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TIKKUN OLAM A FAITH-BASED APPROACH FOR ASSISTING OLDER ADULTS IN HEALTH SYSTEM NAVIGATION

Janice M. Kuperstein
University of Kentucky

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ABSTRACT OF DISSERTATION

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A FAITH-BASED APPROACH FOR ASSISTING OLDER ADULTS IN HEALTH
SYSTEM NAVIGATION

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ABSTRACT OF DISSERTATION
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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Gerontology
in the College of Public Health
at the University of Kentucky

By

Janice M. Kuperstein

Lexington, Kentucky

Director: Dr. Pamela B. Teaster, Associate Professor of Gerontology

Lexington, Kentucky

2008

ABSTRACT OF DISSERTATION

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A FAITH-BASED APPROACH FOR ASSISTING OLDER ADULTS IN HEALTH
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The complexity and lack of coordination of the U.S. health care system is especially challenging for older adults, many of whom have multiple chronic conditions. The faith community is a potential partner to assist them, due to strong religiosity of older adults and specific characteristics of faith communities.

This study explores the knowledge and practices of faith community nurses (FCNs) in meeting care coordination needs of older adults and identifies a model of gap-filling by FCN practice. An approach combining both quantitative and qualitative approaches was used. A survey was distributed to all known FCNs in Kentucky. From the 60 respondents, 15 FCNs were selected for personal interviews, and six care recipients were also interviewed.

Survey data revealed a relatively older workforce, M=57 years, with 73% in nursing for more than 20 years. All served as FCNs in their own congregations, mostly as volunteers. FCNs relied on informal rather than formal assessments, with little consistency in type of health-related information obtained from congregants. The combined interview data revealed themes including, *strong grounding in faith, sense of congregational family, reliance on general nursing assessment skills, intentional empowerment, bridging expanses, trust, and continuity.*

Findings suggest that FCNs in Kentucky identify and fill significant gaps in health care for older adults. Spirituality and religious rituals were important for FCNs and those they served. Congregants sought out FCNs to answer questions, interpret medical information, and assist with health care interactions. The stability of the FCNs in the lives of congregations was regarded as important; congregants counted on FCNs' presence through transitions in health.

A model to explain FCN intervention was developed based on integration of a social ecological perspective with the WHO International Classification of Functioning, Disability, and Health. This model reflects contextual factors that occur throughout nested environments that surround each individual, including immediate family, congregational family, health and social care systems, and societal policies. FCNs serve as a bridge between and among these nested environments, connecting them and facilitating change within each level.

KEYWORDS: Health care delivery system; faith-based interventions; health promotion, older adult health, patient-centered care

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Student's Signature

March 26, 2008
Date

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DEDICATION

This dissertation is dedicated to people of all faiths and of no specific faith, who understand the value of using their gifts and talents toward Tikkun Olam - repairing the world.

ACKNOWLEDGEMENTS

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Chapter One - Introduction

Health care in the United States in the 21st century is a paradox. Remarkable clinical, technological, and pharmaceutical advances, including those seen in the treatment of diabetes, heart disease, and arthritis have led to longer life and greater quality of life for many people. At the same time, these advances have stimulated spiraling costs of care and fueled more complex and fragmented care with multiple medical specialties, more nuanced technology, and faster transitions among levels of care. For many people, the complexity and fragmentation result in disparities in access to care, frustration on the part of patients and providers, and increased risk of medical errors (CSG, 2003; Gillick, 2002; Tsilimingras, Rosen, & Berlowitz, 2003).

The complexity of the existing system is especially problematic for people with multiple chronic conditions, as is the situation of many older adults. Developing an understanding of barriers and facilitators, nationally and in Kentucky, is a first step in proposing a solution that may improve health and quality of life for elders in the state.

Health Care in the United States

Although the U.S. currently spends approximately 16 percent of its gross domestic product on health care (Azar, 2006), more *per capita* than any other nation in the world, U.S. citizens do not enjoy health outcomes commensurate with this enormous investment. In a survey of six leading industrialized nations , the U.S. stood out in the areas of inefficient care, errors, and financial burdens (Schoen et al., 2005). Serious failures to coordinate care, especially during transitions among and between health care settings, and missed opportunities to involve chronically ill adults in decisions about their care were identified. A follow-up analysis by the Commonwealth Fund, comparing results from five nations in its 2004 survey (i.e., Australia, Canada, New Zealand, the United Kingdom, and the U.S.) and six in 2005 with the addition of Germany showed similar results. The U.S. ranked highest in effectiveness - basing care on scientific evidence - but ranked last in overall quality. It was apparent that many of the health interventions pioneered in the U.S. are not consistently utilized by the very health care system that developed them. Americans are more likely to receive incorrect medications,

more likely to visit an emergency room for problems that could be treated in an office setting, and least likely to report their care as patient-centered. Furthermore, greater jeopardy exists for persons without significant resources; Americans with low incomes are more likely to go without health care than similarly situated individuals in the other nations studied (Davis et al., 2006), especially with regard to routine preventive care.

The overall lack of coordination of health and wellness services in the U.S. is especially challenging for individuals with chronic conditions, many of whom are older adults living on fixed incomes. According to the Centers for Disease Control and Prevention (CDC), chronic diseases such as heart disease, stroke, cancer, and diabetes are among the most prevalent, costly, and preventable of all health problems in the United States today (CDC, 2005). Among Medicare beneficiaries, 80 percent report at least one chronic condition. Twenty percent of beneficiaries with five or more chronic conditions account for two-thirds of Medicare spending (Mittler, 2005a).

Especially for individuals with multiple chronic conditions, achieving an acceptable quality of life depends upon the coordination of multiple dimensions of care across biomedical, psychosocial, and spiritual domains. Despite this need, the current health care system consists primarily of multiple silos for delivery of care provided by various independent medical specialists who are often in unaffiliated private practices. Even if the specialists are part of a multispecialty group practice, these being generally limited to practices in large metropolitan areas, outpatient medical records are often kept separated by specialty with little communication among providers. When a person enters an inpatient environment for care, he or she encounters another set of providers and records specific to this new environment. Social and community-based health services, which may decrease individual and family burden, optimize quality of life, and allow a person to remain at home instead of requiring residential care, are often disregarded or dismissed by the biomedical enterprise as superfluous or too complex to coordinate. If such patient-centered services are considered at all, they represent yet another silo. Each potential support program or service is likely to have different eligibility criteria, providers, and organizational structures. Poor communication among all of the providers results in fragmentation of services, and may lead to inadequate care, duplication of care, or conflicting interventions (Anderson & Knickman, 2001).

Gaps in Health Care

Coordinating care is generally regarded as the role of the primary care physician, yet the reality is that many patients, often those least capable of navigating the system, are left moving, with little guidance, among multiple providers and settings. Because most chronic conditions require ongoing self-management, lack of coordinated communication results in inadequate care, poor follow-through, and negative health outcomes. This is supported in proceedings of a summit convened by the Council of State Governments in April, 2003.

> There are limited incentives and inadequate procedures for coordination and communication of information from patient to provider, between providers, and from provider to patient. The fragmented nature of American health care almost ensures that something will go wrong with chronically ill patients, because they use the system more often, their conditions often involve multiple providers and they require greater patient self-management (State Official's Guide to Chronic Illness, 2004).

The fragmentation of our current system is perhaps most evident as a person transitions among various levels of care from ambulatory through acute, rehabilitation, and long-term care. Consider a woman with hypertension and diabetes who lives at home. She receives ongoing outpatient care through her primary care physician, with periodic consultations from an endocrinologist and a cardiologist. One day she is found at home, unresponsive on the bathroom floor. An ambulance transports her to the hospital where she is treated by an emergency room physician who determines she has suffered a cerebrovascular accident. She is transferred to the Intensive Care Unit, where her care is managed by a "hospitalist" physician, one who specializes only in the care of hospitalized patients, and a hospital-based group of health professionals. In a few days, she transitions to a rehabilitation facility or nursing facility and receives care from another set of health professionals. Finally, perhaps, she is able to return home with community-based long-term care services that generally involve yet another set of providers and instructions. Although some documentation will necessarily accompany each transition, true coordination will most often be lacking because there is neither an existing system in place nor reimbursement mechanisms for such coordination. The potentially less than optimal outcome achieved through the fragmented care may likely

have a significant impact on her quality of life and health, including increased dependence in self-care and decreased participation in meaningful social activities.

