace with myself and with God. (CAM)

When an individual's pain level is unbearable and other coping mechanisms have failed, turning to a power greater than oneself becomes an alternative means for managing pain. During painful flare-ups, several spiritual techniques were acknowledged that distracted participants from their pain. Prayer was the most commonly used form for managing or coping with pain. In fact, several of the participants commented on the "prayer-response" mechanism in pain management.

Like with my arthritis, I pray for that in me. And all of a sudden, the pain and all will go out of my hands. It might come back in a week or so. It will go out for a while, then it will come back. (AAM)

Well, when I had the operation, I left it in the hands of the Lord that everything was going to be all right. That's all. I prayed the pain would go away, and it went away. Sooner or later the pain did go away. I believed the pain would go away, and it went away, you know. And I

went through all that pain. When you have bad pain and everything, you pray to the Lord please take it away. And when the pain is gone, you forget that He might have been the one to help you take that pain away, because that pain is gone and you don't remember it anymore. (AAF)

Sometimes when the pain is stronger, I pray probably with a little more frequency, with a little more earnestness. (AAF)

I think it takes your mind off your pain, and I think it takes your mind off everything when you pray. (CAF)

And it helps me with my pain. It takes your mind off the pain. You don't always be dwelling on your pain…I pray about all my pains and whatnots. So that's taking in all the pains that you have by asking Him to help you with them and someone else, too. When I pray, I ask God to help me with my health. (AAM)

When I'm in pain . . . I ask the Lord right there to give me the ability to go to sleep. And He will let me go to sleep and I'm impervious to the pain. (AAM)

Problems with illness were seen as inevitable. The pain and suffering incurred, however, were overcome by faith that God supported them through their adverse circumstances by providing comfort or sustaining the pain, if only temporarily. To these participants, prayer was seen as a powerful pathway to pain management.

Combining Traditional Medicine and Spiritual Practices

It is clear that the participants perceived their personal relationship with God as an extension of His role in the self-management of chronic illness. As previously mentioned, the participants accredited God with giving the medical doctors the wisdom and the knowledge to treat their illness.

When this clotting occurred, I was sitting in the office of my urologist, and these pains, severe pains, started hitting me in the chest. And to my mind, I was sitting there, the more severe the pains became. And so I eventually had to leave. And I told them I wanted to leave. I told the receptionist at the window I had to go. And she told the doctor. The doctor would not let me leave on my own. So he made arrangements for

me to be transported across the way through the hospital to the emergency room, whereas they treated me and come to the conclusion that it wasn't a heart attack that I was having. It was clots. And they came to that conclusion, and they did make arrangements to administer the drugs to dissolve the clots as soon as possible. And it was through God's will that He instilled in the minds of the technicians who saved me and to work with me to dissolve these clots. (AAM)

Therefore, combining traditional and spiritual methods is defined as a therapeutic approach that combines traditional medical practices with spiritual beliefs and practices. Several respondents repeated the need to use a combination of medicine or self-management and God.

I believe you need both God and medicine. You can't just pray and then forget everything else. I think they both work together. I still have to watch my diet and I have to try and exercise and take my meds. (CAF)

Well, it makes you feel good after you've prayed. And then, too, you feel that you've told God about it. And if there's anything He's going to do, He's going to do it and make you feel better. And a lot of times He does make you feel better. I have a little help from pills from the doctor to make it feel better. (CAF)

Well, my knee arthritis, I'm going to see a doctor about it, but I know that someway, somehow, God will help me until I get to that doctor. (AAF)

Selected Spiritual Practices of Self-care

As stated earlier, spirituality plays a key role in the overall management of the participants' chronic illness. Spirituality is manifested through patterns of daily living to provide the ordinary experience with extraordinary meaning. Several participants described other practices they incorporated into their self-management. These practices include using other articles of faith (i.e., blessed water and prayer cloths).

Yeah, but I get this blessed water you send for and rub it on your wounds.
Q. Did you use it on your knees?

A. Well, a little bit, but it didn't help right away. I guess you have to do it--just like they said, prayers aren't answered. They might not be answered in a year or two. You have to wait in line. (CAF)

I think he (priest) helps a lot, you know. And when I was sick, he came to the hospital. When I had my surgery, he came the day of surgery. And I went to him before I went to surgery, and he gave me a blessing on the alter. And he gave me a little thing to--you know, you put on the drops and wear near the surgical area. He gave me a special blessing. It's like a little rag or something.
Q. And you believe that this blessing helped you? New line
A. Yeah. I went into surgery feeling good. I wore it for the longest time,
Q. But you felt that that helped?
A. Yeah. He gave me a St. Nectarios prayer and I pin them to. He was the saint that you prayed to for cancer. (CAF)

Empowering Respondents to Practice Health-promotion Activities

The respondents reported how important the role of spirituality was in empowering them to

practice in health-promoting activities.

My opinion, I am even more dependent on my daily guidance and asking for guidance for the day and for healing and help with my health and give me good gumption in how to take care of myself. Overall, I mean, there's a saying about the Lord helps them who help themselves. (CAF)

A small number of participants described incorporating their spiritual beliefs with their eating

habits.

Well, like I say, I believe God has given us a diet. And He told us what to eat and what we should eat and not to eat. When He put Adam and Eve in that garden, He told them, you know, gave them all the vegetables and everything and told them to eat those things. And nuts and grains and fruits and vegetables and stuff. Those things we know are good for us. But now, like I said, we can mess up by abusing those things and not doing those things. It's not that God didn't tell us how to do it in the first place. It's our problem. But I believe if we follow Him and live this diet and even taking care of our bodies by getting enough rest and, you know, eating the right things and having the right frame of mind. In other words, having the relationship with Him, communing with Him through prayer. I believe that helps us. (AAF)

Because the Bible and it's God's word. It says that my body is the temple of the Holy Spirit. And so I am not to eat or drink in excess anything

that's going to harm it. I know that too much of certain foods would cause flak in my body, salt to retain fluid, not that I don't sometimes eat pretzels and stuff. But in general, that I am to take care of it. This is how God can use me through a healthy body than an unhealthy body. (AAF)

One participant described the integration of her spirituality in her health promotion/health care activities.

God provides, if you listen. I do what He tells me.
Q. And how is that?
A. You need to go to the doctors, don't you? Have you made your appointment? And I look at my medicine and I know when it's time to go back. And it's like, yeah, I should have made an appointment for this. He's actually hit me in the head with the fact that--the reminders. You don't have to worry about it. He reminds you. You need to go to the doctors, don't you? Plus, I know that when the time comes I say, yeah, I'm supposed to be making an appointment. Looks like somebody says to you, hey--the guy upstairs, He says, hey, knock, knock. Are you there? Make an appointment and go. He's influencing the decision to make an appointment to go to the doctors. And He sends a reminder. He reminds you somewhat, a reminder coming in there somewhere. In some ways it makes me more conscious and say, look, I need to take this medicine…Do I need to take it? Are you going to help me. And if I take this medicine--it's a bargain you make with Him. If I take my medicine, I'm going to get better. If something needs done, I figure God gave me a reason--some kind of a warning sign. And you do whatever you're supposed to. So, I mean, He gave me a warning. And I said okay. I need to do something. (CAF)

Personal Responsibility in the Self-management of Illness

As defined previously, intrapersonal transcendence occurs when an individual goes inside himself for guidance or strength. Several participants described relying on themselves in the self-management of their chronic illness. The participants repeatedly used the word "acceptance" when describing the relationship between spirituality and self-management to reflect the theme: personal responsibility. This theme described the participants' belief in their own capacity to execute a specific action that is required for a favorable outcome.

