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# SPIRITUALITY AND EXPECTATIONS OF CARE PROVIDERS OF OLDER PATIENTS WITH CHRONIC ILLNESS IN NORTH CENTRAL FLORIDA

by

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A doctoral thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice in the Department of Nursing in the College of Nursing at the University of Central Florida Orlando, Florida

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# ABSTRACT

A qualitative design was used to explore the use of spirituality and prayer by older adults who have chronic illness and reside in a rural community. Thirteen individuals responded to a flyer soliciting participation in a study of the use of spirituality as part of health care. Participants were at least 60 years of age, had at least one chronic illness and resided in North Central Florida. Twelve participants then responded to six open-ended questions based on an adaption of an instrument used by Dr. Shevon Harvey in her doctoral dissertation. The data was analyzed to identify themes and answer four research questions.

The four research questions were 1) how do older adults living with chronic illness describe spirituality? 2) how do older adults use spirituality while living with chronic illness? 3) how can health care providers assist older individuals with chronic illness to meet their spiritual needs?, and 4) do patients feel that their spiritual needs are being addressed during their outpatient health care? The interview responses demonstrated that several different practices, including prayer and scripture readings as well as adherence to medication, diet, and exercise recommendations were used as coping mechanisms by study participants. The majority of participants want their health care providers to address spirituality and/or refer them to spiritual advisors for counseling. The study showed that some participants stated that their spiritual needs were met, but there were some who did not want spirituality addressed in the outpatient setting.

Four themes were identified, which suggest that 1) spiritual practices were frequently used coping measure for these individual with chronic illness, 2) health care providers are supportive

of their patients' spirituality, 3) participants with chronic illness consider adherence to medication, diet, and exercise a coping measure, and 4) participants with chronic illness want their health care providers to recognize their spiritual needs.

The findings indicated that individuals who self identify as individuals from whom spiritual life is important and who have chronic illnesses and have spiritual needs that can be addressed in the outpatient setting. The findings also demonstrated use of non spiritual coping measures and the importance of health care provider's acceptance of spirituality in this specific population. Recommendations for further research are made.

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# **TABLE OF CONTENTS**

LIST OF TABLES	X
CHAPTER I	1
Introduction	1
Background	2
Specific Aims	2
Research Questions	3
Definitions of Terms	3
Spirituality	3
Faith	4
Health	4
Chronic Illness	4
Assumptions	5
Importance of the Study	5
Summary	5
CHAPTER II	7
Literature Review	7
Spirituality and Health	7

	Summary	8
	Faith and Health	8
	Summary	9
	Health and Well-Being	9
	Summary	10
	Spirituality, Chronic Illness, Faith and Health	10
	Summary	11
	Health Care Providers, Spirituality and Faith	11
	Summary	13
	Spirituality in Outpatient Setting	13
	Summary	14
(	Conclusion	14
Cŀ	HAPTER III	16
]	Design of Study	16
:	Sample	16
:	Setting	16
]	Ethical Consideration	17
	Study Participant Recruitment	17

Instrument
Data Analysis
CHAPTER IV
Study Participants
Reviewing the Themes
Prayer as a Coping Mechanisms24
Adherence to the Treatment Plan as a Coping Mechanism
Health Care Providers and Spirituality
Health care Providers Should Recognize Their Spiritual Needs
Research Questions
How Do Older Adults with Chronic Illness Describe Spirituality?
How Do Older Adults Use Spirituality While Living With Chronic Illness?
How Can Health care Providers Assist Older Adults in Meeting Their Spiritual Needs? 33
Do Patients Feel Their Spiritual Needs Are Being Addressed During Their Outpatient
Health Care?
Conclusion
CHAPTER V 40
Discussion
Definition of Spirituality and Its Importance
viii

Spirituality and Living with Chronic Illness	
Overcoming Barriers through Spirituality	
Health care Providers Promote Spirituality	
Referral for Spiritual Counseling	
Limitations	
Implication for Practice	
Recommendations for Future Research	
Conclusion	
APPENDIX A: FLYER FOR PARTICIPATION	
APPENDIX B: IRB APPROVAL	
APPENDIX C: INFORMED CONSENT	55
APPENDIX D: QUESTIONNAIRE	
APPENDIX E: LETTER OF PERMISSION FOR INSTRUMENT	65
REFERENCES	

# LIST OF TABLES

Table 1	<i>Characteristics of Participants Completing Interview (n=12)</i>	22
	J 1 1 0 ( )	
Table 2	All reported Chronic Illnesses (n=21)	23

# **CHAPTER I**

#### Introduction

As Americans age, the number of individuals who have at least one chronic illness increases. Additionally the number of chronic illnesses each person experiences increases. Chronic illness is a threat to the older population's quality of life. Greenstreet (2006) explains that chronic illness potentially "*shakes up*" and may invalidate a person's world, including their identity. Stressors may cause additional burdens that potentially impact the health of patients. This may cause the patients to use their spiritual support to help them cope with the potential stressors at hand.

A comprehensive health care plan should reflect consideration of physical, emotional and spiritual needs. It is currently unclear whether patients would welcome a discussion of spiritual practices with their health care providers, but many authors suggest that when patients visit their health care providers, they should expect that physical, emotional, and spiritual needs be addressed (Burkhart & Hogan, 2008, Narayanasamy et al., 2004). Despite the fact that many older adults have chronic illnesses, research indicates that they are living longer (De Nardi, French, & Jones, 2005). Many researchers have investigated and found various possible reasons for this longevity. Some attribute it to healthy living (Bassett, Bourbonnais, & McDowell, 2007; Vaupel & Kistowski, 2008), some to biotechnological advancement (Shubha, 2007) and some to genetics (Miller, 2005). Others, however, relate it to spirituality and/or religion (Indrikovs, 2004). Corsentino, Collins, Ericsson, and Blazer (2009) suggest that greater church attendance correlated with decreased cognitive decline. In addition, a study with African American

Protestants showed that church attendance was linked to less depression, loneliness and insomnia, psychosocial factors known to influence health (Gonnerman, Lutz, Yehieli, & Meisinger, 2008).

Another area of research related to spirituality and prayer is focused on complementary and alternative medicine (CAM) interventions. CAM promotes a holistic approach to health care that includes use of the belief system of the patient as a supportive influence on health care outcomes (Barish & Snyder, 2008). Prayer is considered an alternative or supplementary therapy and is commonly used by older adults (Cheung, Wyman, & Halcon, 2007).

#### Background

In 2001, the Joint Commission, an organization that works to help improve the health care of the public, mandated spiritual assessments of patients in hospitals, home care, long-term care facilities, and some behavioral health centers (Provision of Care, 2008). The Joint Commission encourages inpatient facilities to implement methods to meet the spiritual needs of patients and accommodate the patients' rights to spiritual and religious practices. Unfortunately, there are no corresponding guidelines for the outpatient setting requiring that practitioners explore or design plans to meet the spiritual needs of their patients.

#### Specific Aims

The aim of this study is to investigate the experience of spirituality as it relates to wellbeing in older people with chronic illness living in the community. Additionally, it will examine their perceptions of spiritual support from their health care providers and expectations about what the type of support their health care providers should provide.

#### **Research Questions**

This study will explore the experience of spirituality and prayer in an older adult population residing in a rural area in North Central Florida. The research questions include:

- 1. How do older adults living with chronic illness describe spirituality?
- 2. How do older adults use spirituality while living with chronic illness?
- 3. How can health care providers assist older individuals with chronic illness to meet their spiritual needs?
- 4. Do patients feel that their spiritual needs are being addressed during their outpatient health care?

### Definitions of Terms

#### Spirituality

Spirituality is a broadly defined term and encompasses many meanings, which, according to Hummell (2008), involve all aspects of individuals as experienced in relationships with self, others, and a transcendent dimension. Some researchers recognize spirituality as a broad concept, and religion is considered part of being spiritual (Flannelly, Weaver, & Costa, 2004). Kotrotsiou-Barbouta et al. (2006) addressed spirituality and explained that confusion exists due to the lack of an authoritative definition. Spirituality is a difficult concept to describe and is often interchangeable with religion, adding to the confusion. However, Roudsari, Allen and Smith (2007) stated that, "Spirituality refers to beliefs and practices that connect people with sacred and meaningful entities beyond themselves" (p. 142). Roudsari, Allan, & Smith (2007) noted that it is these beliefs and practices that form the relationship with a supreme power and ultimately that give one a meaningful life. Additionally, it has been noted that spirituality is an important factor in the daily lives of adults (Tuck & Thinganjana, 2007). For the purpose of this study, spirituality is defined as an inner peace and strength that is the result of the acknowledgement of the presence of God or a Higher Power, a power believed greater than oneself.