In reaction to these problems, in 2003, Congress established the Citizens' Health Care Working Group as part of the Medicare Prescription Drug, Improvement and Modernization Act (Public Law 108-173). The group was charged to engage citizens in a national public debate about improving the health care system and to use their findings to develop recommendations for national leaders regarding improvements (Grob, 2006). The group identified a clear message from the American people to eliminate difficulties in navigating the system, especially for those with chronic conditions. In a letter to the President, the Chair of the Working Group stated:

> Americans are confronted with a system that has become disconnected from the health and protection of citizens in the event of sickness. Many people are bewildered by its complexity. As one citizen voiced to us, you cannot navigate the health care system without luck, a relationship, money, and perseverance' (Grob, 2006).

Focus on Kentucky

Closer to home, Kentucky, a state with a largely rural population, has additional challenges of uneven distribution of health care providers, a high rate of poverty, lower educational level, and other barriers to care that result in poor health outcomes. According to data from the 2005 Behavioral Risk Factor Surveillance System (BRFSS) of the CDC's National Center for Chronic Disease Prevention and Health Promotion, 41.1% of Kentucky residents 65 years old and older reported their health status as fair or poor as compared to 27.8 % nationwide.

Although more than 97% of older Kentuckians report having some health care coverage, routine preventive care and screenings are often lacking (BRFSS Data, 2005). Kentucky's health rankings are among the poorest in the nation: cardiovascular deaths (46th), cancer deaths (50th) and limited activity days due to poor physical health (48th). Rankings in risk factors including prevalence of smoking (49th) and prevalence of obesity (45th) are also among the worst in the nation (United Health Foundation, 2006). These figures reveal that the leading health problems in Kentucky are largely those that must be managed on a day to day basis by patients themselves, requiring a coordinated plan involving multiple modalities such as medications, activity, nutritional programs,

and ongoing monitoring. However, factors including restricted access to providers, inadequate knowledge of existing resources, lack of transportation, high rates of poverty, and cultural bias often compromise the ability to achieve and follow such a plan. Thus, the citizens of Kentucky face a double burden. They face a high rate of chronic conditions highly responsive to comprehensive multi-dimensional management, but must manage these conditions in an environment in which such coordinated care remains inaccessible to many residents.

A cost effective solution to improve care coordination is likely to have a significant impact on health in the region. A potential solution considered nationally, that of engaging the faith community in a health partnership, holds special promise in Kentucky. Kentuckians exhibit greater religiosity than the national population, with 45% reporting attendance at religious services either weekly or almost every week. The rate varies throughout the state, and it is even higher in those counties with higher elderly populations (Lile & Trawick, 2004).

Faith and Health

The role of spirituality and religiosity in health and well-being is largely overlooked in health care practice, despite robust literature acknowledging their importance. In most of the literature, religion and spirituality are considered the same entity, and measurements of religiosity / spirituality are operationalized based on religious attendance, membership in religious organizations, or perceived importance.

In 2005, approximately 57% of Americans reported that religion is very important in their lives (Winseman, 2005).   Gallup surveys completed between 1992 and 1999, representing 40,610 adults nationwide, found that religion was rated as very important by 73% of respondents between the ages of 65 and 74, and by 77% of those age 75 and older (Ehmann, 1999). Hundreds of studies of varying quality have investigated the link between religion and health outcomes. In many studies there is a consistent link between spirituality and several specific outcomes, including mortality, cardiovascular disease, and recovery from acute illness. Additionally, there is strong evidence that patients consider their faith beliefs when making health care decisions (Daaleman, Kuckelman Cobb, & Frey, 2001; George, Ellison, & Larson, 2002; Koenig, 1999; Pargament,

Koenig, Tarakeshwar, & Hahn, 2001; Powell, Shahabi, & Thoresen, 2003; Seeman, Dubin, & Seeman, 2003). For example, in a meta-analysis, with an effective sample of nearly 126,000 participants, McCullough, Hoyt, Larson, Koenig, and Thoresen (2000) concluded that religious involvement is associated with various measures of health. Given the strong evidence of the public's interest in spirituality, along with the link between faith and health, lack of attention to the spiritual component of overall health and well-being is a serious flaw in the current system.

Faith - Based Health Initiatives

Information presented thus far shows that the lack of health care coordination poses a threat to the health and well-being of our citizens and our economy. The faith community is an important potential source to stem this crisis, in particular through the expanding practice of faith community nursing, which is a relatively new practice in the U.S. A number of diverse services are provided by faith community nurses (FCNs), including education, screening, counseling, referring, and advocating/facilitating, all within the context of spirituality (McDermott & Burke, 1993; Miskelly, 1995; Swinney, Anson Wonkka, Maki, & Corneau, 2001). Research to date has largely been limited to an assessment of the nurses' role in community health promotion (King, 2004). As one of many non-funded parts of the "system," there is little to identify how these important providers interact and serve as a bridge between formal and informal parts of the overall system available to older Americans.

National attention to the faith - health partnership is exemplified in the Interfaith Health Program (IHP), developed in 1992 at the Carter Center. Now part of the Emory University Rollins School of Public Health and associated with the schools of theology and nursing, the IHP envisions congregations and health systems "creatively and effectively flowing their resources into neighboring and more distant communities to advance health" (Interfaith Health Program, 2007). Toward that end, the IHP works with academic, governmental, and faith groups to discover and disseminate knowledge to strengthen the abilities of the faith and health communities to work together toward whole-person, whole-community health. The partners interact through research and training, including an annual National Institute for Public Health and Faith Collaboration.

As of March 2007, teams from 20 states had participated in the Institute, including several states that border Kentucky.

The Kentucky Department of Public Health has not yet participated. However, based on its knowledge of IHP, the Department has expressed a recent interest in collaborating with FCNs in Kentucky to communicate a consistent message of health (Thomas-Cox, 2007).

Issues Affecting Older Adults in Kentucky: Summary and Problem Statement

Mentioned earlier, older adults in Kentucky are burdened by many chronic conditions that have an impact on quality of life. Although the vast majority of elders have some health care coverage, too many report their health condition as fair or poor, and Kentucky's overall health ranking is among the poorest in the nation. Like most Americans, older Kentuckians must contend with a health care system that is both poorly designed and difficult to navigate, problems exacerbated by high rates of poverty and limited access in rural parts of the state. Also, like most Americans, the majority of elders in Kentucky report strong connections to a faith community, suggesting great potential for a faith - health partnership.

Conflicts in Working Definitions of Health

In addressing the issue of improving health of older people, one must first consider conflicting theories regarding health itself. For the most part, the traditional American "health care delivery system" incorporates only one component of overall health. The traditional system emphasizes disease, trauma, or other health conditions that require medical care provided by medical care professionals, most often provided by or under the direction of a physician. As identified by more comprehensive definitions of health, the biomedical component is only one part of health, yet it has achieved prominence in the minds of both health care professionals and many patients. This is largely due to the fact that biomedical interventions are reimbursed by health insurance and that biomedical diagnoses and interventions are the major foci of health professional education and research. Still, this model inadequately explains health from the holistic understanding expressed by the World Health Organization (WHO) and used for this study.