Accepting what you have and doing what you are supposed to do. Like I said, God gives you something to do. He gives you a problem. You need to solve it. He gives you a way to solve it, too, if you're looking. He does. He gives you a way to solve it. My way of solving it is go to the doctor and take your doggone medicine. Accepting what the problem is. You know you got a problem. Accept it and deal with it. And if you are going to deal with it, how are you going to deal with it? Don't tell me I'll deal with, but tell me how. And if you can tell me how--because, like I say, I use it as a nursing thing, too. You are taught as a nurse that you have goals. You want to get this person out of here and you want to get them home. That's my goal to do that. I have a long-term goal and a short-term. So I need to do this, this, and this to achieve the long-term goal, to go home. So how do I go about doing it? (CAF)

I think that my spirituality has caused me to look to other avenues of involvement in my life and thereby cause this serious distraction from the heart problem itself. And, in addition, it has also assuaged some of the symptoms that I felt directly. And that has a definite impact on my part as far as I'm concerned, and it helps me to deal with it. It redirects your attention and your focus to other things. Because I do believe that the work that I do, I don't think that I would have chosen all of these things or as many of the things as I do for myself I am doing. I think they have been really spiritually allocated for me to do. And in this way, it has become a total diversion from--almost a complete diversion from my physical problems with my heart. Because I'm so absorbed in the duties that I need to do to get through some of the functions that it has helped me to deal with it. (AAF)

I would say that if you look at the whole picture you know, it's a time to be young, a time to be old, a time to be healthy, a time to be sick--and I have yet to meet one single person who has no problems, no health ailments, no nothing. So it's just part of life. I mean, I wouldn't stand and ask for it. But, you know, you got it, you deal with it. I deal with my health problems because I am not the only person in the world that has them. I know this for a fact. I'm a registered nurse. Well, you know, I'm trying to be more responsible as I'm getting older. And my feeling is you're going to get something. (CAF)

6.1.1.   Summary

This chapter described the results of question two from the research study: how does the study population use spiritual practices in the self-management of their chronic illness? It presented findings based on in-depth interviews with 88 individuals. Using a thematic content analysis, this research identified nine themes linking spirituality with chronic illness, namely

cardiovascular disease, diabetes, and arthritis, in the self-management of these chronic illnesses. They are 1) God: the healer; 2) God: the enabler through doctors; 3) faith in God; 4) prayer as a mediator; 5) spirituality as a coping mechanism; 6) combining traditional medicine and spiritual practices in self-management; 7) selected spiritual practices of self-care; 8) empowering respondents to practice health-promoting activities; and 9) personal responsibility in the self-management of illness. The next section described the similarities and the differences of the themes among the study population based on race and gender.

Race

In discussing spirituality, the participants included several references to God in the self-management of their chronic illness. African Americans were more likely to conceptualize spirituality in their self-management of chronic illness than Caucasian Americans. When asked directly whether spirituality played a role in the self-management of their chronic illness, African Americans were more likely than Caucasian Americans to: indicate God as a healer (17 vs. 10); God as an enabler working through their medical doctors (10 vs. 1); and combining traditional medicine and spiritual practices (4 vs. 2). Caucasian Americans were more likely than African Americans to: put their faith in God (5 vs. 2); utilize selected spiritual practices of self-care (6 vs. 3); use their spirituality to enhance their practice health-promoting activities (9 vs. 3); and take personal responsibility in the self-management of their chronic condition (14 vs. 2). Both African Americans and Caucasian Americans were likely to use prayer as a mediator (14 vs. 12) and spirituality as a coping mechanism (18 vs. 14) (see Table 6).

Table 6. THE ROLE OF SPIRITUALITY IN SELF-MANAGEMENT OF CHRONIC ILLNESS BASED ON RACE AND GENDER (N=88)

Themes	Race			Gender	
	African American N = 47	Caucasian American N = 41		Male N= 47	Female N= 41
	n (%)	n (%)		n (%)	n (%)
God: The Healer	17 (36)	10 (24)		13 (28)	14 (34)
God: The Enabler through Doctors	10 (21)	1 (2)		9 (19)	2 (5)
Faith in God	2 (4)	5 (12)		5 (11)	2 (5)
Prayer as a Mediator	14 (30)	12 (29)		8 (17)	17 (41)
Spirituality as a Coping Mechanism	18 (38)	14 (34)		15 (32)	17 (41)
Combining Traditional Medicine and Spiritual Practices in Self-management	4 (9)	2 (5)		0 (0)	6 (15)
Selected Spiritual Practices of Self-care	3 (6)	6 (15)		1 (2)	8 (20)
Empowering Respondents to Practice Health-promoting Activities	3 (6)	9 (22)		3 (6)	9 (22)
Personal Responsibility in the Self-management of Illness	2 (4)	14 (34)		7 (15)	9 (22)

Gender

The female participants in this study mobilized their spirituality resources to help with adjusting and coping with their chronic illness. When compared by gender, the female respondents were more likely than their male counterparts to: indicate God as a healer (14 vs. 12); use prayer as a mediator (17 vs. 8); use their spirituality as a coping mechanism (17 vs. 15); perform selective spiritual practices of self-care (8 vs. 1); use their spirituality to enhance their practice health-promoting activities (9 vs. 3); and take personal responsibility in the self-management of their chronic condition (9 vs. 7). The female respondents exclusively combined traditional medicine with their spiritual practices in the self-management of their chronic illness.

The male respondents were more likely than the female respondents to have faith in God (5 vs. 2) and believe that God work through their medical doctors (9 vs. 2) (see Table 6).

The in-depth qualitative interviews were useful for understanding the relationship between spirituality and self-management of chronic conditions, and identifying themes related to the research question. I identified nine themes in the role of spirituality in the self-management of chronic illness through thematic content analysis. These narrative-based themes suggest that the self-management of chronic illness is deeply embedded in the participants' spiritual beliefs. One theme (i.e., God: the enabler through doctors) emerged in recent literature in older diabetics. In their study with 19 older African American diabetics, Chin, Polonsky, Thomas, and Nerney (2000) found that their respondents believed that God directed their lives and some justified their use of self-care by discussing how "the Lord" works through others. The study identified this and several other themes based on the participants' race, and gender. Additional studies with larger sample size are needed to analysis the relationship among age, gender, and chronic illness. However, the use of qualitative research in terms of thematic analysis provides the first step to understanding connection between spirituality and self-management of chronic illness. The findings of this study offer new insight into the self-management of chronic conditions through spirituality among older adults. Findings, limitations, implications, and directions for future research are discussed in the next chapter.