#### Faith

"Faith is considered as an individual's strength of belief in a Higher Power" (Meisenhelder & Chandler, 2000, p. 193). In addition, faith is considered the center of one's belief system. For the purpose of this study, faith is defined as a continuum of belief in God or a Higher Power.

#### Health

Health is considered a mental and physical function (Meisenhelder & Chandler, 2000). Health was defined by the World Health Organization (WHO) as, "A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 2010, p. 100). Dunn (1959) suggested that people originally did not grasp the concept of health, but rather thought of it as the opposite of disease and death. Dunn argued that being well was not just being without disease but was an aspect of life itself. He concluded that "Wellness is not just a amorphous condition, but a complex state that is made up of overlapping levels of wellness" (Dunn, 1959, p. 786). For the purpose of this study, health is defined as optimal functioning of body, mind, and soul within the ever- changing conditions it experiences.

#### Chronic Illness

Chronic illness is generally considered as any health disorder that persists over a long period of time and affects physical, emotional, intellectual, mental, vocational, social or spiritual functioning (Mosby, 2006). For the purpose of this study, chronic illness is defined as a disease or illness that may cause physical or mental disruption over a sustained period of time (e.g. six months).

#### Assumptions

For the purpose of this study, it is assumed that spirituality and spiritual needs may be determined through participants' interviews as can the participants' perception of how their health care providers may or may not contribute to meeting these spiritual needs.

#### Importance of the Study

One of the goals of health professionals is to encourage their patients to live long and healthy lives. As researchers continue to explore spirituality and its role in overall health and well-being, health care professionals will have a way to connect to human experiences and help alleviate the concerns related to spirituality. Some nurse practitioners may not be comfortable doing this, and therefore appropriate referrals or adapting a guiding framework may need to be generated and/or taught to patients and colleagues (Figueroa, 2008). The knowledge obtained from this study will potentially enhance patient care and allow the health care provider to meet the patient's spiritual needs.

#### Summary

According to the Joint Commission, spirituality is an important component of health care and although it is mandated that these needs are met in the inpatient environment, there are no suggestions for the outpatient setting. Research-based evidence supports that spirituality is an important part of health care, and health professionals are now recognizing that addressing patients' spiritual needs is an essential part of patient-centered care (Parsian & Dunning, 2009). If spirituality is as beneficial as some research suggests, then future health care should also focus the research in the outpatient setting.

## **CHAPTER II**

#### Literature Review

This chapter will review the literature relevant to spirituality for older people with chronic illness while exploring their perceptions and expectations of spiritual support from health care providers. It will also examine the effects of how spirituality is believed to affect the health and well-being of an older population. A further exploration will be made to determine what is being done by health care providers to help meet these spiritual needs. A computerized search of CINHAL, Medline, WorldCat, Religious Studies, Pubmed, and Cochrane was performed using the following keywords: prayer, faith, chronic illness, spirituality, well-being, health care providers, and health. The search included the years from 1967-2010.

Much of the literature identified focuses on the older population, their well-being, and the association of spirituality within this population as it relates to their health.

#### Spirituality and Health

A small study consisting of 11 participants explored spirituality in non-religious persons, including people who are not members of an organized religion and who had a chronic illness (Creel & Tillman, 2008). Through a phenomenological approach, the researchers determined that five themes emerged through the data analysis: 1) belief, 2) spiritual awakening, 3) spiritual enhancements, 4) reflective awareness, and 5) disillusionments with religion and religious people (having a negative attitude towards a previous religion or person because of an untoward outcome). The study authors concluded that all persons are spiritual and have spiritual needs regardless of their religion or lack of religious affiliation (Creel & Tillman, 2008).

A study by Kotrotisou-Barbouta et al. (2006) of older persons examined the spirituality of 25 hospitalized patients between the ages of 67-83 years of age. The interviews focused on the patients' thoughts regarding spirituality while hospitalized (Kotrotsiou-Barbouta et al., 2006). They found the following: the patients perceived that spirituality was associated with good health; spirituality was based on their personal experience; and prayer was used as an expression of spirituality. The results of this study were similar to those of previous studies which showed that there was a connection for the participants between spirituality and good health (Harris, Wong, & Musick).

One non-research article examined the connection between spirituality and chronic illness. The analytical article by Kelly (2004) discussed spirituality as a coping mechanism for patients with chronic illness and suggested that spirituality can be powerful as it may provide comfort, resolution and peace.

#### Summary

The reviewed literature suggests that spirituality plays a significant role in the lives of persons with health issues at least in the hospital setting. Spirituality whether encased in religious belief or not appears to provide hope, comfort, and peace when patients are faced with situations that involve their health. More study is needed in how spirituality relates to the experience of chronic illness in the community.

### Faith and Health

A study by McIllmurray et al. (2003) examined faith and psychosocial needs in 354 cancer patients who responded to a questionnaire about chronic illness, health, faith and psychosocial needs. The study subjects were patients 18 years of age or older and who had one of four types of cancers (breast, colorectal, lymphoma, or lung). The study's conclusion were the following: 1) 83% of the participants had a proclaimed spiritual faith, 2) the participants who asserted their faith did not rely on health professionals as much as the participants that did not have faith, 3) the faith-based participants had less need for information about the illness and available services from the health-care providers, and 4) the faith-based participants had fewer unmet needs (McIllmurray et al., 2003).

In a study by Holt, Shultz and Wynn (2009) many participants associated maintaining a healthy lifestyle with the belief that their "bodies are the temple of God." The authors explored religion and health in 400 African American participants. The participants were asked seven open-ended questions related to religion, health, illness, spirituality, prayer, and God. The study's results suggest that there is a positive association between religion and health outcomes.

#### Summary

The reviewed literature explored faith and health in various environments and showed that an individual's faith beliefs may allow him or her to have greater acceptance of the illness. Several authors concluded that there is a positive link between faith and health. There was also a finding that person with strong spirituality may be less dependent upon health care providers to have him or her needs met.

#### Health and Well-Being

A study by Lawler-Row and Elliott (2009) examined spirituality, health, and well-being in 425 participants aged 50 to 95 years of age. The study used five instruments: 1) Spiritual Well-Being Scale, 2) Health Outcomes Scale, 3) Health Behaviors Scale, 4) Social Support Scale, and the 5) Religious Involvement Scale. The researchers concluded the following: 1) healthy

behaviors partially mediate the contribution of religious factors to health, 2) individuals with higher levels of existential well-being have lower physical symptoms and depression 3) church members (Baptist, Methodist, Catholic, and non-denomination) who frequently attend church showed a positive correlation with religion and health, and 4) church membership is the link between religion and health, not frequency of attendance as previously suggested.

In another study, 105 African Americans ages 19-90 were interviewed face to face and more than 80% of the interviewees attributed healing power to God and prayer (Gonnerman et al., 2008). In the analytical review by Kelly (2004), mentioned above, prayer was also described as offering consolation, providing an inward strength and enhancing the ability to deal with difficult situations. The article examined spirituality and stated that there was an integration of mind, body, and soul that may bring forth harmony and unity of health. If there is an unbalancing, then that can lead to spiritual distress. Kelly further explored how health care often neglects the spiritual needs of the patient, but there should be a refocus as spirituality is important to the patient and health care.

#### Summary

Prayer and religion are subsumed within spirituality and are shown to be beneficial to the health state and feelings of well-being. When prayer is initiated, studies have shown that prayer can positively affect health outcomes.

#### Spirituality, Chronic Illness, Faith and Health

Meisenhelder and Chandler (2000) examined faith, prayer, and health in seventy-one Native Americans. The participants were 65 years of age, agreed to participate in a correlation study, completed questionnaires anonymously, and resided in one of two communities in Massachusetts. Seventy-one Native Americans were enrolled in the study. The sample was predominately Christians of different affiliations. According to a self-rating scale, the participants felt they were in good health and had good social and mental functioning. They had a strong belief in God and prayed routinely. The study's conclusions were that age and social support are related to health outcomes and are positive influences on health, the belief in a Higher Power appear to be associated with a positive mental outlook and according to the regression analysis, and that the frequency of prayer is probably a behavioral measurement of strength of faith.