World Health Organization Perspective

Defined by the WHO in 1946, health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. More recently, WHO developed a model for the purposes of providing a unified and standard language and framework with which to describe health and disability. The International Classification of Functioning, Disability, and Health, known as the ICF Model, considers the broad perspective of health defined above. Recently, the Institute of Medicine (IOM) has joined WHO in recommending the adoption of the ICF for all disability related monitoring and research (Field & Jette, 2007).

ICF Model
International Classification of Functioning, Disability, and Health [From World Health Organization]

Health Condition
(disorder or disease)

Body Functions & Structure ⟷ Activity ⟷ Participation

Environmental factors   Personal factors

Contextual Factors
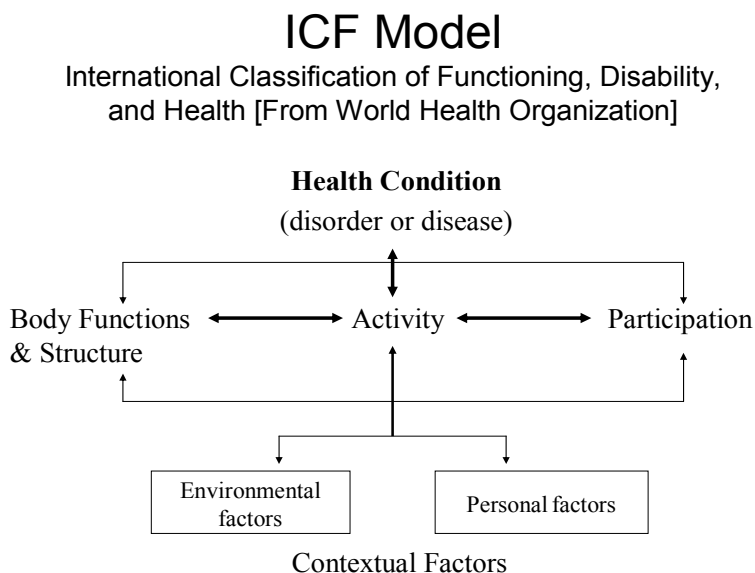
Figure 1.1 International Classification of Functioning, Disability, and Health

The three levels of human functioning are at the level of the body, the whole person, and the person in a social context. Chronic conditions such as diabetes cause physical manifestations on the structures or tissues of the body, including damage to nerves and blood vessels. This is noted in Figure 1.1 as Body Functions and Structures. Such damage often affects the whole person, for example, by affecting the ability to walk without loss of balance (Activity). A person may then have difficulty participating in work, recreation, worship, and other social functions that are major contributors to quality of life (Participation). As a patient, an individual does not identify pathologies such as nerve and blood vessel damage. She may be more likely to identify fear of

falling (at the level of the person), although insidious onset of balance difficulties may cause this problem to be overlooked until it affects her ability to walk up the stairs to attend church.

As noted in Figure 1.1, functioning, disability and health are outcomes of the interaction between health conditions and contextual factors in personal and environmental realms, both of which are dynamic. Environmental factors, such as accessibility of the home, transportation options, social support, and availability of adaptive ambulation devices have an impact on the person's ability to participate in desired activities and thus on her quality of life. Likewise, personal factors such as age, gender, coping style, education, and work experience contribute to overall health by mediating the effects of the physical deficits on participating in the desired activities. For instance, the presence of friends or family to assist with shopping may enable an individual to continue to live at home independently. Friendly visitors may keep people engaged, even when they are unable to attend outside activities.

Essentially, the ICF model may be seen as an "enablement" model in that it explicitly recognizes that "reductions in the incidence and severity of disability in a population can be brought about both by enhancing the functional capacity of the person and by improving performance by modifying features of the social and physical environment" (World Health Organization, 2001, p. 5). The model recognizes the importance of general tasks, demands, and interpersonal interactions in all major life areas, including home, community, social, and civic life (Allan, Campbell, Guptill, Stephenson, & Campbell, 2006). Faith and spirituality may be an important component of any of these life areas, or they may be the underpinning of all of these life areas for an individual.

This model fits well with the concept of holistic health that is prominent in FCN education and practice, which include considering the person from all perspectives – biological, psychological, social, emotional, and spiritual, and engaging community resources toward promoting health and well-being (American Nurses Association & Health Ministries Association, 2005; Maddox, 2001; van Loon, 2001).

Public Health Perspective: Healthy People in Healthy Communities

Beginning in 1979 with *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* and followed by *Healthy People 2000 and Healthy People 2010,* the U.S. Department of Health and Human Services has developed health objectives for the nation, seeking to engage medical, business, educational, faith, and other communities. The two overarching goals of *Healthy People 2010* are to increase quality and years of healthy life and to eliminate health disparities. These goals are supported by specific objectives in 28 focus areas (e.g., Cancer, Diabetes, and Disability and Secondary Conditions) that serve as a guiding document for addressing emerging health issues, reversing unfavorable trends and expanding past achievements in health (U.S. Department of Health and Human Services, 2000).

The Healthy People document acknowledges the array of determinants of health, as indicated in Figure 1.2 and accompanying description, which complements the ICF definition.
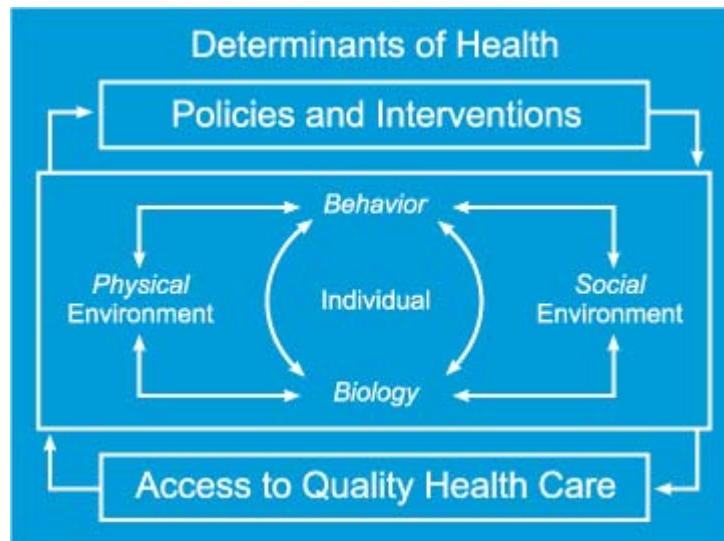
Individual *biology* and *behaviors* influence health through their interaction with each other and with the individual's *social* and *physical environments.* In addition, *policies and interventions* can improve health by targeting factors related to individuals and their environments, including *access to quality health care.*
(U.S. Department of Health and Human Services, 2000, p. 18)

Figure 1.2 Determinants of Health – Healthy People 2010

As previously noted, there is evidence that religious participation is linked to health behaviors, to physical and social environments, and possibly to access to health care. In addition, the *Healthy People Initiative* explicitly calls for greater involvement of the community in promoting health for individuals and the nation and considers the importance of policies on overall health.

Theoretical Perspectives

Social Ecology Theory

A conceptual framework that is consistent with the more comprehensive understanding of contributors to health is an ecological perspective as developed by Brofenbrenner in his landmark work on human development. He described development as being dependent on the individual, the immediate settings in which he lives, and the larger settings in which these immediate settings are imbedded (Bronfenbrenner, 1979). In an expansion of his initial theory, he identified the importance of not only the presence of these elements, but also the interaction between and among them (Bronfenbrenner, 1989).

Specifically, a social ecological perspective considers characteristics of the individual within a set of nested interactive systems that Bronfenbrenner described as the micro-, meso-, exo-, and macrosystems of influence. The microsystem describes the closest personal environment to the individual, generally immediate family members, friends and co-workers. The mesosystem refers to social influences on the individual, including local community groups, peer groups, work groups, and faith community. The network of health and social service providers within the community are part of the exosystem for purposes of this study. At any given point in time, they may not be directly serving the individual, but they are or may be available in the larger community environment. The macrosystem refers to the highest social level including social norms, cultural ideology and social policy (Bronfenbrenner, 1989; Grzywacz & Fuqua, 2000). McLeroy and colleagues were influenced by this theory when developing their social ecological perspective of health promotion, which is widely considered in the literature and used in practice today (Grzywacz & Fuqua, 2000; Stokols, Grzywacz, McMahan, & Phillips, 2003).