7. CHAPTER 7

7.1. DISCUSSION

The findings presented in Chapter 6, "The Role of Spirituality in the Self-management of Chronic Illness," represent the interviews of 88 chronically ill elders in Allegheny County, Pennsylvania. The predominately qualitative, theory-driven research study explored the definition of spirituality and the influences of spirituality in the self-management of chronic illness among older adults. This study set out to understand these constructs by asking the following research questions:

1. How do older adults living with chronic illness define spirituality?

2. How does the study population use their spiritual practices in the self-management of their chronic illness?

In this chapter, the definition of spirituality is integrated into the self-management of chronic illness. Finally, this chapter addressed the limitations of the dissertation research, the implications for public health practice, and directions for future research.

7.2. DEFINING SPIRITUALITY

Understanding the participants' definition of spirituality is the first step in determining a working model for self-management of chronic illness. It is therefore important to analyze the first research question independently: "How do older adults living with chronic illnesses define spirituality?" The results show that the vast majority of the participants define spirituality as their relationship with a higher power, which became my working definition of spirituality. In other words, spirituality is the way a person understands life in terms of his or her ultimate *beliefs*. It may or may not express his or her religious *rituals or religious roles*. It is embedded in the person's "whole-being" that shapes his or her lifestyle and includes a *relationship with*

God. The participants' lives reflect their spirituality and their spirituality reflects their lives.

This definition incorporates the three levels of spirituality: transpersonal transcendence,

interpersonal transcendence, and intrapersonal transcendence.

Comparison with Literature

It should be reiterated that we did not ask the participants specifically about God or their

relationship with God. They commonly referred to "God" or "Jesus" when they talked about a

supreme being. It is possible that the responses represent them expressing their religious beliefs

(Wink & Dillon, 2002). These findings support the definition in prior research studies

(Burkhardt, 1994; Fryback & Reinert, 1999; Sowell & Misener, 1997). Providing support for

Fryback and Reinert (1999) and Sowell and Misener's (1997) descriptive findings, the

terminology of "God" was the participants' most frequently reported description regarding a

personal relationship with a higher power they identified as "God." Women in Burkhardt's

(1994) study of spirituality spoke of their connectedness with God. In spite of the differences in

demographics (e.g., race, gender, and age), the results of these studies regarding the terminology

of a higher power or "God" were comparable to mine.

In transpersonal transcendence, spirituality develops through a connectedness to "God"

or a higher power. My definition corresponds with the work of several researchers who defined

spirituality as a transcendent relationship with God (Albaugh, 2003; Elkins et al., 1988; Reed,

1987; Stoll, 1989). As stated by Reed (1992), spirituality empowers an individual to find

meaning in living with a major health issue. Haase, Britt, Coward, Leidy, and Penn (1992)

stated that adversity such as chronic illness often makes a person receptive to spirituality. This

relationship allowed the participants in the Haase et al. study to move beyond (transcend) their

current health issues.

The previous theme also corresponds with Stoll (1979) who noted that religious resources provided a stabilizing force to individuals who were chronically ill. Religious resources are the external representation of spirituality (Aldridge, 2000). It provides "a sense of continuity, particularly for the elderly" (Stoll, 1979). God played a major role in the participants' lives, especially concerning their chronic illness (McAuley, Pecchioni, & Grant, 2000). According to Solomon (2002), religious resources represent the day-to-day activities of individuals. He stated that spirituality is the philosophical oddity that requires action as a demonstration of its essence.

The participants in my study integrated their religious resources in their everyday life experiences. They repeatedly stated in their interviews the various religious resources, which included praying, going to church, and reading the Bible. Prayer was the most prevalent form of religious resources reported by the participants. Praying for one's health did not require a specific time or place. Participants prayed early in the morning, throughout the day, before going to bed, on the bus, in the doctor's office, in the dialysis clinic, in church, in their homes, with family or friends, with religious leaders, with medical professionals, or by themselves. They prayed for healing, acceptance of their current life situation, or relief from health problems. The participants believed that their prayers helped them to feel better in spite of their health conditions.

In some ways, the high usage of prayer is consistent with other literature (Ai et al., 1998; Ang, Ibrahim, Burant, Siminoff, and Kwoh, 2002). In the Ai et al. (1998) study, prayer was the most reported spiritual practice. The participants in the Ai et al. study used prayer as a form of a coping mechanism. They prayed for their recovery following their cardiac surgery. The participants in the previous studies affirmed Schaefer's (1995) conclusion that people turn to a higher power (i.e., God) during a physical crisis and that their spirituality acts as a major factor

in their coping with chronic illness. Several studies also identified prayer as a coping strategy among the chronically ill (Ai et al., 1998; Ai et al., 2002; Ang et al., 2002; Meisenhelder & Chandler, 2000; Taylor & Outlaw, 2002). Taylor and Outlaw gave a comprehensive account regarding the utilization of prayer among cancer patients. Prayer was recognized as "a personal communication involving the transcendence, to ease the physical distress of illness," which the participants articulated in this Taylor and Outlaw study. As defined by the previously mentioned research studies, prayer was important to the participants in my study.

Interpersonal transcendence, by definition, involves the connection with others and the natural environment (Reed, 1992). This definition has some similarities to research found in the literature but it also adds knowledge to the existing literature (Reed, 1987; Soeken & Carson, 1987). The incorporation of spiritual activities shared with others included attending church, ministering to others, performing religious duties within their religious organization, or helping others. Reed, Soeken, and Carson integrated religion into their definition of spirituality. Religion, as defined by current literature, is a systematic set of beliefs or rituals associated with an institutionalized group designed to generate intimacy with God or a higher being (Koenig et al., 2001). Activities such as attending church represent religion. Religion or religious activities were important to the participants in my study. Several of the participants performed duties with their religious organization or attended religious services. For these participants, their sense of spirituality and religiosity were intertwined to the point that their spirituality reflected their religious activities. Religious resources therefore became a category in my definition of spirituality, as described by Reed, Soeken, and Carson.

The theme "helping others" added to the existing literature under the domain of interpersonal transcendence. This theme was important to the participants in the study. In spite

their own physical limitations, many of the participants described various ways in which they helped others. This activity occurred through volunteerism at a local elder center or special needs program. It included reading their illiterate neighbors' mail to them, praying with others over the telephone, or caring for neighbors who were terminally ill. Helping others put their own chronic illness in perspective. They considered their physical limitations minimal when they compared themselves to others. Elkins et al. (1988) stated that "the spiritual person believes he is his 'brother's keeper' and is touched by the pain and suffering others" (p. 11) Burkhardt (1993), Dyson et al. (1997), Elkins et al. (1988), and Koenig (2002) reported that participants in their study found comfort and meaning through their spirituality. Spirituality provided meaning and purpose to their life, which helped them to transcend their illness. In other words, helping others often made it easier to forget about their own aches and pains. Several of the study participants believed that their illness served a purpose in their lives in that it set an example on how to handle pain for those close to them.

The definition of intrapersonal transcendence is the connectedness with oneself (Heriot 1992; Reed, 1992). The definition of intrapersonal transcendence in my study incorporates findings from several published articles (Burkhardt & Nagai-Jacobson, 1994; Elkins et al., 1988; Heriot, 1992). The participants in the study described their intrapersonal transcendence as an interpretation of their life, as well as their inner resources. It was demonstrated in their lifestyle. Their spirituality reflects their response to their chronic illness (Burkhardt & Nagai-Jacobson).