Harvey (2005) conducted a descriptive qualitative study of 414 older adults, age 65 or older, and examined the relationship between spirituality and self-care behaviors among older adults with chronic illness. The study's findings suggest that there is a connection between spirituality and self-management for older adults. According to Harvey (2005), "The in-depth, semi-structured interviews allowed for further explanation regarding the influences on spirituality on self-care practices in regard to managing chronic illness" (p. 89).

#### Summary

The examination of the literature has shown that spirituality, prayer and faith relate to health especially with chronically ill patients. Studies indicate that when faced with obstacles, chronically ill patients turn to their faith in God. Despite physical changes, many continue to perceive themselves as healthy and use prayer and their spiritual faith as coping mechanisms.

#### Health Care Providers, Spirituality and Faith

Health care providers have a distinct opportunity to help meet the spiritual needs of their patients. According to an article by Narayanasamy (2008), it is important for health care

practitioners to determine the role of faith and prayer in a patient's life as this may be part of his or her coping mechanism. Burkhardt and Hogan (2008) used a grounded theory approach with four groups of nurses to examine spirituality in health care with chronically ill patients. The study's participants consisted of 25 nurses taking care of chronically ill patients in various aspects of the health care environment, which included pediatric and adult populations. The findings suggested the following: 1) spirituality is complex to define as there is no theoretical framework; 2) nurses should not approach patients to employ spirituality unless they are invited, however nurses should maintain an environment that allows an invitation to provide spirituality to the patients; 3) once invited, the patient and nurse may use prayer and/or religious rituals to connect to a Higher Power; and 4)the spiritual encounter can cause either a positive (growthfilled) or negative (distressing) effect with the participants. In this study, some participants reported that negative encounters led to leaving the nursing position and/or leaving the profession.

The place of spirituality in nursing care is sometimes a controversial issue because some nurses do not identify with their own spirituality. One study states that, "The concept of spiritual care is evolving with some practitioners maintaining the traditional view linking spirituality with religion; thus medical professionals have not yet come to a consensus" (Shirahama & Inoue, 2001, p. 65). In addition, Agrimson and Taft (2008) propose that nurses lack understanding and education related to spirituality, and this area should be left to religious professionals. However, the American Nurses Association Code of Ethics indicates that nurses should provide an environment that promotes the values, customs and beliefs of individuals (Rath, 2009). One study reviewed 26 nursing theories and determined that the majority of the theories acknowledged spirituality in some manner (Oldnall, 1996). Although controversial, it was argued that nurses should go beyond the standard questioning regarding religious affiliation (Agrimson & Taft, 2009). Furthermore, it is suggested by Narayanasamy and Narayanasamy (2008) that a spiritual history assessment be completed and implemented as part of routine patient care. Many studies show that nurses and nurse practitioners have the opportunity to explain holistic philosophy (Bennett, 2009) and that nurses have the opportunity to establish spirituality as a vital part of nursing practice (Swinton, 2006).

#### Summary

According to various authors, health care professionals are positioned to assist in meeting the spiritual needs of patients. It is important that nurse practitioners and other health care providers increase their level of knowledge regarding spirituality. Although controversial, many researchers agree that it is important for health care providers to address spirituality with the patient.

# Spirituality in Outpatient Setting

With the Joint Commission's influence, multiple articles encourage spirituality at the bedside (Narayanasamy et al., 2004; Narayanasamy & Narayanasamy, 2008; Weaver, Koenig, & Flannelly, 2008). Spirituality is primarily addressed in outpatient care when patients are terminally ill and/or in need of palliative care or hospice (Jones et al., 2007; Lang, Poon, Kamala, Ang, & Mordiffi, 2006; Narayanasamy, 2007; Puchalski, 2007). Only a few articles identified in this literature review addressed this topic exclusively for outpatient care.

One article that involved CAM focused on obstetrics and gynecological patients in an outpatient clinic. The author noted that this was not a common topic of study, so the literature

was limited. Using a descriptive design, a Likert scale questionnaire was implemented, and 250 patients were enrolled in the study. The study's focus was to determine the use of CAM in this environment and concluded that 172 participants used CAM with prayer being the most common therapy used (Pettigrew, King, McGee, & Rudolph, 2004).

Logan and colleagues studied women who were diagnosed with breast abnormalities in relation to their spirituality. A qualitative phenomenological study of 20 Caucasian women age 30-89 completed definitive diagnostic testing that showed a breast abnormality. Two themes emerged from the study. The first theme focused on isolation as the women created a private mental world in which to concentrate on the stressful diagnostic process. During this phase, the women explored their personal strength and their connection to God or their spiritual beliefs. The second theme emerged when the stress became overwhelming; the women sought out loved ones for support and diversion. The study's conclusion showed that nurses can be supportive to the women and their families during the diagnostic phase (Logan, Hackbusch-Pinto, & De Grasse, 2006).

#### Summary

The review of the literature is limited related to spirituality in the outpatient care setting and need to be further explored. No literature focused on primary care settings and when used, prayer is the most utilize among the participants.

#### Conclusion

Advances in technology, use of evidenced-based research, preventative measures, and adherence may be the reason(s) patients are living longer. In addition, some relate advanced age to good genetics, lifestyles, and faith in God. Multiple studies have examined the older population across a continuum, and although their cultures are diverse, many share a faith and belief in God and use their spirituality as part of their lifestyle, especially in the face of chronic illness. As people are living longer, it may be beneficial to further explore the reasons why people are living longer, as well as what impacts not only the quantity of life but also the quality of this increased longevity. Since spirituality has been found to impact both these areas, it might be to the health care practitioners' advantage to learn how they might incorporate spirituality in aspects of health care.

Although the older population may not have optimal health as it is medically defined, they continue to flourish and experience a sense of well-being, and this may be because their spiritual beliefs and practices help to sustain them through troubled times. Unfortunately, the data related to spirituality in the outpatient care setting is limited, which confirms that there is a further need for research in this area.

# **CHAPTER III**

#### Methodology and Research Design

This chapter will present the study's design, sample population, setting, timeline, cost, ethical considerations, instrument, and plan for analysis.

#### Design of Study

This study was a qualitative descriptive investigation of the experience of spirituality in a population of older adults with chronic illness. An interview format was used to explore the participants' experiences.

#### Sample

The study population consisted of individuals aged 60 years and older, who reside in North Central Florida. Participants were recruited via study advertisement posters (Appendix A) and word of mouth. Inclusion criteria specified participants who are at least 60 years old, resided in North Central Florida, had at least one chronic illness and spoke English. Participants were excluded if they did not meet inclusion criteria. Recruitment efforts and interviews continued until the data was saturated. Although it was originally anticipated that the sample size would be seven to ten participants the study yielded twelve participants.

### Setting

Participants were primarily drawn from rural towns in North Central Florida. All participants resided in Marion County. According to the United States Census Bureau (Census, 2000), the Marion county towns of Reddick, McIntosh, and Micanopy have a combined population of 1,677 citizens. The majority of residents was born in the United States, is Caucasian, speaks English only, has graduated high school, is married, and has a median income of almost \$34,000, with a mean income of almost \$45,000 (Census, 2000). At the discretion of the participants, all interviews were conducted in the participant's home except for two participants who met in a different private home.

#### Ethical Consideration

This study was approved by the University of Central Florida (UCF) Institutional Review Board (IRB) (Appendix B). All individuals verbally agreed to participate. Although written informed consent form was included in the IRB application, no informed consent was required by the IRB. The individual interviews were exempt from the written inform consent process since consent was implied by the individual's voluntary verbal agreement to participant (Appendix C). The investigator read the flyer to the participants verbatim to assure that participants were aware they were participating in a research study. Participants were then identified by numbers and letters on the interview transcripts and data not relevant to participants' comments was changed in descriptions used in this report. The data is stored in a secured area, in a locked file cabinet in the investigator's office. According to IRB record retention of data can be retained for up to three years after the study is completed. At that time all tapes, electronic files and transcriptions will be destroyed.