The ICF model describes health as the interaction between health conditions (of the person) and contextual factors in personal and environmental realms, and the Determinants of Health model explicitly includes public policy. In considering health and health promotion, the social ecological theory seems to take these considerations one step deeper. Social ecology considers health to be influenced by the interaction among genetics, biology, personality, social and family relations, environment, and policy, and further defines the environment (Smedley & Syme, 2001; Stokols, 2000). McLeroy et al. (1988) described health behavior as being determined by:

1. intrapersonal factors – characteristics of the individual such as knowledge, attitudes, behavior, self-concept, skills, etc.
2. interpersonal processes and primary groups – formal and informal social network and social support systems, including the family, work group, and friendship networks.
3. institutional factors – social institutions with organizational characteristics, and formal and informal rules and regulations for operation.
4. community factors – relationships among organizations, institutions, and informal networks within defined boundaries.
5. public policy – local, state, and national laws and policies.

Social ecological theory provides an inclusive framework for considering the many dimensions of health and well-being of older adults, and thus, is valuable to providers, researchers and policymakers. The Prevention Research Centers Healthy Aging Research Network (PRC-HAN), funded by the Centers for Disease Control and Prevention's Healthy Aging program, addressed their support of the social ecological framework within their mission statement (Lang, Anderson, James, & Goins, 2006). The National Task Force on Community Preventive Services within the Department of Health and Human Services used the social ecological perspective in examining community-based interventions to promote health-enhancing social environments, including it in the *Guide to Community Preventive Services* (Anderson, Fielding, Fullilove, Scrimshaw, & Carande Kulis, 2003). Because of its comprehensive and inclusive properties, the social ecological perspective is consistent with the broad view I sought in considering the roles of FCNs in health promotion.

Political Economy

A second perspective germane to any consideration of health care delivery in the U.S. is the political economy perspective, which considers the way the economy and polity interact to affect the distribution of social goods. The delivery system is viewed as a medical-industrial complex that provides medical services to constituents through providers and payers. Thus health care is a commodity to be purchased and sold, rather than a social good (Estes, 2001). It follows that the medical-industrial complex and the policies that support it are major environmental considerations at the macrolevel from the perspective of social ecology. Any consideration of modifying the health care system must therefore begin with an understanding of its current financing.

Financing Health Care

With specific reference to the older population, Medicare is the major payer of medical care, covering over 97 percent of Americans 65 years old and older. Since its inception in 1966, it has dramatically improved access to health care for elders and has been a major contributor to improvements in health status and quality of life. Medicare is funded largely through payroll taxes and general fund revenues, with approximately 10 percent of funding coming from premiums paid by recipients. It is funded largely by transferring income from working-age persons to retired or disabled former workers, and may be seen as a form of redistributive politics (Vladeck, 1999). The dramatic rise of health care costs over the past few decades has created a concomitant increase in political pressure to modify Medicare for cost containment purposes. Fear of bankrupting "the system" because baby boomers are moving into retirement and will dramatically increase the number of health care recipients has fueled much political debate and resulted in incremental changes to payment methodologies.

Despite these changes, reimbursement, for the most part, is based on utilization. Hospitals are reimbursed when they have patients occupying their beds. Physicians and other providers are reimbursed when patients are "seen." The relative value system used to determine the Medicare fee schedule rewards use of technology over evaluation and management. The current biomedical model is still focused on management of acute problems, often due to exacerbation of chronic conditions, rather than on prevention of

chronic disease or on appropriate management of chronic conditions (Wenger et al., 2003). Providers prioritize technology and pharmaceuticals at the expense and lower cost of health behavior modification, as the latter does not generate substantial revenue.

The predominant system is built on a culture that conflicts with the true needs of its recipients and the purported definition of health. Furthermore, it fails to give adequate consideration to personal and environmental factors critical to overall health and well-being. In its 2007 Annual Report, the Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds reported the inadequacy of funding in the Hospital Insurance Trust Fund (Medicare Part A) to meet the anticipated growth in the next ten years. This fund is expected to be exhausted by 2019 (Board of Trustees Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds, 2007).

Rising costs are fueled in part by medical and technological advances, lengthened lifespan for many, and the increasing number of older Americans. Despite the many advances and billions of dollars expended, older adults are often frustrated by the complexity of the system and miss opportunities to achieve better health outcomes. Pending significant changes in health care delivery, successful navigation of the existing system, along with enhanced focus on prevention, individual responsibility, and environmental support, holds great promise for improving outcomes and reducing cost. A faith – health partnership offers a holistic framework to achieve this goal.

Purpose

The purpose of this study is to explore the knowledge base and practices of FCNs in meeting the care coordination needs of older adults and to identify a model of gap-filling by FCN health care delivery. Because FCNs tend to be trusted members of both the health care system and the faith communities they serve, and because they are not constrained by traditional separations in medical and social service health systems, they are uniquely positioned to assist elders in navigating existing health care dilemmas. Contributing information about the current and potential role played by the faith community in coordinating and integrating biopsychosocial and spiritual dimensions of

health has the potential to impact the health care system, the social service network, and the faith community in moving toward a more deliberate and functional partnership.

Specific goals include:

- Understanding the types of services offered by FCNs within congregations in Kentucky;
- Identifying the frequency and type of assistance or advocacy provided in navigating the health care system, including medical and social, throughout the continuum of care;
- Identifying the FCNs' practice with respect to identifying risks of functional decline (preventive screens) and resources available in both the biomedical and home based systems;
- Understanding the meaning of interventions provided in practice for the FCN and the congregant recipient.

Overview of Methods

The study design uses a mix of quantitative and qualitative approaches, which includes three distinct phases. Phase I, an FCN survey, consists of questions about the demographics of individuals serving as FCNs, their training, specific focus of practice, whether individual or population focused, and major activities performed. These data were analyzed using descriptive statistics, and related to the first three goals of the study. Following the analysis of Phase I data, 15 FCNs were selected from among respondents who had volunteered to participate in personal interviews and had identified that at least 40% of their activities were in service to people 65 years and older. Selection for this phase, Phase II, was based on the diversity of experiences reported by FCNs in the survey (e.g., FCNs in large, medium, and small congregations; FCNs from various regions of the state; and one FCN serving a largely African American congregation). Phase II respondents distributed flyers to patients who met study inclusion criteria (e.g., received services for at least one month, cognitive status appropriate for interview). In Phase III six patients agreed to participate and all were interviewed to facilitate a deeper understanding of the specific practices and motivations inherent in the individual FCN,

care recipient relationships. Interviews from Phases II and III were taped and transcribed for analysis using standard qualitative methods.

Summary and Organization of Dissertation

This chapter sets the stage for the dissertation with its overview of the current U.S. health care system. Gaps inherent in the system's design negatively affect care provided, thus health outcomes achieved on both individual and societal levels. Narrowing the lens, the specific additional burdens in Kentucky, including uneven distribution of health care providers and other barriers to access were noted. A discussion of the link between faith and health followed, including a description of the role of FCNs. Theoretical frameworks related to health and the health care system, including the ICF model, the WHO Determinants of Health, social ecological theory, and political economy, provide a basis for understanding the challenges involved in addressing issues of health and health care delivery.

Chapter Two offers an in-depth discussion of the relevant research in the areas of current health and needs of older Americans, the quality of care delivered and gaps in care, spirituality and health, and the evolution of faith community nursing.