In conclusion, the definition of spirituality is similar to findings of other gerontological researchers (Heriot, 1992; Koenig, 2002; Koenig et al., 1988). This study added to the body of literature in defining spirituality. One of the major contributions is the comprehensive and

thorough definition of spirituality, as defined by chronically ill elders. In addition, this study

presented a comprehensive examination of the three levels of spirituality.

7.3.   THE ROLE OF SPIRITUALITY IN SELF-MANAGEMENT OF CHRONIC ILLNESS

In approaching the relationship between spirituality and the self-management of chronic

illness, the key question is how do the different levels of spirituality help us understand what

older adults derive from their beliefs? Transpersonal transcendence reminds us that "spirituality"

is the connectedness to God. Interpersonal transcendence, on the other hand, sensitizes us to the

relationship we have with others, which can give meaning and purpose in life. Intrapersonal

transcendence is concerned with the inner resources of self. In addition to understanding the

definition of spirituality, this study sought to understand how a population of chronically ill

elders used spirituality in the self-management of their health condition. Although it is

documented that spirituality provide benefits in terms of recovery from illness or enabling people

to cope with illness (Ai et al., 1998; Matthews et al., 1988; Taylor & Outlaw, 2002), very little is

known about the levels of spirituality used in self-care.

The study participants demonstrated a variety of responses from God as the healer to

taking personal responsibility in the self-management of their illness (see Chapter 6). In fact, the

qualitative analyses revealed that a vast majority of the participants attributed several of their

self-care practices to their spirituality. The findings in the study suggest that each level of

spirituality plays a part in documenting the self-management process (see Table 7).

Table 7. THE ROLE OF SPIRITUALITY IN THE SELF-MANAGEMENT OF CHRONIC ILLNESS

LEVELS OF SPIRITUALITY

	Transpersonal Transcendence	Interpersonal Transcendence	Intrapersonal Transcendence
THEMES	God: The Healer	Selected Spiritual Practices of Self-care	Empowering Respondents to Practice Health-promoting Activities
	God: The Enabler through Doctors		Personal Responsibility in the Self-management of Illness
	Faith in God		
	Prayer as a Mediator		
	Spirituality as a Coping Mechanism		
	Combining Traditional Medicine and Spiritual Practices in Self-management		

First, transpersonal transcendence, as derived from multiple points of view, is the most salient domain concerning self-management of chronic illness. Within the domain of transpersonal transcendence, the participants viewed the role of God as the healer or as a conduit for physicians. They placed their faith in God, used prayer as a mediator, used spirituality as a coping strategy, and combined traditional medical practices with their spiritual practices.

The qualitative interviews provided some evidence for the influence of spirituality on self-care practices. Participants attributed some of their self-care practices to their spirituality. The participants in this study actively used their spirituality to help deal with their illness. Findings from the study demonstrated that prayer was the most referenced of spiritual practices. It acted as a mediator between the participants and God, and as a coping strategy. African American women in Abrums's (2000) study said that God worked through them to control their illness, which occurred through prayer. It helped the women to cope with their chronic illness. Sodestrom and Martinson (1987) demonstrated the use of prayer as a coping mechanism. In

their interview of 25 cancer patients, prayer had the highest ranking for spiritual coping strategies (84%) followed by religious television programs (64%), reading the Bible (56%), attending church (52%), and taking communion (32%). Prayer, as a coping mechanism to physical pain among older adults, is relevant in the field of gerontology, but it remains an uninvestigated topic among researchers (Bearon & Koenig, 1990).

Spirituality has a profound influence on health (Ai et al., 1998; Bartlett, Piedmont, Bilderback, Matusmoto, and Bathon, 2001; Byrd, 1988). However, very little is known about combining spirituality with traditional medical practices. The participants in this study combined their "faith in God" and formal health care to manage their illness. For example, the participants talked about changing eating habits because of their belief in the Bible.

Second, the results in this study regarding interpersonal transcendence suggest a promising direction for future research in the management of chronic illness. Participants who described using interpersonal transcendence utilized others to help in the management of their illness. The participants relied on their family members, friends, church members, pastors, priests, and bishops as a form of social support. This relationship is supported by Hasse et al. (1992), stating that connectedness is viewed as a rich social support network.

Third, intrapersonal transcendence can be viewed more broadly as the promotion of the overall well-being of self. Research showed that spirituality can be instrumental in shaping health-promoting behaviors, but to my knowledge, no previous research has investigated the effect of spirituality on self-management. However, Strawbridge, Shema, Cohen, and Kaplan (2001) saw improvements in health behaviors (i.e., stop smoking, start exercising, and reduce heavy drinking) among those who attended weekly religious services. Their data came from the Alameda County Study, a longitudinal study of health behaviors that started in 1965. In a recent

study, Benjamins and Brown (2004) found that older adults, who reported high levels of

religious involvement, were associated with a high usage of preventative services (i.e., flu shots,

cholesterol screenings, Pap smears, and prostate screenings). They concluded, "Religious beliefs

may motivate individuals to lead healthier lives, including the use of regular preventative care"

(p. 117).

7.3.1.   Race

Current research on religion/spirituality and health has made important strides in

understanding the role of race and ethnicity in these relationships. Many research efforts have

contributed to the literature (Chatters & Taylor, 1994; Ellison, 1995; George et al., 2000; Koenig

et. al., 2001; Matthews et al., 1998; McAuley et al., 2000; Morgan, 1996). With the expanding

literature base, it is important that research examine the role of spirituality in the lives of older

African Americans as it pertains to how they view their chronic illness and disease management.

The results of this study add to the current literature. First, this study confirmed that African

Americans used their transpersonal transcendence at a higher rate than Caucasian Americans for

the management of their chronic illness (see Table 9). Morgan reported that African Americans

value daily interactions with God in their daily lives. The study findings were consistent with

Mansfield, Mitchell, and King (2002). They found that African Americans were more likely

than Caucasian Americans to endorse a belief in divine intervention in healing and that God acts

through physicians to cure illnesses.

Studies suggest that prayer is more common among African Americans (Chatters &

Taylor, 1989; Koenig et al., 1992; Levin, Taylor, and Chatters, 1994) than Caucasian Americans.

Silverman et al. (1999) reported that although the usage of prayer was low among older arthritic

African Americans and Caucasian Americans in managing their chronic illness, African

Americans tended to report higher use of religious activities compared to Caucasian Americans. In spite of limited sample size, this study showed an equal distribution of the usage of prayer between both groups.