#### **Study Participant Recruitment**

One hundred flyers were printed and distributed by the investigator over the North Central Florida area. After obtaining permission, flyers were placed, given out individually at gas pumps or mounted on the premises of restaurants, supermarkets, post offices, libraries, convenience stores, churches, gas stations, and ice cream parlors in the targeted community. Information about the study was also spread by study participants and church members via word of mouth and community announcements, as some of the participants called friends to encourage them to take part in the study. Representatives of a chain of convenience stores did not allow posting of the flyers with the rational that it was a controversial topic.

#### Instrument

The interview instrument used for this study was adapted from one used by Dr. Shevon Harvey in her dissertation project, *The Role of Spirituality in the Self-Management of Chronic Illness Among Older Adults* (Harvey, 2005). The adapted instrument included a series of six open-ended questions that examined the participant's chronic illness, importance of spirituality, and expectations related to health care providers (Appendix D). Permission has been obtained from the author, Dr. Shevon Harvey, to use and/or adapt this instrument (Appendix E). Content validity was ascertained through the expertise of the thesis committee overseeing this study.

The interviews and data collection were conducted by the investigator in the private homes and were audio-taped recorded and transcribed verbatim. Each interview took 20-60 minutes to complete.

#### Data Analysis

Qualitative analysis of themes and relationships was used to evaluate the interview data. Specific categorization of the data in a systematic pattern was initiated after the interview transcripts were read thoroughly several times and compared to the audio-tapes. Identified errors in transcriptions were corrected by the investigator.

The data from the interviews were analyzed by carefully reading the transcriptions five times each to identify responses, which were then compared for similarities and differences as well as consistencies. A list of themes related to the participants' responses were identified. Verbatim quotes were collected to support the interpretations and allow for validation of the findings. Only the researcher had access to this data. The research advisor had access to the interview transcripts with no identifying information.

# **CHAPTER IV**

This chapter reviews study results and details the process of data collection, sampling, and demographics and measures that were used to ensure reliability of the data.

#### **Study Participants**

Thirteen individuals contacted the researcher, and they were all interviewed in their homes. All participants resided in private homes (Table 1). One interviewee was not included in the final data analysis because that participant spoke in great detail about unrelated information without responding to the interview questions despite many attempts by the researcher to have her focus on the interview questions. The final study participant group consisted of eight African American women, one Caucasian woman and three African American men. Chronic illness was identified in all 12 participants, as this was the criterion for participation in the study. There were 21 chronic diseases named by the participants (Table 2). The collection of data ended after the last participant completed the interviews. After the interviews were tape-recorded, the tapes were given to a transcriptionist with nine years of experience in the health care setting. She stated adherence to Health Insurance Portability and Accountability Act (HIPAA) requirements. She transcribed the data verbatim. The tapes were then retrieved from the transcriptionist and kept in a secure locked location. The transcriptions were read by the researcher to ensure accuracy and congruence with the recorded version. Several of the transcriptions had blank spaces, but after listening to the tapes repeatedly, it was possible to insert all but a small number of the missing words. The final transcripts were also read by the committee chair to verify themes identified by the researcher were reflected in the interview content. Responses to each

interview question were organized according to the questions. This allowed the researcher to focus on each question and its responses during data analysis in addition to reviewing the interviews for themes. After thoroughly reviewing the data multiple times, the information was organized according to the four themes that emerged.

# Table 1

# Characteristics of Participants Completing Interview (n=12)

Characteristics	n	(%)
Sex		
Female	9	75%
Male	3	25%
Age group (years)		
>80	1	8.333%
75-79	0	0.%
70-74	4	33.332%
65-69	6	50%
60-64	1	8.333%
Race		
Caucasian	1	8.333%
African American	11	91.63%

# Table 2

Chronic Disease	n
Acid Reflux	1
Anemia	1
Arthritis	1
Breast Cancer	1
Bronchial Asthma	1
Chronic Back Pain	1
Chronic Knee Pain	1
Chronic Obstructive Pulmonary Disease	1
Chronic Sinusitis	1
Coronary Artery Disease	
Open Heart Surgery	1
Depression	1
Diabetes	9
Gastric Ulcers	1
Gout	1
Hyperlipidemia	2
Hypertension	9
Left Eye Glaucoma	1
Lung Cancer	1
Osteoporosis	1
Peripheral Neuropathy	2
PTSD	1

# All reported Chronic Illnesses (n=21)

#### Reviewing the Themes

Four themes emerged 1) Prayer as a Coping Mechanism, 2) Adherence to the Treatment Plan as a Coping Mechanism, 3) Health Care Providers and Spirituality, and 4) Health Care Providers Should Recognize Their Spiritual Needs. This section will review the themes in detail.

#### Prayer as a Coping Mechanisms

Six of the 12 participants stated that "prayer" or "communicating with God," helped them to cope. Although some participants stated they did this by reading the Bible, listening to spiritual tapes, and/or reciting biblical passages, prayer was the primary spiritual coping mechanism. One participant said:

I think that the sickness that I got, we know we are going to the doctor and the doctor gives us medication for pain, but I never forget about God and I say unto God move me from the sickness, from my body, and heal my body. I know he is a healer and that is what I bet on a lot of times. Like yesterday, I was so sick and just went to praying. I was in the bathroom and I began to talk to the Lord that the sickness would leave, and I felt better, but I went back and laid down. And, I have him (God) that did that because I asked him to. He said, "ask, and you shall be given."

And I was given for a little while. He moved that little bad feeling I had. Another participant who uses prayer as a coping mechanism and had kidney failure stated, "The good Lord brought me back."

Yet another participant said,

Yes, and I was praying to God, for him to heal me, you know, heal my body, all the time, everyday, I said, I know everybody speaks to you. But, he is our keeper and I go through the day like that sometimes and sometimes when I pray that to God ...

When faced with discomfort, she communicated with "God" and was content that the "sickness" left, if only for a little while.

One participant prayed in her physician's office even though she did not get a response. She states,

You know sometimes, I go into the doctor's office and they come in and check my pressure. And I say oh Lord have mercy, help me. They don't say a word.

When you say oh my Lord, they don't say nothing (sic).

In addition, the kidney functions of one participant improved and lastly, another participant stated she prays every day for healing. These participants with chronic illness used prayer as a coping mechanism during challenging times.

#### Adherence to the Treatment Plan as a Coping Mechanism

Many of the participants stated that adherence to the treatment plan and/or the combination of prayer and adherence were used as coping mechanisms. Five participants specifically stated that taking their medications, "doing what the doctor said," and/or diet and exercise helped them to cope with the problems related to their chronic illness (es). One participant stated "I don't think about it (disease) as long as I take my medications and I listen to my doctor." He further stated

I have to watch what I eat and what goes into my body and I know I have to exercise. Believe me. I walk about eight to nine miles every day that I can...which is five days a week. Another participant with chronic back pain after multiple surgeries stated,

And, I put him (God) first because if I do the things that I need to do, if I eat right and if I exercise, see that is my problem, because of my back, I cannot walk very far and so, I cannot exercise to keep the weight down like it needs to be. So, therefore, it causes my back much more problems. But, I know that the doctors are working with me (sic) know with my medication. As a matter of fact, I am going today to try to get me something so that I can walk a little more. I have had physical therapy and that did very little, because the back is just in bad shape.

Even though they were faced with multiple ailments related to chronic diseases, the participants tried to be active, adhere to a healthy diet and take their medications as recommended by their health care providers.

#### Health Care Providers and Spirituality

The third theme observed was related to health care providers and their response to their patients who are spiritual. Some of the participants stated that they had interactions with their health care providers directly related to their spirituality. One stated that her surgeon prayed with her prior to having a surgical procedure. She said, "It gave me a very good feeling" and further stated,

You see, a lot of doctors don't believe in praying with you and having the spirit of the Lord in them, but when you get one, it is good, you know they got the spirit of the Lord in them.

She was happy that her spirituality was addressed at a very critical time in her life. Another participant shared that after a procedure she went for a follow-up.

You know what; I had an instance where I was talking to my cardiologist, after I had the surgery and everything, and I was thanking him for all the help he gave me. And, the first thing he said to me was thank the man upstairs. And, right then,

I knew I had an opening to discuss my spirituality with him.

Yet another participant was grateful that she was able to talk to her provider related to problems that she was facing. She stated that the physician asked her, "Have you prayed about it?" One participant had this to say about her health care provider,

When I can talk to my doctor about God, I feel very comfortable because he knows the same things that I know because he knows the God that I know and I definitely question him about the God that he was talking about when we started this spiritual relationship. And, so I know that he knows the God that I am talking about, you know, it is not like he is dealing with some idol God or some foreign God and I do not know it when he talks about Jesus Christ, then I know that he knows that I know what is what.