Chapter Three describes the mixed methods utilized in this study, including use of a survey and semi-structured personal interviews. Analysis of quantitative data, using descriptive statistics, allowed selection of diverse FCNs for the in-depth interviews and provided a broad overview of current practice of respondent FCNs in Kentucky. Traditional qualitative methods, including reading, grouping, and coding data as categories or themes emerged, allowed a deeper understanding of the current practice of the FCNs. A similar analysis of care recipients' interviews provided the unique perspectives of this group of people.

Chapter Four presents findings of the research. Surveys and interviews revealed great diversity in current practice throughout Kentucky. Responsibilities ranged from primarily a community-based focus of education and screening, to a deeply personal focus with close individual contact and assistance. In all cases, spirituality was included in the relationship, sometimes explicitly through prayer or a religious ritual, and

sometimes implicitly through a faithful presence. Almost all respondents reported great potential for further intervention.

Chapter Five considers implications of the current practice of FCNs in Kentucky and potential opportunities to enhance its impact on all citizens, with a specific focus on older adults. Opportunities for additional research include examining driving and restraining forces for increased interaction among FCNs and congregants, and modeling of "best practice" initiatives.

On a personal note, this dissertation is based in part on my religiosity in the Jewish faith, in which saving a life is the highest obligation and repairing the world (Tikkun Olam) is an expectation. These core beliefs, combined with my experience as a health care provider and hospital administrator, provide an unique and important lens through which to view the potential for this faith – health partnership.

Chapter Two – Literature Review

An understanding of the role of FCNs in assisting elders in health care navigation is undergirded by the relevant literature regarding the status of the older population and their health and health care utilization. This chapter begins with a general description of the elder population and then focuses on their current health status. Next, I consider the health care system as it currently exists and the quality of care delivered through the system through the interdisciplinary lens of a gerontologist. My approach is a biopsychosocial and spiritual one, consistent with both the ICF model and the WHO model of health discussed in Chapter 1. Significant gaps in the system are evident at societal, organizational, and individual levels. Third, I turn the focus to spirituality, both a passion of mine and an area that has gained recognition in gerontological scholarship and, albeit slowly, in medical literature and practice. I move from the broader view of the religiosity of older people to examine research on the impact of religiosity and spirituality on health, acknowledging some of the inherent challenges in this type of research. Linking the two communities, I then consider attitudes, behaviors, and education of physicians and nurses with respect to the inclusion of spirituality in their patient care.

Having established this background, I consider the traditional view of health within faith communities, along with specific characteristics common among faith based organizations that make them exceptional partners for promoting individual and community health. Finally, I discuss the expanding practice of faith community nursing, specifically examining its role in enhancing health and well-being of older adults.

A Snapshot of the Older Population

National Statistics

In July 2003, 35.9 million people in the United States were aged 65 and older, representing 12% of the population. According to projections by the U.S. Census Bureau, this number will double to 72 million people by 2030, nearly 20% of the population. By 2050, the older population will include 86.7 million people. People are living longer and healthier lives with a life expectancy at birth in 2000 of 76.9 years with

the rate of disability and functional limitation declining. The oldest old (age 85 and older) comprise a small but rapidly growing group, representing 4.2 million people in 2000. Cultural diversity of the older population will increase as it is currently increasing in the general population. This diversity is far reaching, including a substantial difference in educational attainment by race and Hispanic origin, differences in income, and cultural differences in health beliefs, family connectedness, faith, and community (Wan, Sengupta, Velkoff, & DeBarros, 2006).

Kentucky Statistics

Unlike the rest of the nation (Wan et al., 2006), a larger percent of Kentucky elders live alone. The percent of Kentucky elders who live in nursing facilities increased 7.2% between 1990 and 2000, in contrast with a decrease seen nationally. Migration patterns of older adults during health and during illness, coupled with the fact that as a largely rural state, Kentucky may have fewer options for home and community-based services, contribute to the increased utilization of nursing homes. In addition, persons in rural areas may have more positive attitudes about residing in a nursing facility in later years than their urban counterparts (Rowles, Beaulieu, & Myers, 1997; Schoenberg & Coward, 1997). I suggest additional possibilities. Given higher rates of chronic disease and disability in Kentucky and its high poverty rate, home management may be a less viable option. In addition, given transportation challenges in many parts of the state, the cost of services for home-based alternatives may be disproportionately higher than in more accessible regions.

The Health of the Older Population

As previously noted, approximately 80% of older people have at least one chronic condition, and 50% have two or more (Wan et al., 2006). Conditions such as arthritis, hypertension, heart disease, diabetes, stroke, and respiratory disorders are among the leading causes of activity limitations for older people and among the leading contributors to increased health care costs (Mittler, 2005b). These chronic conditions have medical implications but also a significant impact on quality of life. For example, the CDC reported that in 2004-2005, 48.3% of people 65 years old and older reported a diagnosis of hypertension (CDC, 2006). Along with the high cost of medication and treatment,

hypertension dramatically increases the risk of heart attack and stroke, which in turn affect functional independence and quality of life, in addition to cost of care. In this same document, 20% of respondents reported a diagnosis of cancer, 44.2% of older adults reported arthritis and related chronic joint syndromes, and an estimated 20.9% of Americans aged 60 and older were diagnosed with diabetes (CDC, 2005). The fear of developing Alzheimer's disease (AD), a progressive degenerative disease resulting in the irreversible destruction of brain cells and progressive dementia, is perhaps the greatest fear related to chronic conditions and aging. The risk and severity of AD increase with age, and the resultant dependency of the individual affected significantly impacts the person, his or her significant others, particularly the primary caregivers, and health and social care systems. Estimates place the financial cost to society at $148 billion annually for direct health care expenses and lost wages of individuals and caregivers (Alzheimer's Association, 2007).

There has been substantial progress made in addressing many of these conditions. Active life expectancy, or the number of years people can expect to live without disability, has increased for the current generation of older people, who are less disabled and healthier than their predecessors. Improvements in medical and health care interventions (e.g., earlier diagnosis and intervention, pharmaceuticals, joint replacement), individual behavioral changes (e.g., dietary changes, smoking cessation, exercise), more widespread use of assistive devices (from simple canes or reach devices to the more complicated technological environmental controls), and improved socioeconomic status (which in turn has an impact on health risks and access to care) all contribute to the declining trend in disability prevalence.

Current Health Report Card for the Nation and Commonwealth

The National Report Card on Healthy Aging (CDC & The Merck Company Foundation, 2007) provides a current examination of health status, health behaviors, preventive care and screening, and injuries for the U.S. population as a whole, and for each state and the District of Columbia. Eleven of the 15 indicators in this report card are from the *Healthy People 2010* goals. Table 2.1 summarizes key data for the U.S. and Kentucky taken from this report card. These findings, consistent with data presented in Chapter 1, indicate that Kentucky's health rankings are among the poorest in the nation:

cardiovascular deaths (46th), cancer deaths (50th), and limited activity days due to poor physical health (48th) (United Health Foundation, 2006).

Table 2.1 *Health Rankings – U.S. and Kentucky*

Indicator	US Data	KY Data	*Healthy People 2010* Target (when available)	KY Rank
Health Status				
Physically unhealthy days (mean number of days in past month)	5.5	6.6	NA	45
Frequent mental distress (%)	6.3	10.3	NA	51
Oral health – complete tooth loss (%)	21.3	38.1	20	49
Disability (%)	34.0	38.5	NA	42
Health Behaviors				
No leisure time physical activity in past month (%)	31.9	36.2	20	42
Eating ≥ 5 fruits and vegetables daily (%)	29.8	23.0	NA	48
Obesity (%)	20.2	20.4	15	28
Current smoking	9.3	12.5	12	48
Preventive Care and Screening				
Flu vaccine in past year (%)	68.1	64.3	90	46
Ever had pneumonia vaccine (%)	64.7	57.7	90	49
Mammogram within past 2 years (%)	75.1	73.9	70	32
Colorectal cancer screening (%)	63.1	56.3	50	47
Up to date on selected preventive services (%):				
▪ Men	38.4	32.4	NA	44
▪ Women	31.6	25.1	NA	49
Cholesterol checked within past 5 years (%)	90.4	87.2	80	49
Injuries				
Hip fracture hospitalizations (per 100,000 persons):		No state level data available		NA
▪ Men	558		476	
▪ Women	1113		416	

From the National Report Card on Health Aging (CDC and the Merck Company Foundation, 2007)

Improving the health and well-being of older Kentuckians will require a major comprehensive approach that involves multiple communities working in partnership. Prior national efforts have been largely unsuccessful in affecting Medicare costs and

health care outcomes, even when combining medical and social support systems (Gold, Lake, Black, & Smith, 2005). Missing from the literature is an approach that combines all available systems along with the support of the faith community. In order to consider the potential of a such a multifaceted approach to improving the health and well-being of older adults, one must begin with an understanding of the current health care delivery system.