Table 8. RACE AND THE ROLE OF SPIRITUALITY IN THE SELF-MANAGEMENT OF CHRONIC ILLNESS (N=88)

	Levels of Spirituality					
Themes	Transpersonal Transcendence		Interpersonal Transcendence		Intrapersonal Transcendence	
	African American	Caucasian American	African American	Caucasian American	African American	Caucasian American
God: The Healer	17	10				
God: The Enabler through Doctors	10	1				
Faith in God	2	5				
Prayer as a Mediator	14	12				
Spirituality as a Coping Mechanism	18	14				
Combining Traditional Medicine and Spiritual Practices in Self-management	4	2				
Selected Spiritual Practices of Self-care			3	6		
Empowering Respondents to Practice Health-promoting Activities					3	9
Personal Responsibility in the Self-management of Illness					2	14

A limited comparison can be made between the results of this study and those of McAuley et al. (2000). These studies differ in several important ways so their comparison should be made with caution. McAuley et al. completed a semi-structured interview that investigated the role of God in health and illness in rural Oklahoma. Data for both studies were collected in a single

county. There are some similarities in the results of the two studies. Among African Americans and Caucasian Americans to a lesser degree, God is acknowledged as the healer of disease. Both African Americans and Caucasian Americans indicated that they pray for the improvement of their health. There are also important differences in the results. McAuley et al. focused their study entirely on "expressions of God's role in health and illness" (p. 31) rather than on the role of spirituality in the management of chronic illness. They addressed only the health belief system within their population.

Spirituality defined through interpersonal and intrapersonal transcendence was more likely to play a major role in the self-management of chronic illness among Caucasian Americans compared to African Americans (see Table 9). The participants who saw their spirituality in these terms provided us with a clearer understanding of how this type of spirituality encourages self-management. To the best of my knowledge, this information is not in the empirical research on this topic. The role of interpersonal or intrapersonal transcendence has not been described in the self-care or self-management literature.

The effect of spirituality on an individual's personal sources of strength deserves more consideration as a way to clarify the relationship between spirituality and self-care. These results offer new information that may prove helpful to future research.

7.3.2.   Gender

This study found that spiritual beliefs in healing are strong, that prayer is a common practice, and that people are inclined to use spirituality in the self-management of their chronic illness. The study also found that those beliefs and practices vary by gender (see Table 10). The women in this study believed more strongly in the role of God in healing and made more use of the three levels of spirituality (transpersonal transcendence, interpersonal transcendence, and

intrapersonal transcendence) than men did. Little empirical data exist to detail the relationship in the use of spirituality in the self-management of chronic illness by gender. The Arcury, Quant, McDonald, and Bell (2000) study found little variability in the use of religion self-management of health care among their study participants.

Table 9. GENDER AND THE ROLE OF SPIRITUALITY IN THE SELF-MANAGEMENT OF CHRONIC ILLNESS (N=88)

Themes	Levels of Spirituality					
	Transpersonal Transcendence		Interpersonal Transcendence		Intrapersonal Transcendence	
	Male	Female	Male	Female	Male	Female
God: The Healer	13	14				
God: The Enabler through Doctors	9	2				
Faith in God	5	2				
Prayer as a Mediator	8	17				
Spirituality as a Coping Mechanism	15	17				
Combining Traditional Medicine and Spiritual Practices in Self-management	0	6				
Selected Spiritual Practices of Self-care			1	8		
Empowering Respondents to Practice Health-promoting Activities					3	9
Personal Responsibility in the Self-management of Illness					7	9

With the exception of the research on prayer and coping, there does not appears to be studies examining the spiritual differences by gender. Studies suggest that prayer is more common among women (Chatters & Taylor, 1989; Koenig et al., 1992; Levin et al., 1994) than among men. The study's findings were consistent with the literature. Both genders tended to

show a strong usage of spirituality as a coping mechanism. This finding is consistent with previous research regarding spirituality as tool for coping with chronic illness (Gurklis & Menke, 1988).

7.4. LIMITATIONS

As a qualitative study, this study did not pursue advanced statistical technique but focus on the development of themes. However, this was an exploratory study, which broke ground and provided the first step into inquiry that linked spirituality and self-management of chronic illness. Furthermore, this study focused on the participant and was suited to investigate and examine the participants' perceptions on meaning and use of spirituality and self-management of chronic illness. A quantitative survey study would have been less useful in creating a meaningful person-centered definition of spirituality and in providing in-depth information in the self-management of chronic health conditions.

Another limitation was the relationship between interviewer and interviewee. This study used five interviewers with varied expertise in interviewing older adults. We hoped that the semi-structured interviews would act as a guide for us. However, it is not known if when or in what sequence were addressed. Additionally, challenges occurred on deciding whether to probe for detail or allow the participant to digress from the interview. These decisions may have lead to interviewer bias. On the other hand, while one interviewer may ascertain more detail information than another or one respondent may articulate the relationship between spirituality and self-management better than another, it is the sum total of interviews that provided the foundation for the development of themes.

Because the study population was limited to Allegheny County, Pennsylvania, the results of this study therefore cannot be generalized to other geographic locations or to younger people

who are chronically ill. In addition, no differentiation was made for those who are at different

stages of their illness. The attitudes about spirituality might be different for those whose

illnesses are more or less severe.

Finally, the sample was predominately Christian and of European American and African

American descent. It is unknown how Asian or Latino Americans use spirituality in the self-

management of their chronic illness. Most research in spirituality/religion and health care has

typically occurred in populations from this Caucasian American and African American

background. Further study on the role of spirituality in the lives of the chronically ill elders

should include others of non-Christian religions, as well as agnostics, allowing a broader

understanding of spiritual issues across religious and nonreligious sectors. Given the increase in

diversity among older adults, more attention needs to be given to other religions and spiritual

groups.

7.5.   IMPLICATIONS

The preceding section demonstrates ways in which spirituality may help promote health-

promoting behaviors by helping people cope with illness. Spirituality offers a significant benefit

to older adults who are experiencing challenges to their health. Public health research

institutions need to incorporate research focused on spirituality and its significance for health

promotion. The implications for health-promoting behaviors and coping with health problems

are evident. Therefore, it would be beneficial that a collaborative relationship exist between

public health research institutions and faith communities. Faith communities have served a

critical role in older people's lives, especially in the African American community (Chatters &

Taylor, 1994). This study suggests that a connection between spirituality and self-management

for older adults can make a difference in their health experience by helping to promote positive

health outcomes. Public health educators and researchers are in a position to collaborate with

faith-based institutions to assess, plan, develop, and evaluate interventions within the context of

the target population. This study supports the increased interest in health education and

intervention methods for enhancing spirituality and spiritual health in target populations.

7.6.   FUTURE RESEARCH

Spirituality plays a vital part in the life of a chronically ill individual. To the best of my

knowledge, there are gaps in gerontological research as it pertains to our understanding of

spirituality and the self-management of chronic illness. We clearly need to learn more about the

complex relationship between spirituality and self-care in a chronically ill population. Collection

and analysis of data needs to be comprehensive and systematic in the areas mentioned to develop

effective approaches to enhance the understanding of spirituality and the self-management of

illness in the older population. Recent studies have begun (Samuel-Hodge et al., 2000; Tull et

al., 2001) to address the complex relationship between spirituality and self-management of

diabetes. The current study validates that association and further research is needed to

understand this phenomenon. Additional research could build on this study and extend the

knowledge base. Future research should do the following: identify factors associated with

spirituality and patterns of self-management in older adults, increase the sample size, incorporate

a mixed-method research design, and identify spiritual factors that both promote and prohibit

effective self-managing techniques. The focus of these recommendations should be based on the

relationships between healthcare and public health professionals and the older population as well

as their caregivers to enhance self-management programs

7.7. CONCLUSION

Spirituality is considered the process of unfolding life in connection with a dimension beyond self (Elkins et al., 1988; Tornstam, 1994). An individual's spirituality is related to his culture, and his spirituality can be determined by his cultural norms. Culture is often associated with one's ethnic background. A broad definition of culture is "the values, beliefs, norms and practices of a particular group that are learned and shared and that guide thinking, decisions, and actions in a patterned way" (Leininger, 1988, p. 158). A specific culture will share similar norms, lifestyles, language, and beliefs. Miller (1995) reported that culture and spirituality are interrelated. The belief system between ethnic/cultural heritages is so interwoven into a spirituality/religious affiliation that it becomes difficult to separate the two. Thus, the meaning of self-care among older adults can occur within the context of beliefs and experience regarding aging, health, and spirituality. As indicated in this study, the experience of spirituality, self-care, and chronic illness is complex and multifaceted, emerging from interrelationships between individuals and God. In addition, an understanding of the experience of chronically ill elders may offer hope in developing more culturally appropriate and competent public health education programs including interventions.