These participants were excited as they discussed the above scenarios. They were faced with challenging situations, and their health care providers were there to support them at a very stressful time in their lives.

#### Health care Providers Should Recognize Their Spiritual Needs

The fourth theme was the participants' desire to discuss spirituality with their provider and/or be referred for spiritual counseling. Although five of the twelve participants did not want spiritual interaction from their providers, the majority thought it was beneficial. One participant stated that he would like his health care provider to discuss God with him, but they (doctors) only talk the "medical thing." Several participants agreed that it would be "nice," "good idea" or "comforting." One participant stated that the time for referral should be when the person is first diagnosed with a disease, while another participant thought that a referral should take place when the patient was diagnosed with a terminal illness. Another participant stated,

I guess if I have a grave disease or something. Because I believe God gave the doctors the knowledge and the power to heal. If he thinks I should go to one, I will go.

#### **Research Questions**

This section will review the four research questions for this study namely 1) How do older adults living with chronic illness describe spirituality? 2) How do older adults use spirituality while living with chronic illness? 3) How can health care providers assist older individuals with chronic illness to meet their spiritual needs?, and 4) Do patients feel that their spiritual needs are being addressed during their outpatient health care? There will also be a discussion regarding adherence as a coping mechanism. Five of the participants referred to methods that have helped them to cope with problems related to chronic illness.

#### How Do Older Adults with Chronic Illness Describe Spirituality?

The first research question asked how older adults living with chronic illness described spirituality. Because no specific question asked the participants to define spirituality, no definitions of spirituality emerged from this data. However, some of the participants used the term spirituality during the interview process when discussing various aspects of their lives. One participant with coronary artery disease who was status post coronary artery bypass surgery stated that the only way she can manage her illness was, "with the spirituality of the Lord." It

was common for participants to give short excerpts regarding specific incidences in their lives where spirituality was their way of life. One participant described spirituality as being, "…like hope or relaxation." Another participant said, "… It just does something to the spirit, to (the) mind and body." Another participant stated, "Well, because I believe in God and a lot of things that you pray for, you usually may not get them right then, but they come on (sic) time."

The participants described how spirituality affected their lives even when challenged with unforeseen obstacles like the death of loved ones, physical pain, and life-changing surgical procedures. Spirituality encompassed some of the participants' lives and was not confined to their home life but extended into travels, hospital stays, and physician's offices.

#### Importance of Spirituality

All 12 participants stated that spirituality was important in their lives as consistent with the student description on the recruitment flyer. When the participants were faced with individual obstacles, it was common to use their spirituality to confront the challenges. One participant whose mother died when he was a child said he "was a product of the streets," expressed why spirituality was important to him. "I know someone up there took care of me, I did not do it on my own."

Another participant with a history of cardiac disease stated she was healed of a heart condition while visiting the Holy Land. This participant said previous testing had confirmed the disorder, but multiple tests including a cardiac catheterization, performed after her declared healing, were fine. She stated the doctor informed her husband that it seemed to be a miracle as there were no enlargements or problems with her aorta. She repeatedly stated that spirituality was very important to her. The participants openly expressed how their spiritual relationship and spirituality was so important to them. One participant stated that, "spirituality was so important that my whole life was based on it." Another participant stated, "I was raised up going to church and I thought that was the best thing that ever happened to me." Another participant who lived alone hugged herself and threw her arms in the air as she stated the following,

It's so hard to me because I know without God in my life I would not be able to endure the pain that I have and with him, I could talk to him and he comforts me through the pain and stuff, so spirituality is very important in my life.

When some of the participants answered the questions they spoke with excitement and used body language to help express their feelings. One participant used her arms as if directing an orchestra as she stated,

And, then I read the 91st Psalm that I am in his arm. I am under the shelter of the almighty. I know that he is here all the time. I do not have to ring him up and wait until somebody has to get off the line. See, he is an all, all present God. He is omnipresent. He is everywhere. He knows everything, even before I ask him, he knows what my problem is. But, he wants us to acknowledge him by asking him to do the things that he promised us that he would do for us.

Others became misty eyed as they reflected on their spirituality and their connection with their Higher Power. Spirituality was the most important thing in one participant's life, which was living with a lung disease. She stated she was greater than 80 years old. The older adults with chronic illness described spirituality in different ways, but they all seemed to have a connection with their Higher Power that allowed them to cope with their chronic diseases. The similarities of the participant's definitions and link to spirituality were interesting as the commonality seemed to be faith based.

#### How Do Older Adults Use Spirituality While Living With Chronic Illness?

The second research question asked how older adults use spirituality to cope with chronic illness. The participants had various ways of using their spirituality to include prayer, reading the Bible, listening to spiritual tapes, family teaching, church affiliation, family and adherence to recommendations from their health care provider.

Prayer was the most common measure identified by the participants. It was used at various times and for various reasons, and was identified by some as, "communicating with God." One participant used prayer when sitting in her physician's office, while another openly talked to God while vacationing in the Holy Land. Prayer was often used when pain was a factor.

Another spiritual measure used was reading the Bible. When the participants were faced with challenges, such as insomnia, they would read the Bible. One participant described the following approach when she encountered pain and could not fall asleep at night. She stated, "I grab my Bible…I get to reading and I am going to read my Bible until I get sleepy and the pain just sort of goes away." This participant used the Bible passages to manage the pain that was caused by having a chronic disease.

Yet another means of diverting attention from pain was through listening to spiritual tapes. One participant stated the following,

To me it does not really bother me, because I really don't dwell on it because

like I said with spirituality, for whenever I get to hurting I can go to my Bible or I could put on a tape or whatever, you know, and I concentrate on that and not on my sickness.

In addition, some relied on family teachings and church affiliation when faced with the challenges of chronic disease. A participant with poorly controlled diabetes with frequent episodes of hypoglycemia stated,

I play the guitar but I tell them a lot of times, they don't know me otherwise. I told them in church yesterday and brother "John Doe" (name changed for privacy), my nephew that we need to start recognizing God in anything we do and things will go better with us.

Another participant with lung problems stated that her family and friends help her to cope by being supportive. She continues to go to church routinely and pays her tithe, but states she is not as active in other church activities.

Although the participants had chronic diseases, they continued to rely on their faith in their Higher Power. One participant said she wished she did not have the diseases; however she felt that, "God puts people through sickness to see if they stand." She concluded by saying, "You (sic) got to be strong in the Lord for him to carry us through the sicknesses that we go through."

Various means of spirituality are incorporated into the lives of the participants which help them to endure the challenges of having a chronic illness. Focusing on these measures allowed for pain control, comfort, and peace, enabling one participant to fall asleep. Study participants seemed to use spirituality in various ways while living with chronic illness. Prayer and talking to God appeared to be a common coping mechanism. How Can Health care Providers Assist Older Adults in Meeting Their Spiritual Needs?

The third research question asked if health care providers could assist older adults with meeting their spiritual needs. The participants' seemed to welcome the questions and answered in a wide variety of ways. Many felt there has to be a more inclusive relationship between the provider and the patient that also incorporate spirituality. While five of the twelve participants did not feel spirituality was an issue to be addressed in the physician's office, others felt that their health care providers should address both spiritual and physical needs as they arose.

According to some participants, their health care providers incorporated spirituality with their outpatient visit as well as during surgical procedures while hospitalized. Some agreed that referral to another source should also be incorporated into care. In order to summarize the responses related to this particular research question it was important to first determine if patients wanted their health care providers to address spirituality.

#### Participant Views Regarding Health care Providers and Spirituality

During the interview process, the participants were asked if they expected their health care providers to offer spiritual guidance or refer them to another provider to meet their spiritual needs. Some of the participants felt that it would be good to have their provider address their spiritual needs.

One participant stated that,

A lot of things are not medical; some things are spiritual that needs to be dealt with. So, it, you know, would be good if medical doctors and nurses were able to communicate in that way...now, listen, let me tell you something! Ministers are not the only people that God have empowered to do these things, to be witnesses, to give spiritual guidance, ministers are not the only ones. God's spirit lives and abides in every believer. Because the Bible tells me the moment that I accept Jesus Christ as my savior, the holy spirit comes in, seals that salvation, and so that there are hundreds and thousands of Christian people, not doctors, Christian people walking around. So, therefore they have the same power that God has given to ministers, only they got called to be preachers and ministers and we are (sic) all have a ministering spirit.