The Promise and the Peril of Health Care Delivery

Medicare (Title XVIII) and Medicaid (Title XIX) were created as part of the Social Security Act of 1965 and were enacted in July 1966. Medicare was specifically created to assure medical coverage for older adults in a time when acute care and hospitalizations were the greatest health policy concerns. That time has passed. People are now more likely to die from acute exacerbation of chronic conditions (Wan et al., 2006). Chronic conditions such as cancer, heart disease, diabetes, arthritis and pulmonary disease are often characterized by extended periods of gradual functional decline and an increased need for long-term care and assistance with activities of daily living (ADLs). Costs of these services were never considered to be part of Medicare, and with the exception of a few added preventive services (e.g., mammography, prostate screening, the new Welcome to Medicare Assessment) and the recent inclusion of a prescription drug plan, little has changed. Traditionally, these gaps have been filled by family members, by institutions paid for privately, or by Medicaid if and when an individual crossed the poverty threshold and became classified as medically indigent.

The major source of Medicare financing is through mandatory contributions by employers and employees. As with Social Security, the system is "pay as you go" - money collected now is used to pay medical bills for current beneficiaries. Medicare therefore is a form of redistributive politics providing access to health care to many persons who would otherwise be unable to obtain services, significantly improving their health and life expectancy through a mildly progressive income transfer program (Vladeck, 1999). Administered by the Centers for Medicare and Medicaid Services (CMS), Medicare consists of Part A, which covers acute care hospital, short-term skilled nursing facility, home health care and supplies, and hospice care; Part B, a voluntary

supplemental insurance product, which covers 80% of the cost of physician services, outpatient rehabilitation, outpatient diagnostic testing, and physician-ordered equipment and supplies; and Part D, partial financial assistance for prescription drug purchases (U.S. Department of Health and Human Services, 2007). Since the mid 1980s, prospective payment system (PPS) methodology for various levels of care has been gradually implemented resulting in a shift in utilization of care environments. Often, patients are moved from higher to lower levels of care "quicker and sicker".

The Medicaid program, also administered through CMS, is a joint federal and state program for individuals deemed medically indigent. It is administered at the state level and therefore specific coverage varies from state to state. Whereas Medicare pays for nursing facility care only for short term intervention following hospitalization, Medicaid covers nursing facility care, including custodial care, but only for those who are medically indigent. Medicaid funds for home and community-based services are limited to those identified as being at significant risk of nursing facility placement without these services.

Home and Community Based Services

In the same year Medicare and Medicaid were authorized, the Older Americans Act was passed with the intent to establish a national network of public and private agencies organized to help older people stay at home for as long as possible, to prevent disease and disability through community-based activities, and to support the efforts of family caregivers. Benefits available under the Act include supportive services, such as homemaking, transportation, personal care, and adult day care; nutrition services through home delivered meals or congregate meal centers; preventive health education and health screenings; caregiver support; and services to protect the rights of vulnerable older persons (U.S. Department of Health and Human Services, 2003).

In spite of these major initiatives, 95% of all chronically disabled elders living in the community receive at least some unpaid family care and two thirds of these people rely exclusively on unpaid family care. The dollar value of informal care is estimated to be $257 billion per year due to a system that is fragmented, confusing, inefficient, and financially unaffordable for individuals, families, and our society at large (Carbonell, 2005). When older people and their families seek care, they face a complex maze of

public and private options, administered by providers operating under different, sometimes conflicting, and often duplicative rules and regulations, resulting in serious difficulty and frustration in trying to understand and access services (Carbonell, 2005).

Cost and Quality of Health Care in the United States

In <u>Crossing the Quality Chasm: A New Health System for the 21st Century</u>, the Institute of Medicine described the frustration of patients and of clinicians that "health care harms too frequently and routinely fails to deliver its potential benefits" (Institute of Medicine, 2001, p. 1). Despite rapid advances in medical science and technology, the system itself has fallen short in translating knowledge to practice and in applying new techniques safely and appropriately, and does not make the best use of its resources. At the level of the individual, this results in less than optimal care and outcome.

Measured Quality of Delivery System – Health Services Research

Robust evidence in the health services literature shows that the current health care system is not delivering an acceptable level of care in its current format. As noted earlier, the cultural focus is still on management of acute disorders, despite the knowledge that chronic conditions are more prevalent and are the leading causes of death. Using medical record review and telephone interviews with patients, McGlynn et al. (2003) compared care delivered to adults in 12 metropolitan areas to indicators of quality from the RAND Quality Assessment Tools, assessing 439 quality indicators for 30 acute and chronic conditions. Overall, participants received 54.9% of recommended care. Care requiring an encounter was the most likely to be provided (73.4%), and care requiring counseling or education was least likely (18.3%). With specific reference to chronic conditions:

- Only 24.7% of participants with diabetes had glycosylated hemoglobin testing done at least three times in the two year period;
- People with hypertension received 64.7% of recommended care, leaving them at increased risk of heart disease, stroke and death;
- In the area of coronary disease, 68% of recommended care was provided, but only 45% of people presenting to the hospital with myocardial infarction received beta blockers when indicated and 61% of appropriate candidates for aspirin therapy received it;

- Among elders, only 64% had received or been offered pneumococcal vaccine; and
- 38% of participants had been screened for colorectal cancer

In a follow-up study examining disparities in care among the group studied, Asch et al. (2006) found that individuals over 64 years old received 52.1% of recommended care as compared to adults under 31 years old who received 57.5% of recommended care.

Researchers at RAND Health established the Assessing Care of Vulnerable Elders Study (ACOVE) as a means to assess the quality of health care delivered specifically to older Americans. A team of researchers convened a group of nationally recognized experts in geriatric care and identified 22 conditions that account for the majority of health care received by older adults. A set of indicators establishing a minimum standard of care were developed for each condition based on literature review and expert consensus. Quality indicators were evaluated by expert panels and by the American College of Physicians Task Force on Aging, with 236 quality indicators ultimately accepted (RAND Health, 2004).

Wenger et al. (2003) used these quality indicators to assess care given to a group of community dwelling elders identified as vulnerable using a questionnaire assessing self-rated health, limitations in physical functioning, and functional disability (Wenger et al., 2003). Like the earlier study, the investigators conducted chart reviews of all physicians caring for the patients and interviewed patients or caregivers. They found that vulnerable elders receive about half of the recommended care and that the quality of care varies widely from one condition and type of care to another. Preventive care suffers the most, with only 43% of the study population having the recommended interventions, and care for geriatric conditions, such as incontinence and falls, is poorer than care for general medical conditions such as hypertension that affects adults of all ages (RAND Health, 2004). For those conditions considered primarily geriatric, the adherence to recommended indicators was 41% for acute conditions and 29% for chronic conditions. Given the data regarding the prevalence of chronic conditions in older adults and the need for self-management of these chronic conditions, these findings identify a significant gap that must be filled to improve health outcomes and quality of life.