This qualitative study was appropriate and helpful to the study of spirituality and self-care among older adults. It assessed the differences in the role of spirituality across racial and gender groups. The in-depth, semi-structured interviews allowed for further explanation regarding the influences of spirituality on self-care practices in regard to managing chronic illness. This study, therefore, adds to the literature in the under-studied area of spirituality and the self-management of chronic health conditions among older adults.

APPENDIX A

PARENT STUDY (TIME 3) SPIRITUALITY INTERVIEW

RELIGION AND SPIRITUALITY SCALE

1. **Now I'd like to ask you a few questions about religion and spirituality. First, how often do you currently go to religious services?**

    1. **Every day or nearly every day**

    2. **At least once a week**

    3. **At least once a month**

    4. **A few times a year**

    5. **Once a year**

    6. **Never**

    8. DON'T KNOW

    9. REFUSED/NO RESPONSE

2. **Using the following answer categories, please tell me …** [SHOW CARD]

	More than once a day	Every day	Most days	Some days	Once in a while	Never or almost never	DON'T KNOW	RE-FUSED
a. **How often do you pray or meditate privately in places other than at a church or synagogue?**	1	2	3	4	5	6	8	9
b. **How often do you watch or listen to religious programs on TV or radio?**	1	2	3	4	5	6	8	9
c. **How often do you read the Bible or other religious literature?**	1	2	3	4	5	6	8	9

3. **To what extent do you consider yourself to be a religious person? Would you say you are:**

    1. **Very religious**

    2. **Moderately religious**

    3. **Slightly religious**

    4. **Not religious at all**

    8. DON'T KNOW

    9. REFUSED/NO RESPONSE

4. **To what extent do you consider yourself to be a spiritual person? Would you say you are:**

    1. **Very spiritual**

    2. **Moderately spiritual**

    3. **Slightly spiritual**

    4. **Not spiritual at all**

    8. DON'T KNOW

    9. REFUSED/NO RESPONSE

5. The next questions deal with possible spiritual experiences you may have. To what extent can you say you experience the following? [SHOW CARD]

	More than once a day	Every day	Most days	Some days	Once in a while	Never or almost never	DON'T KNOW	RE-FUSED
a. I find strength and comfort in my religion.	1	2	3	4	5	6	8	9
b. I feel God's presence.	1	2	3	4	5	6	8	9
c. I feel deep inner peace and harmony.	1	2	3	4	5	6	8	9

6. If you had a problem or were faced with a difficult situation, how much help and comfort would the people in your congregation be willing to give you?

    1. **A great deal**

    2. **Quite a bit**

    3. **Some**

    4. **None at all**

    7. NOT APPLICABLE (NO CONGREGATION)

    8. DON'T KNOW

    9. REFUSED/NO RESPONSE

7. The next questions are about how you try to understand and deal with the major problems in your life, and the role that religion and spirituality play in this. To what extent is each of the following involved in the way you cope with things? [SHOW CARD]

	A great deal	Quite a bit	Some what	Not at all	DON'T KNOW	RE-FUSED
a. I think about how my life is part of a larger spiritual force.	1	2	3	4	8	9
b. I look to God for strength, support and guidance.	1	2	3	4	8	9
c. To what extent do you try to make sense of a situation and decide what to do about it on your own <u>without</u> relying on God?	1	2	3	4	8	9
d. To what extent has religion and spirituality been a source of help and comfort to you in dealing with life's problems, including your health problems?	1	2	3	4	8	9
e. How about for your heart condition? To what extent has religion and spirituality been a source of help and comfort to you in dealing specifically with your heart condition?	1	2	3	4	8	9

APPENDIX B

PILOT INFORMED CONSENT

NOTE: The following informed consent includes the study investigators. However, these listed investigators will not be obtaining final informed consent. Instead, this will be completed by the trained interviewer at the first face-to-face contact since they will, in fact, be the one who will interview the participants. It would not be feasible or cost-effective for this to be completed by the investigators.

DESCRIPTION:

You are participating in a four-year study with older adults who have either osteoarthritis (loss of soft tissues between joints) or ischemic heart disease (heart problems that may cause chest pain or discomfort).
Now at the third interview, we are conducting a pilot study regarding how older adults with chronic illness define spirituality and the process by which spirituality acts as a resource in managing their chronic illness.

      1.   If you agree to participate in this study, you will be requested to answer questions pertaining to your spirituality and religious beliefs, and how your spirituality or religious beliefs affects your care of your chronic illness. We will ask these questions only one time. These questions should take 30- 40 minutes and we will audio record it. We will record the interviews to make sure that we have all of the information that you give us, just in case we forget to write anything down. After we review the tapes at the office, they will be destroyed.

RISKS AND BENEFITS:

      There may be a risk of discomfort when answering questions about religion and spirituality. You can refuse to answer any questions that may make you feel uncomfortable. While there will be no direct benefit to you, the results of this study could lead to benefits regarding improved health care and service needs for future generations of older adults.

CONFIDENTIALITY

      If a participant is experiencing a serious problem such as severe depression or anxiety where medical treatment may be needed, the interviewer is required to report this to the Principal Investigator and the PI would then consult with the Benedum Geriatric Center.

      This research study will not involve the recording of current and/or future identifiable medical information from the questionnaire; any information about you obtained through this research will be kept confidential. The information obtained in this study will belong solely to the investigators and only authorized project personnel will have access to the information. Any information, which will carry person-identifying material, will be kept in locked files and a secure computer system. All questionnaires will be kept in a separate location away from demographic information. Additional information such as questionnaires and audiotapes are identified by identification numbers, which ensures participant confidentiality. Information (written and audio taped) will be kept for a period of five years after initial publication and then will be destroyed; audiotapes made during the interview will then be erased. Your identity will not be revealed in any description or publication of this research. You should understand that these research records, just like hospital records, might be subpoenaed by court order.

In addition to the investigators listed on the first page of this consent form and their research staff, the following individuals will or may have access to identifiable information (which may include your identifiable demographic information) related to your participation n this research study.

Authorized representatives of the University of Pittsburgh Research Conduct and Compliance Office may review your identifiable research information (which may include your identifiable demographic information) for the purpose of monitoring the appropriate conduct of this research study.