This participant was adamant that all professionals should address spirituality with their clients.

Other participants said while they thought it was a good idea for their health care providers to address spirituality but they did not expect it. One participant stated that because her doctor had prayed with her, she expected to have her spiritual needs addressed, to include referral if needed. Many participants were receptive to referral for spiritual counseling if needed, with one stating that it may be a good idea because they may help her deal with pain.

According to some of the participants, their providers have incorporated spiritual care into their routine visits. One participant stated,

Well, I am blessed because I have a doctor and he is from India and he is a Christian... and, sometimes when I go in and I want to complain about something and he will say, now, Mrs. Alphabet Soup (sic), you are a minister, did you pray about this? Because, I do not want to give you something that is going to make you worse than what you are. And, I just love him for that because he has been through with the death of two children, divorce of my husband and all of my illnesses. I have been with him probably 12 or 13 years now. Other participants shared individual stories about primary care providers, specialists and surgeons that addressed spirituality.

Some participants did not relate such experiences, and one participant in particular felt that there should not be a mixture between the medical and spiritual. He said that he personally separates the two. His rationale was,

I never tried it, but him being from India, I think he is either Muslim or what other religions they have in the Middle East. I am Christian, which is catholic and he might (be) Hindu, he might be Muslim, he might be you know other things.

So, you know, we have never really crossed over.

In addition, other participants said that they were not receptive to having their medical providers approach this subject. One participant who did not feel spirituality should be addressed in the community setting, described the following,

I don't because I just don't think they all are (spiritual). I think that their

background is so scientific that they probably have to have a strong faith;

I do not know how much they rely on God and Jesus to assist them in their practice.

I think that they probably think it is just their own skills.

Do Patients Feel Their Spiritual Needs Are Being Addressed During Their Outpatient

#### Health Care?

The final research question asked if the participants' spiritual needs are being met at their outpatient health care visit. Although there was no direct question on this topic, the answers

from several of the interview questions helped to answer this research question. The participants spoke openly regarding the spiritual encounters or lack thereof with their health care providers.

#### Real Experiences

One participant who was diagnosed with Post Traumatic Stress Disorder (PTSD) stated that spirituality was introduced into his life during childhood. Due to his disease state, he was referred to a psychiatrist. He shared the following information,

Well, one time I went and I got down to two hours of sleep at night because I was having so many nightmares about being in war in Vietnam and my son had got killed and all like that and that is when he (his psychiatrist) asked me whether I was a religious person. And, I told him I was raised in Christianity and I told him that sometimes when I get really depressed and everything, I did not want to take any medications or anything, but for depression I just say a prayer to myself. And, he told me that he does the same thing.

Another participant stated that when she walked into her physician's office for the first time, she was excited to see a feature she found surprising.

There was a picture hanging on the wall in the office where every patient would be able to see it, and praying in the picture, of a women evidently, very ill, in bed, hovering over her was some members of her family and the doctor with his stethoscope and you can see by the grave expressions on their face, you could tell that she was seriously, perhaps terminally ill and standing in back of the doctor, in a faint, faint depiction was Jesus standing over the shoulder of the doctor. And, I told him and his nurses, I love that picture. And, he has told me that he is a Christian...

Although these two participants shared their experiences, six of the participants have never had a spiritual interaction with their health care providers. On the other hand, two participants did not think that the health care environment is the place to address spiritual concerns. One participant stated, "Well, I can talk to my God myself."

Although controversial, the majority of participants want their health care providers to address their spiritual needs and/or refer them to a spiritual counselor.

#### Adherence and Spirituality

When patients are counseled at their outpatient visits, they are frequently encouraged to adhere to a specific diet, exercise, and take medications as prescribed. In addition to spirituality, some participants coping measures were related to adherence. Five study participants mentioned that eating right, exercising, and/or taking medications was also important. When one participant was questioned regarding coping with chronic illness she said,

I take my medication. I try to eat right. This is all new, trying to exercise right and eat the things that I am told to eat. And avoid stress. I think I would like to see more health care providers get involved with the patients on a spiritual level, even as well as medication and the benefits of care that they give and you know, to help the patient understand the procedures that they are going to need, routine procedures and spiritually based as well.

One participant said he is able to cope with his chronic diseases because he trusts his doctor. "I take my medication and do what the doctor says." Another participant said there are two ways that he is able to cope, "The Lord is one thing and taking the medications that they give me."

These individuals saw adherence to be a part of their responsibility. Their well-being did not come just from their spiritual relationships.

#### Conclusion

The purpose of this study was to examine spirituality in older persons with chronic illness. The participants agreed to be interviewed either in their home or at a local restaurant or business; however, they all were interviewed in their homes. After the interview the responses were transcribed by a professional transcriptionist. The transcriptions were then analyzed by the lead investigator and read by the committee chair. Four themes emerged: 1) Prayer as a Coping Mechanism, 2) Adherence to the Treatment Plan as a Coping Mechanism, 3) Health Care Providers and Spirituality, and 4) Health Care Providers Should Recognize Their Spiritual Needs.

These four themes were applied to the research questions posed by the investigator and discussed individually. The first question defined how the participants describe spirituality. They reported that spirituality is important in relation to their chronic illness and used prayer, reading the Bible, and listening to spiritual tapes as the most common methods of communicating with God, Jesus, or a Higher Power. The second question determined that older adults with chronic illness use spirituality to help them overcome pain and/or other obstacles. They also reported several coping measures related to spirituality that was used to manage their chronic illness. The third question examined how health care providers assist older individuals with chronic illness to meet their spiritual needs. The respondents conveyed a variety of responses by their health care providers ranging from active participation in spiritual practices with the patient to no response at all. A majority of the participants felt referral for spiritual care

was a valuable option, but none reported receiving this care. The final research question explored how the participants thought their spiritual needs were being addressed during their outpatient health care. Although not all participants reported attention to spirituality by their health care providers, they all felt this was an important part of the outpatient visit and would appreciate this consideration.

The themes identified showed the importance of spirituality in participants with chronic illness. Although there was an occasional negative statement about addressing spirituality in the community setting (e.g., concerns if the religion of the provider differed from that of the participant), the majority of participants were receptive. Results will be compared to the literature and implications for practice will be addressed in the following chapter.

#### **CHAPTER V**

#### Discussion

This qualitative study examined the use of spirituality by older adults with chronic diseases and their expectations of their health care providers related to spirituality was used. The study's purpose was to describe the use of prayer and spirituality by older adults with chronic illness and to explore their perceptions and expectations of their health care providers in addressing their spiritual needs in the community setting. The data were analyzed after being transcribed from audio-taped interviews. The data analysis yielded several themes that were used to answer four research questions. This chapter will compare results to the literature and research topics, explore the study's assumptions and limitations, and present recommendations for practice and suggest future research needed in this area.

#### Definition of Spirituality and Its Importance

Spirituality has many meanings. As Meraglavia, (1999) states: "Spirituality is a term that encompasses many definitions and is abstract and elusive" (p.18). Although no specific definitions were stated by the participants during the interviews, the participants used many terms to personally express spirituality. Some participants stated that spirituality was a factor that originated from childhood as their families were spiritual and frequented church. All of the participants revealed that spirituality is important in their lives and is used in various ways. Several participants adamantly reported that spirituality is the most important aspect of their lives, with one participant stating that it was "major." The participants relied on spirituality to deliver them from sickness, comfort them through trials and help relieve pain. This was similar to the findings by Gonnerman et al.(2008). Despite having a chronic illness many of the participants seemed to accept their illness and resist negativity. That study result is similar to that found by Yoon (2006), who studied rural patients and the importance of their spirituality. This study found that, elderly patients that trust in God and rely on Him for strength and comfort seemed to have greater life satisfaction.

#### Spirituality and Living with Chronic Illness

Chronic illness can impact a person's life and can lead to deterioration (Greenstreet, 2006). Participants used their spirituality to help buffer the associated symptoms of the chronic disease(s). The majority of participants described spiritually based coping measures to help deal with the disease state. One participant who was diagnosed with breast cancer stated that she "talks to my God and does what the doctor say" to help her cope with her illness.