In the Healthcare Research and Quality Act of 1999 (Public Law 106-129), Congress charged the Agency for Research and Quality (AHRQ) to measure the nation's health care quality and disparities and to track changes over time. As with the other studies, *The National Healthcare Quality Report, 2005* revealed a significant divide between recommended care and provided care, especially in the area of prevention and chronic disease management (Agency for Healthcare Research and Quality, 2005; Kelley, Moy, Stryer, Burstin, & Clancy, 2005). Such omissions, which result in poorer health outcomes and higher costs, may jeopardize the nation's financial future if the gaps are not filled.

Predicting Future Costs

Healthy elders spend less money on health care goods and services over their lifetime than elders with co-morbidities. People with one or two limitations in activities of daily living (ADL) spend twice what the non-disabled do annually. If all incoming Medicare beneficiaries had no co-morbidities, lifetime medical spending for the average person would fall by 17% (Cutler, 2005). Given the trends for decreasing disability among elders, this could suggest that fears of future spending growth are exaggerated. In contrast, however, Chernew, Goldman, Pan, and Shang (2005) found that the greatest increases in Medicare spending were among the less disabled elderly, in part due to health advances that keep individuals less disabled.

Dana Goldman and colleagues developed the Future Elderly Model (FEM) to allow consideration of different scenarios and the impact on health condition and the costs of health care for future Medicare recipients. The model took the health status of a sample of 100,000 Medicare beneficiaries in 2000, estimated what health services would be utilized and then simulated the outcome of the interventions. A new set of 65 year olds was introduced for each subsequent year through the year 2030. Importantly, the health status of the new cohorts was predicted based on the current health status of that cohort (Goldman et al., 2005; RANDHealth, 2005).

The team then considered the impact on Medicare spending under three different scenarios. In Scenario A, the health of the current younger cohorts is considered in the estimate of the health of future beneficiaries. In Scenario B, predictions were based on the healthy cohorts of the 1990s. In Scenario C, the most optimistic scenario, the

declining rates of disability seen over recent decades was assumed to continue into the entering cohorts. Figure 2.1 shows the anticipated rates of limitations of ADLs under each of the three scenarios. As noted previously, increased ADL limitations result in increased health care spending, and they also increase the risk of requiring nursing facility care and of mortality (Goldman et al., 2005).

Disability Among The Elderly Under Three Scenarios, Prevalence Of Any ADL Limitation, 2000-2030

SOURCE: Simulations based on data from the 1992–1999 Medicare Current Beneficiary Surveys (MCBS) and the 1990–1996 National Health Interview Surveys (NHIS).
NOTES: For description of scenarios, see text. ADL is activity of daily living.
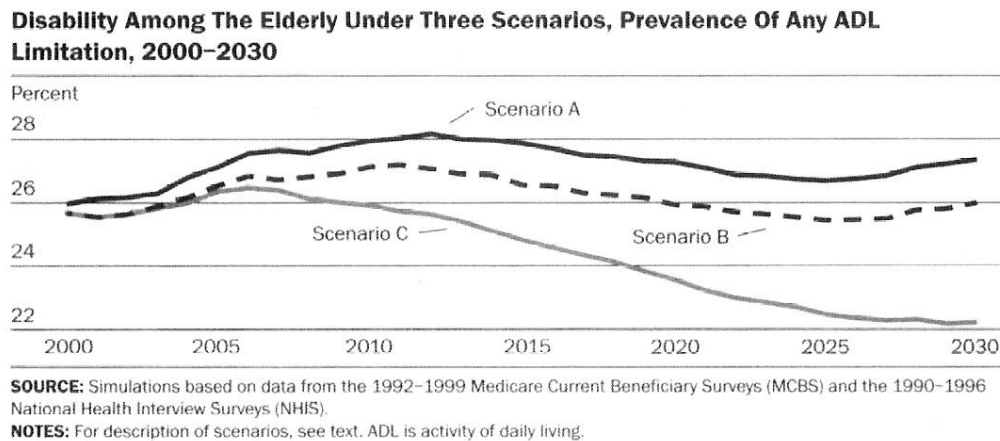
Figure 2.1 Predictive Disability Model

Given the rising rate of obesity and related chronic conditions such as diabetes, heart disease, and arthritis, Scenario A, which will further stress the existing system, seems most likely. Partnering with the faith community to meet the needs of the increasing number of older adults could have significant financial implications in addition to improving quality of life of U.S. citizens.

Challenges to Improving Care and Reducing Cost

Despite substantial research and numerous demonstration projects to improve care and manage costs for Medicare recipients, results have been generally disappointing (Gold et al., 2005). To identify factors contributing to the lack of success, Gold et al. analyzed programs funded through the California HealthCare Foundation's Program for Elders in Managed Care (PEMC). The program funded nine implementation grants, seven of which were ultimately executed, including five focused on elders at high risk for declining health and two focused on improving care for elders with dementia. The grants were targeted to consortia of managed care organizations, providers, and community organizations in California.

In identifying why the demonstration projects did not result in meaningful change on the outcomes measured, investigators found flaws in concept, problems translating concept to design, and problems in execution. Conceptually, the grantees defined success using "big" results in improved health status and functioning, reduced health care utilization, and decreased costs (Gold et al., 2005). Expecting such results within a three year window is unrealistic given the underlying problems, which are chronic in nature and would thus have longer term outcomes than could be observed in the evaluation period. Nevertheless, that is what the market expects.

Although substantial progress has been made in identifying quality of care indicators, strategies to implement these best practice guidelines have been largely ineffective in changing practice habits of providers (RAND Health, 2004). Most interventions have been targeted at improving knowledge, attitudes and behaviors of providers through educational meetings, visits, and reminder systems, when in reality many interventions are dependent on more than an individual provider (Grimshaw et al., 2004).

Integrated systems for care delivery involving multifaceted interventions with pathways for screening, education, treatment and monitoring of specific diseases may be particularly promising. These generally include revised professional roles, multidisciplinary teams, computer support, ongoing professional education and patient education, and facets of quality management, thus addressing many of the barriers for change and the most effective interventions. Unfortunately, most of the coordinated models fail to address interconnected medical and social needs of an individual, or the health of the whole person from biopsychosocial and spiritual domains.

Examples of Care Coordination

Benefits of care coordination have been identified in the literature. Medical care coordination for individuals with high cost and high risk conditions, also known as the *disease management model*, has proven to be cost effective and is increasingly used in managed care and fee-for-service health care markets. The Medicare Prescription Drug, Improvement and Modernization Act of 2003 included provisions to test mechanisms to improve care and decrease cost for beneficiaries with chronic conditions. Two of the initiatives, the Chronic Care Improvement Program (CCIP) and the Medicare Disease

Management Demonstration, include ongoing care coordination as a component of the models to be tested (Mittler, 2005b). The focus of disease management is on safety and compliance with physician-ordered treatments, with little attention given to the individual's home environment, functional capacity, and community support (Mollica & Gillespie, 2003).

Care coordination in the social model is available through a variety of independent and agency-based sources. Emphasis is on independence and consumer choice, with support including personal care, meal delivery, homemaker and chore services, and respite care, with a focus on maintaining the individual in his or her home environment and optimizing quality of life. Home and community based services are also available through Medicaid waiver programs designed to assist older beneficiaries in avoiding nursing home placement. As opposed to the disease management model, beyond receiving medical history information, there is little contact with the medical community on behalf of clients (Mollica & Gillespie, 2003).

A major problem with all of these models is the fact that different funding streams apply to the medical and social interventions, despite the fact that everyday life involves needs in both domains. Integrated models of medical and supportive care coordination have emerged to meet the needs of low-income older people dually eligible for Medicaid and Medicare services. A notable example is the Program for All Inclusive Care for the Elderly (PACE), a program targeted to provide all inclusive services to people age 55 and older who meet eligibility criteria for nursing home admission. An interdisciplinary team of professional and paraprofessional staff assesses participants' health and functional status and develops and coordinates plans of care to include acute and long-term services. Similar programs exist and are in development in several other states, particularly as a means of controlling Medicaid expenses, although data thus far do not indicate cost savings. Unfortunately, such programs miss the vast majority of elders who do not qualify for inclusion based on income.