In unusual cases, the investigators may be required to release identifiable information (which may include your identifiable demographic information) related to your participation in this research study in response an order from a court of law. If the investigators learn that you or someone with whom you are involved is in serious danger or potential harm, they will need to inform, as required by Pennsylvania law, the appropriate agencies.

COSTS AND PAYMENTS:

You will not be charged in any way to participate in this pilot study. After completing Time 3 interviews you will receive $25.00. You will not receive any additional payment.

RIGHT TO WITHDRAW:

You understand that you do not have to take part in this pilot research study and, should you change your mind, you can withdraw from the study at any time. Your other care and benefits will be the same whether you participate in this research study or not.

VOLUNTARY CONSENT:

I certify that I have read the preceding, or it has been read to me, and I understand its contents. Any questions I have pertaining to the research have been, and will continue to be answered by the investigators listed at the beginning of this consent form at the phone numbers given. Any questions I have concerning my rights as a research subject will be answered by the Human Subjects Protection Advocate at the University of Pittsburgh IRB Office (412-578-8570). A copy of this consent will be given to me. My signature below means that I have freely agreed to participate in this project.

Subject Signature	Date

INVESTIGATOR'S CERTIFICATION:

I certify that I have explained the nature and purpose of this research study to the above-named individual(s), and I have discussed the potential benefits and possible risks of study participation. Any questions the individual(s) have about this study have been answered, and we will always be available to address future questions as they arise.

_____   _____

Printed Name of Person Obtaining Consent   Role in Research Study

_____   _____

Signature of Person Obtaining Consent   Date

APPENDIX C

PILOT QUESTIONNAIRE

PILOT RESEARCH QUESTIONS

I would like to begin by telling you the purpose of this interview. We are trying to find out how older adults with chronic illness define spirituality and the process by which spirituality acts as a resource in managing their chronic illness.

1. What is your most important health problem?

2. You mentioned that you consider _____ to be your most important health problem. Tell me about this illness. (**Probe**: How long have you had this condition? Briefly, how did you learn about it? How has it affected you? Do you ever wonder why you became ill?

We are going to talk about your spirituality or spiritual beliefs. We are interested in your thoughts views concerning your personal connection and belief in a higher power.

3. Do you consider yourself a spiritual person? (**If YES, PROBE:** What does it means to you?)

4. How do you define spirituality? (**PROBE**: Why is it important to you?)

5. How has your spirituality changed since being diagnosed with_____? (**Probe**: How has it changed? Can you tell me about that? Why has it changed? How is it different?)

6. How has your spirituality helped you to deal with your illness? (**Probe**: In what ways does your spiritual belief help you manage or cope with your illness? How has your spirituality influenced the way you deal with your illness?)

Now I am going to ask you some questions about how you use your spirituality in day-to-day care for your _____.

    1. Do you communicate with a higher presence or a higher power?

IF NO, SKIP TO 13

    2. How do you communicate with a higher presence or higher power (e.g. prayer, chant, etc.)?

    3. How would you describe what _____ means to you? (Probes: Why is it important to you? What are your beliefs about _____?)

    4. Do you ever pray for your health?

IF NO, SKIP TO 10

    5. What is it about your health that causes you to pray (e.g. pain, health getting worse, etc.)?

6. What health conditions cause you to pray?

7. How has prayer helped you deal with your _____?

8. How do you use prayer to help manage your _____? (**Probe**: Do you pray before seeing you doctors? Do you pray before taking your medicine?)

9. Has prayer changed your life since being diagnosed _____? (**Probe**: How has prayer influenced how you deal with your illness?)

10. In general, how does prayer help you cope with everyday life situations?

11. Do others pray for your health (**IF YES: ASK WHO**)?

12. Do you pray with others regarding your health problems previously mentioned?

13. Do you ask others to pray for your health (**IF YES: ASK WHO**)?

We have just talked about prayer, now I would like to ask you about any other forms, methods or techniques that you may use to communicate with God, a Higher Presence, or a Higher Power.

14. Besides prayer, are there any other forms or techniques you use to communicate with a Higher Being, God, or a Higher Power (**Probe: meditation, reading, visualization**)?

15. How do these other forms or techniques help you deal with your illness from day to day?

The next question deal with ways people use to describe their spiritual and religious beliefs.

16. Based on the following statements, how would you describe your religiousness and spirituality? **(Circle the respondent answer)**

     1.   I am spiritual and religious
     2.   I am spiritual but not religious
     3.   I am religious but not spiritual
     4.   I am neither spiritual or religious

APPENDIX D

RESEARCH QUESTIONS FOR SPIRITUALITY STUDY

ASK QUESTIONS 8 TO 16 FOR THOSE WHO
"DO NOT KNOW" OR WHO ARE "NOT SPIRITUAL AT ALL"

I would like to ask you a few more questions about spirituality and spiritual beliefs.

1. You said you were _____ spiritual. There are many ways that people define spirituality. It can mean different things to different people. We would like to know, what does being spiritual mean to you? (PROBE: We really would like to understand, how you define spirituality.)

a. Can you tell me why you consider yourself _____spiritual? (PROBE: What do you do in your life that you think is spiritual? What is it about your life that is spiritual?)

2. You also mentioned that your most important health problem is _____. People have told us many different ways that their spirituality or spiritual beliefs have helped them with their most important health problem. Can you tell me how your spiritual beliefs or feelings about spirituality have helped you? (PROBE: Is there any other way?)

a. How has your spirituality or spiritual beliefs changed? (PROBE: Can you tell me about that? What made them change? How are they different?)

3. People have also told us that there are many different ways in which spirituality or their spiritual beliefs have helped them. How have your spiritual beliefs or spirituality helped you deal with your illness? (PROBE: Can you tell me in what ways your spiritual beliefs or spirituality helped you manage or cope with your illness? What <u>did</u> help you get through this?)

4. People talk about the way in which they feel connected to or in touch with a higher power or presence. Can you tell me about the ways that you feel you are in the presence of or connected to or in touch with a higher presence or a higher power? For example: prayer, meditation, singing, reading the Bible. (PROBE: Are there ways you can make this happen? Why is this important to you?)

   a. Has this always been part of your life or was there some specific event or time when it became a part of your life?

b. In general, how does this help you cope with everyday life situations?

c. How does this help you deal with your health problems? (PROBE: Do you do this before seeing you doctors? Do you do this before taking your medicine? Do you do this before going to treatment or during your treatment?)

5. Are there specific aspects about your health problems that cause you to rely on _____ (e.g. pain, health getting worse, etc.)? When there are 2 or more responses to Question 4, ask: Which one is the most important? Why? When would you use one rather than the other?

6. Are there some health conditions that cause you to_____ and others that do not?

7. **Sometimes people pray for each other's health. Do others pray for your health? Can you tell me who prays for your health?**

a. **Have you asked others to pray for you? Can you tell me why you may or may not have asked others to pray for your health? Have their prayers brought comfort to you in any way? Can you tell me if you think their prayers had an effect on your health in any way?**

b. Do you pray with others regarding your health problems? Can you tell me about that? Can you tell me why you may or may not pray with others?