No one discussed death. Rather, participants concentrated on the measures that helped them to cope with living with chronic illness. The coping measures varied, but each participant discussed the relationship of spirituality with coping. According to Harris, Wong and Musick (2006), individuals from no other country use spirituality as a coping measure more than those in the United States of America.

#### **Overcoming Barriers through Spirituality**

Living with chronic illness can present barriers that can affect the quality of life. "The prudent individual with chronic disease must employ strategies to reduce the impact of the illness (Adegbola, 2006, p. 42). Many participants used spirituality when they were in pain, or for healing. One participant read the Bible which she found promoted relaxation so that she could fall asleep. There were similarities in responses of the participants who mentioned praying to their Higher Power and receiving strength, pain control, or other measures of comfort as a result. A cross sectional survey that examined participants who either prayed or did not pray for health found that 47.2% prayed for health and 90.3% of the participants believed prayer improved their health (Yoon, 2006). Patients that communicated with their Higher Power or used other means of spirituality seemed to have better quality of life, which correlates with the literature. Adegbola (2006) examined spirituality and quality of life in the chronically ill person by means of a theoretical review and found that spirituality and quality of life were inseparable.

#### Health care Providers Promote Spirituality

Several of the participants discussed interactions with their health care providers where spirituality was discussed. The participants stated that their health care providers prayed, listened, encouraged, and/or examined them to help meet their spiritual needs. These actions were reported as things that made the participants feel good. This is congruent with a published phenomenological qualitative study that examined practitioners who assessed spirituality with their patients. That study indicated that when providers promoted a genuine, nonjudgmental atmosphere, it allowed provision for spiritual care to be implemented (Tanyi, McKenzie, & Chapek, 2009).

Although spirituality was welcomed in the community setting by most participants 5 of the 12 participants did not agree. They felt that spirituality should not be addressed in their provider's office as "the two should not be mixed." One of the participant's rational was related to possible conflict of religions. Previous studies have discussed potential barriers to health care providers addressing spirituality. One study showed that the key to administering spiritual care is educating the primary care providers (Tanyi et al., 2009).

42

#### **Referral for Spiritual Counseling**

The majority of participants thought it would be beneficial for health care providers to refer for spiritual counseling with several participants stating that they expected it. They also stated that referrals for spiritual counseling should take place at the beginning of an illness. One of the participants felt that referral may help her deal with the pain related to her chronic illness. As some health care providers may not feel comfortable discussing spirituality with their patients, referral may be an option to help meet the patient's spiritual needs. The participant who prayed without her provider's acknowledgement may have benefitted from a referral for spiritual counseling rather than being ignored.

Several researchers suggested that referral to a hospital chaplain or minster may be beneficial; however, this data was based on a study of hospitalized patients only (Galek, Flannelly, Koenig, & Fogg, 2007). No studies addressing this topic in the outpatient setting were identified. However, content of these interviews indicate such referrals would be desired by some individuals.

#### Limitations

Limitations of this study are multiple. First, there was no question that asked the participants' definitions of spirituality. Although participants described spirituality, a definition may have been more effective to answer the first research question as the participants expounded with their remarks. Also, the flyer targeted participants who felt that spirituality was important to them. Perhaps if this was not so defined non-spiritual persons would have been included in the interview, and this would have broadened the type of responses.

Another limitation was that the researcher unintentionally made remarks after the participants' statements that could have affected the study. The remarks were simple, e.g., "Okay and Good," but could have influenced subsequent responses.

Another limitation was that the majority of participants were African Americans with only one Caucasian. If the study population was more varied, (cultural, race, religious belief, or nonbeliever), the results may have provided a much broader practice application as the research has shown that African Americans are more spiritual and use prayer more than any other race (Taylor and Chatters, 1991). The study may also be limited by the fact that the participants are not necessarily representative of the community population, but may instead be a subset.

An additional limitation was that there was no question that allowed the participants to expound on their chronic illness or the potential complications. Some of the participants did provide information regarding their illness even though a direct question was not asked.

Lastly, the town in which the researcher resides was one of the targeted towns in the North Central Florida area. Three of the participants were known to the researcher which could have affected the responses of those participants. However, while the participant and researcher were known to each other because they reside in the same small community, none had a social relationship to the investigator.

#### **Implication for Practice**

The study findings have implications that can be used by the health care providers in the community setting based. These are the importance of health care providers to 1) address spirituality, 2) obtain educational enhancement about how to assess for and address spiritual

needs, 3) use an assessment tool, and 4) obtain a list of local spiritual advisors to whom they can refer patients for spiritual counseling.

Addressing spirituality in the outpatient or community setting should be done by providers since spirituality can be important to patients. Health care providers should include this assessment in the same manner that they would when discussing, for example, diabetes, hypertension, and/or chronic illness. If the patient's diabetes is not controlled, practitioners examine the cause by asking, "Are you adhering to a diabetic diet?," "Are you exercising?," and "Are you taking your medications?" These assessment questions tend to help the patient and providers identify factors relevant to the problem. If there is a spiritual issue, the same type of questioning format should be applied. For example, the provider could say, "You are not your usual self, is there a problem?," or "What helps you to cope?," "I see from your demographics sheet that you are spiritual, have you talked with your priest?," or "How can I help you meet your spiritual needs?" As noted in the review of the literature, Agrimson and Taft (2009) suggested that nurses go beyond the standard questions of addressing religion.

Many times, health care providers may not feel comfortable addressing spirituality (Narayanasamy & Narayanasamy, 2008). Some providers may face other barriers (e.g. time constraints or conflicting religious beliefs). Completing continuing education programs is a step providers can take to address this. Health care providers constantly maintain their continuing education to stay abreast of the newest research. In addition, if a patient presents with a disease or symptom that is not familiar, the practitioner tends to use resources, such as books, media, or another practitioner to ensure that the appropriate steps are taken to address the issue at hand.

45

Health care providers can go to educational classes and take steps to increase their level of knowledge regarding spirituality. Studies show that as part of their curriculum, some medical students are educated regarding addressing spiritual needs of the patients (Helming, 2009). Tanyi's (2009) study identified barriers to meeting the spiritual needs of the patient; however, the practitioner was able to overcome the barriers, e.g., as time restraints and not wishing to intrude on the patients' personal spirituality. They were then able to focus on meeting the patient's needs.

Providing a spiritual assessment tool may help promote spiritual care. The use of a tool may also allow patients to accept or opt out of spiritual care. As identified in the review of the literature, Narayanasamy and Narayanasamy (2008) suggested that a spiritual history assessment be completed and implemented as part of routine patient care. A patient should be able to opt out by checking the appropriate box on the tool since, as demonstrated in this study, not all patients are receptive to having their spiritual needs addressed by their providers.

Spiritual needs should be documented in the medical records for continuity of care as suggested by Tanyi et al (2009).

If a provider is not comfortable in addressing issues related to spiritual needs, patients' referrals to a spiritual counselor should be considered. To facilitate this, providers can develop a list of local spiritual advisors (e.g., priest, ministers, pastors, counselor, etc.) for potential referrals. The list can be generated from patient's demographic sheets or from the local religious community. Many times the local newspaper (especially on Sundays) provides a list of local ministers, priest, associates, etc. This list should be devised and kept with the other referral sheets (e.g. orthopedics, general surgeons, etc.). This may aid in the ease of making referrals.

46

As spirituality is important to the patients, the suggestions as noted should be considered by the health care providers to assist in meeting the spiritual needs of the chronically ill patients in the community setting. It is important that the provider not force spirituality on the patient; however, if presented, spirituality should be addressed(Meisenhelder & Chandler, 2000; Narayanasamy & Narayanasamy, 2008) . In addition, the health care provider should not be forced to include spiritual care with the patient (Narayanasamy & Narayanasamy, 2008). Referral for such care can be implemented.

#### **Recommendations for Future Research**

It is recommended that subsequent research be implemented with a sample of participants who do not identify themselves as being spiritual. It is also recommended that research further explore methods to teach health care providers how to assess for spiritual needs, develop a screening tool that addresses spiritual needs, and employ methods so that the patients are comfortable with discussing their needs. It is also suggested that further research be implemented to explore the benefits of having health care practitioners with the same belief system versus those of another belief system.

#### Conclusion

The study explored spirituality in a population with chronic illness. After exploring the data it was determined that spirituality is important to the participants in this study and should be addressed during routine visits. The participants defined spirituality in personal terms and used multiple coping measures to help overcome barriers. It is important that health care providers be aware that patients have spiritual needs that should be addressed and seek ways to provide spiritual care when needed. Although all participants did not agree that providers needed to be

the ones to address spiritual needs in the community setting, this was expected with some of the participants. By implementing a spiritual assessment tool, the patients' spiritual belief, religion, or lack thereof could be identified and addressed accordingly. In addition, a general assessment can allow the experienced health care provider to identify needs even if they are unspoken.

### **APPENDIX A: FLYER FOR PARTICIPATION**



# Is your spiritual life important to you? Are you sixty years of age or older? Do you have a chronic illness? Then you may be able to be part of a research study.

**WHO:** Lead investigator Myra Sherman MSN, FNP-BC, from the University of Central Florida will be completing a study to fulfill completion of graduation in the Doctorate of Nursing Program.

**WHAT:** A study that consists of answering questions. Responses will be kept private according to the Institutional Review Board of UCF.

**WHY:** The purpose of the study is to increase the knowledge of the use of spirituality for older persons with an illness.

**Criteria**: To be part of this study, you must be 60 years of age or older, have a zip code in the North Central Florida areas, speak English, have at least one chronic illness and be willing to sign a form to be in the study. You must be able to travel to a local meeting place or allow Myra to come to your home. Please allow about 30-60 minutes for the interview. You will be taped recorded.

Contact Person: Myra Sherman 352-229-4533 and Diane Wink EdD, FNP-BC, ARNP, FAANP (407) 823-5440.

## **APPENDIX B: IRB APPROVAL**



University of Central Florida Institutional Review Board Office of Research & Commercialization 12201 Research Parkway, Suite 501 Orlando, Florida 32826-3246 Telephone: 407-823-2901 or 407-882-2276 www.research.ucf.edu/compliance/irb.html

#### **Approval of Exempt Human Research**

From: UCF Institutional Review Board #1 FWA00000351, IRB00001138

To: Myra D. Sherman

Date: January 05, 2011

Dear Researcher:

On 01/05/2011, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Project Title:	Spirituality and Expectations of Care Providers of Older Persons
	with Chronic Illness
Investigator:	Myra D Sherman
IRB Number:	SBE-10-07333
Funding Agency:	
Grant Title:	
Research ID:	n/a

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Joseph Bielitzki, DVM, UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 01/05/2011 11:40:35 AM EST

Joanne muratori

**IRB** Coordinator

**APPENDIX C: INFORMED CONSENT** 



#### Spirituality and Expectations of Care Providers of Older Persons with Chronic Illness

#### **Informed Consent**

Principal Investigator(s):	Myra Sherman MSN, FNP-BC
Sub-Investigator(s):	Susan Chase, PhD, FNP Rose M. Rivers, PhD Elizabeth Rash, PhD, FNP
Faculty Supervisor:	Diane Wink, EdD, FNP-BC, ANRP
Investigational Site(s):	At a local restaurant or similar site or at the participant's home

**Introduction:** Researchers at the University of Central Florida (UCF) study many topics. To do this we need the help of people who agree to take part in a research study. You are being invited to take part in a research study which will include about 10 or more people in the North Central Florida area. You have been asked to take part in this research study because you are over 60 years old, have a chronic illness, reside in North Central Florida, English speaking and believe in spirituality.

Myra Sherman MSN, FNP-BC is conducting the research: The researcher is a doctoral student at the University of Central Florida, College of Nursing. Because the researcher is a graduate student she is being guided by Dr. Diane Wink, a UCF faculty supervisor in the College of Nursing.

#### What you should know about a research study:

- Someone will explain this research study to you.
- A research study is something you volunteer for.
- Whether or not you take part is up to you.
- You should take part in this study only because you want to.
- You can choose not to take part in the research study.
- You can agree to take part now and later change your mind.
- Whatever you decide it will not be held against you.
- Feel free to ask all the questions you want before you decide.

**Purpose of the research study:** The purpose of this study is to investigate the experience of spirituality in a population of older adults with chronic illness and how health care practitioners can assist them in meeting their identified spiritual needs. Chronic illness may present challenges to many older adults by limiting their ability to continue their pre illness lifestyle. The literature indicates that people who actively engage in spiritual practices are better equipped to manage the life changes accompanying chronic illness. The expectations of older adults with chronic illness in regard to the use of prayer and spirituality by the health care provider have not been studied to the fullest extent. The Joint Commission's focus on consideration for the patient's spiritual belief's suggest that health care providers are required to be prepared to meet spiritual needs.

What you will be asked to do in the study: Sign a consent stating that you are informed regarding the potential risks and benefits; the researcher (Myra Sherman) will inform each participant of his or her right to terminate their participation at any time without penalty, prejudice, or loss of benefits to which the participant may be entitled. A demographic form will be completed to assign you a specific code that will allow privacy of your information. You will be asked questions regarding your chronic illness, spirituality and your health care provider (e.g. you physician, nurse practitioner, etc.). The interviewing process will be audio taped and will take 30-60 minutes for completion and will take place at a local restaurant or at your (the

participants) home. After the completion of the study all audiotapes will be destroyed. The researcher will guide you through each step of the process and you will be free to ask question if you do not understand.

You do not have to answer every question or complete every task. You will not lose any benefits

if you skip questions or tasks.

**Location:** At the discretion of the participant, interviews will be conducted at your home or at a local area in North Central Florida.

**Time required:** We expect that you will be in this research study for one visit that will last approximately 30-60 minutes.

**Audio taping:** You will be audio taped during this study. If you do not want to be audio taped, you will not be able to be in the study. Discuss this with the researcher or a research team member. If you are audio taped, the tape will be kept in a locked, safe place. The tape will be erased or destroyed when the study is completed.

**Risks:** There are no reasonably foreseeable risks or discomforts involved in taking part in this study.

**Benefits:** There are no expected benefits to you for taking part in this study. We cannot promise any benefits to you or others from your taking part in this research.

**Compensation or payment:** There is no cost for you. There is no compensation or other payment to you for taking part in this study.

**Confidentiality:** We will limit your personal data collected in this study to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of UCF.

**Study contact for questions about the study or to report a problem:** If you have questions, concerns, or complaints, or think the research has hurt you, talk to Dr. Diane Wink, College of Nursing, (407) 823- 5440 or Dr. Susan Chase, Associate Dean, Graduate Affairs at (407) 823- 3079 or by email at schase@mail.ucf.edu.

**IRB contact about your rights in the study or to report a complaint:** Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901. You may also talk to them for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You want to get information or provide input about this research.

**Withdrawing from the study:** If you decide to leave the study, contact the investigator so that the investigator can remove your personal information from her list (e.g. contact number and/address). The person in charge of the research study or the sponsor can remove you from the research study without your approval. Possible reasons for removal include not meeting the study's criteria.

Your signature below indicates your permission to take part in this research.

#### DO NOT SIGN THIS FORM AFTER THE IRB EXPIRATION DATE BELOW

Name of participant

Signature of participant

Signature of person obtaining consent

Date

Date

Printed name of person obtaining consent

# **APPENDIX D: QUESTIONNAIRE**

- A. Is spirituality important to you? Why?
- B. You mention that you have a chronic illness, explain how it makes you feel to have this problem. What helps you to cope with your illness?
- C. Some people feel the need to speak with their health care provider regarding their spiritual needs. How do you feel about this?
- D. Describe your spiritual experience with your health care provider?
- E. Do you expect health care providers to offer spiritual guidance or refer you to someone that can help you spiritually? (**Probe: When, how, how often?**)

# **APPENDIX E: LETTER OF PERMISSION FOR INSTRUMENT**

#### UNIVERSITY OF ILLINOIS AT URBANA-CHAMPAIGN

Department of Kinesiology and Community Health College of Applied Health Sciences 127 Huff Hall, MC-588 1206 South Fourth Street Champaign, IL 61820 USA



March 21, 2010

#### Hello Myra,

24

In reference to our recent conversation, this is to confirm that you have my permission to use and adapt the questionnaire from my dissertation, *"The Role of Spirituality in the Self-Management of Chronic Illness among Older Adults."* Be encouraged as you complete your project, it can be taxing, but rewarding as graduation is insight.

Sincerely, Dr. Idethia Shevon Harvey

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