QUESTIONS 8 TO 16 ARE FOR THOSE WHO
"DO NOT KNOW" OR WHO ARE "NOT SPIRITUAL AT ALL"

8. Even though, you said you were "NOT SPIRITUAL AT ALL" or "YOU DO NOT KNOW" if you are spiritual. We really would like to know what being spiritual means to you. Can you describe what spirituality means to you? What do you think spirituality means to others?

9. Can you tell me why you consider yourself not to be spiritual at all?

10. You also mentioned that your most important health problem is _____. Have your spiritual beliefs or feelings about spirituality changed in any way because you were diagnosed with_____? How have they changed? Can you tell me about that? What made them change? How are they different?

11. **People use different ways to help them deal with the emotional and psychological part of their illness. Can you tell me what other ways you may use on a day-to-day basis to help you care for your illness (e.g. meditation, visualization, positive attitude)? (PROBE: Are there any other ways or things you may use to help?)**

    a. **Has this always been part of your life or was there some specific event or time when it became a part of your life?**

b. Does this help you cope with your health problems? (PROBE: Do you do this before seeing your doctors? Do you do this before taking your medicine? Do you do this before going to treatment or during your treatment?)

c. Are there specific aspects about your health problems that cause you to rely on _____ (e.g. pain, health getting worse, etc.)? When there are 2 or more responses to Question 11, ask: Which one is the most important? Why? When would you use one rather than the other?

12. Are there some health conditions that cause you to_____ and others that do not?

13. Was spirituality ever a part of your life? (PROBE: What made it change?)

14. **Do you think it will ever be a part of your life? (PROBE: If your illness worsens, do you think you would become spiritual?)**

15. **Sometimes people ask others for spiritual support in coping with their health problems. I am going to ask you what type of spiritual support you receive from others. Do others pray for your health? Can you tell me who prays for your health?**

a. Have you asked others to pray for you? Can you tell me why you may or may not have asked others to pray for your health? Have their prayers brought comfort to you in any way? Can you tell me if you think their prayers had an effect on your health in any way?

16. Do you pray with others regarding your health problems? Can you tell me why you may or may not pray with others?

APPENDIX E

CHARACTERISTICS OF PARTICIPANTS IN SPIRTUALITY STUDY

PARTICIPANT IDENTIFICATION NUMBER	ETHNICITY	GENDER	AGE	MOST IMPORTANT HEALTH PROBLEMS
10027	African American	Male	80	Diabetes & Heart Disease
10029	African American	Male	73	Gastrointestinal Problems
10317	African American	Male		Arthritis
10910	African American	Male	86	Heart Disease
11042	African American	Male	83	Thrombosis
11117	African American	Male	74	Prostate Cancer
11341	African American	Male	74	Heart Disease
11678	African American	Male	83	Prostate Cancer
12791	African American	Male	74	Congestive Heart Failure
12835	African American	Male	71	Heart Disease
12928	African American	Male	69	Arthritis
13048	African American	Male	73	Heart Disease
13182	African American	Male	74	Legally Blind
13222	African American	Male	88	Losing Hearing
13476	African American	Male	76	Diabetes
13581	African American	Male	79	Heart Disease
14069	African American	Male	79	Diabetes
14685	African American	Male	72	Diabetes & Hypertension
15184	African American	Male	78	Heart Disease
15216	African American	Male	78	Arthritis
15345	African American	Male	78	Diabetes
15512	African American	Male	82	Heart Disease
15545	African American	Male	74	Heart Disease
15893	African American	Male	76	Arthritis
15934	African American	Male	74	Heart Disease
16230	African American	Male	77	Hip Arthritis
21109	Caucasian American	Male	75	Heart Disease
21199	Caucasian American	Male	76	Back Problems
21386	Caucasian American	Male	84	Heart Disease
21904	Caucasian American	Male	69	Diabetes
22614	Caucasian American	Male	73	Heart Disease
24693	Caucasian American	Male	74	Diabetes & Foot Problem

PARTICIPANT IDENTIFICATION NUMBER	ETHNICITY	GENDER	AGE	MOST IMPORTANT HEALTH PROBLEMS
25343	Caucasian American	Male	77	Diabetes & Hypertension
26068	Caucasian American	Male	69	Cancer
26648	Caucasian American	Male	79	Heart Disease
27449	Caucasian American	Male	75	Heart Disease
28036	Caucasian American	Male	83	Gastrointestinal Problems & Hiatus Hernia
28448	Caucasian American	Male	77	Heart Disease
29285	Caucasian American	Male	74	Arthritis
29853	Caucasian American	Male	76	Spinal Stenosis
30514	Caucasian American	Male	74	Diabetes
30829	Caucasian American	Male	83	Aneurysm
30832	Caucasian American	Male	79	Hypertension
31333	Caucasian American	Male	75	Heart Disease
32131	Caucasian American	Male	75	Heart Disease
32462	Caucasian American	Male	69	Heart Disease
35032	Caucasian American	Male	77	Heart Disease
40050	African American	Female	78	Hypertension
40635	African American	Female	77	Heart Disease
40697	African American	Female	69	Hypertension
41012	African American	Female	72	Heart Disease
41579	African American	Female	70	Diabetes & Hypertension
41625	African American	Female	68	Gastrointestinal Problems
41642	African American	Female	73	Knee Arthritis
42105	African American	Female	78	Knee Arthritis
42533	African American	Female	76	Hypertension
43072	African American	Female	73	Kidneys & Dialysis
43149	African American	Female	78	Heart Disease
43238	African American	Female	68	Hip Arthritis
43813	African American	Female	70	Heart Disease
44506	African American	Female	71	Diabetes
45083	African American	Female	81	Heart Disease
45372	African American	Female	75	Broken Knee
46007	African American	Female	70	Heart Disease
46088	African American	Female	70	Hypertension

PARTICIPANT IDENTIFICATION NUMBER	ETHNICITY	GENDER	AGE	MOST IMPORTANT HEALTH PROBLEMS
46549	African American	Female	85	Emphysema
46568	African American	Female	77	Dialysis
48285	African American	Female	75	Kidney Problems
62361	Caucasian American	Female	77	Arthritis
62364	Caucasian American	Female	72	Arthritis
62368	Caucasian American	Female	71	Heart Disease
63395	Caucasian American	Female	68	Heart Disease
65218	Caucasian American	Female	83	Heart Disease
65631	Caucasian American	Female	68	Hip Arthritis
65794	Caucasian American	Female	78	Leukemia
66891	Caucasian American	Female	78	Arthritis
68641	Caucasian American	Female	73	Diabetes & Hypertension
72305	Caucasian American	Female	87	Heart Disease
72552	Caucasian American	Female	76	Heart Disease
73142	Caucasian American	Female	73	Heart Disease
73794	Caucasian American	Female	71	Hip Arthritis
74280	Caucasian American	Female	76	Hypertension
74500	Caucasian American	Female	68	Arthritis & Immune Problem
75835	Caucasian American	Female	82	Back Pain
75851	Caucasian American	Female	87	Heart Disease
76167	Caucasian American	Female	75	Arthritis
76532	Caucasian American	Female	70	Heart Disease
76990	Caucasian American	Female	75	Mitral Valve Prolapse

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