Goals for Improving Overall Quality

In *Crossing the Quality Chasm*, the Institute of Medicine (IOM) identified widespread defects in American health care. Among the 13 major recommendations in the report, they identified rules to redesign health care processes. They include the

following: care based on continuous healing relationships, customization based on patient needs and values, patient as source of control, shared knowledge and free flow of information, evidence-based decision-making, safety as a system priority, transparency, anticipation of needs, continuous decrease in waste, and cooperation among clinicians (Institute of Medicine, 2001).

The literature is replete with proof that current initiatives to improve care are limited by the distinct and fragmented health and social care systems, each with their own rules and payment methodologies and each with overwhelming structures. Perhaps greater success is possible if, instead of fitting the needs of older people into available systems, we reverse the focus. An approach that considers the health of individuals as initially described by WHO and considers the many contributors to health described by the ICF model, would start first with the whole person and then modify systems to fit. Consistent with the IOM recommendations, it is clear that one cannot consider overall health and quality of life without considering the impact of religion and spirituality.

Religion and Spirituality

Religiosity and Spirituality of Older Americans

In 1952, the Gallup organization began asking about the importance that people place on religion in their lives. Seventy-five percent of Americans stated that religion was "very important" to them. By 2005, 57% of Americans reported that religion was very important in their lives (Winseman, 2005). With specific reference to older Americans, data collected between 1992 and 1999 representing 40,610 adults found religion was rated as very important by 73% of respondents between the ages of 65 and 74 and 77% of those ages 75 and older (Ehmann, 1999). In this same study, 56% of those ages 65 to 74 and 57% of those 75 and older reported that they attended a house of worship either weekly or almost every week. Longitudinal studies of U.S. adults indicate that people generally become more religious as they age (McCullough, Enders, Brion, & Jain, 2005).

In a random telephone poll of 1008 adults, 60% of people aged 65 and older reported attending religious services at least once per week. Percentages were higher for women than for men and higher in the Southern U.S. than in other parts of the country

(Sussman, 2002). In a telephone survey conducted for the American Association of Retired Persons, more than 50% of adults aged 45 and older reported attending church at least every two weeks (Montenegro, 2004). Although there is evidence that Americans tend to over-report religious attendance, there is also literature indicating that health related stress is related to religious coping and increased seeking of religious consolation (Anandarajah, Long, & Smith, 2001; Ellison & Taylor, 1996; Ferraro & Kelley-Moore, 2000; Presser & Stinson, 1998; Smith, 1998).

Harold Koenig, a leader in this field of inquiry, has participated in several studies involving religious coping to life challenges. Significant findings were summarized by Cohen and Koenig (2003). Of over 100 nursing home residents surveyed, nearly 60% reported using religion as a coping mechanism, with one third of these reporting it as the most important coping mechanism. Of over 300 medical patients over the age of 60, more than 40% spontaneously named religion as the most important factor in helping them cope with illness. When probed specifically about religion as a coping mechanism, nearly 90% reporting using it at least to a moderate degree. Among 100 people ages 55 to 80 interviewed using open-ended questions about coping during life stresses, 45% spontaneously mentioned religion as a coping mechanism.

Although it is important to consider inaccuracies in reporting, empirical evidence supports the contention that faith is important to a significant percent of Americans and warrants a thorough consideration of its impact on health and well-being. Furthermore, because the majority of older people report affiliation with a faith community, the potential for engaging this community to improve health holds significant promise. This may be especially true in Kentucky, where religiosity is higher than the national average (Lile & Trawick, 2004).

Spirituality and Health

Health Outcomes

Despite strong evidence that Americans value faith and participation in religious and spiritual activities, faith belief and practice became peripheral to health and well-being as defined by the medical community. Since the 1990s, perhaps based on the move for more patient-centered care, hundreds of studies of varying quality have investigated

the link between religion and health. Overall, research findings show a consistent link between religion and health (Daaleman et al., 2001; George et al., 2002; Hummer, Ellison, Rogers, Moulton, & Romero, 2004; Kilpatrick et al., 2005; Koenig, 1999; Seeman et al., 2003; Van Ness & Larson, 2002).

Impact of Religiosity at the Cellular Level

At the cellular level, religiosity has been associated with improved immune function (Koenig, Weiner, Peterson, Meador, & Keefe, 1997; Lutgendorf, Russell, Ullrich, Harris, & Wallace, 2004; Seeman et al., 2003). For instance, in a study of 1700 adults, those attending church regularly were half as likely to have elevated Interleukin-6 (IL-6) levels as those attending infrequently or not at all (Koenig, Cohen et al., 1997). In a community-based sample of 557 older adults, Lutgendorf Russell, Ullrich, Harris, and Wallace (2004) found that attending religious services more than once per week was a significant predictor of lower subsequent 12-year mortality and decreased risk of elevated IL-6 levels. IL-6 has a role in the pathogenesis of heart disease, osteoporosis, frailty, muscle wasting, certain cancers, and functional disability (Lutgendorf et al., 2004).

Impact of Religiosity at the Level of the Individual

In a meta-analysis with an effective sample of nearly 126,000 participants, McCullough, Hoyt, Larson, Koenig, and Thoresen (2000) concluded from available research that religious involvement is associated with various measures of health. Upon review of 41 studies examining a measure of religious involvement as a predictor of all-cause mortality, highly religious individuals had 29% higher odds of survival after controlling for other covariates of mortality. Further analysis indicated that religious involvement might be a stronger predictive factor for women than for men and that the 29% odds ratio may be a conservative estimate. The authors concluded that rather than continue to investigate whether such an association exists, researchers should examine the mechanisms of this effect.

An NIH Working Group on Spirituality, Religion and Health convened by the Office of Behavioral and Social Sciences Research conducted a thorough analysis of available literature using a level of evidence strategy similar to Cochrane reviews (Miller & Thoresen, 2003). The Working Group examined those with the strongest

methodologies and found persuasive evidence that church or other religious service attendance protects against death, and some evidence that religion or spirituality protects against cardiovascular disease and that being prayed for improves physical recovery from acute illness. Somewhat surprisingly, they also found some evidence that religion or spirituality impedes recovery from acute illness. In medically ill older patients, those who believed they had been abandoned by God or were being punished by the devil, were more likely to have died at a two year follow-up (Pargament et al., 2001; Powell et al., 2003)

In their consideration of the impact of religiosity and spirituality on health, Seeman, Dubin, and Seeman (2003) found ample evidence in the literature of a link to physiological processes including cardiovascular, neuroendocrine, and immune function. They found reasonable evidence that religiosity/spirituality is associated with lower blood pressure, less hypertension, and better immune function and some evidence of association with better lipid profiles. Upon narrowing their literature search specifically to the impact of Zen, yoga, meditation, and relaxation, they found reasonable to persuasive evidence of an association with lower blood pressure, persuasive evidence of association with better health outcomes, reasonable evidence of association with lower cholesterol and lower stress hormone levels, and some evidence of less stress hormone reactivity to challenge and decreased oxidative stress (Seeman et al., 2003).

George, Ellison, and Larson (2002) noted that there are four primary dimensions considered in the literature as measurements of religiosity and spirituality: public participation, religious affiliation, private religious practices (e.g., reading religious literature, praying) and religious coping. They note that with continued research, the quality of sampling has improved, as has control of other risk factors for morbidity and mortality that may be correlated with religion (e.g., demographic factors, socioeconomic factors, social stress and measures of health status); however, the majority of studies have been conducted only considering Christians and have been cross-sectional in design. The authors reiterated the belief that the central effort of research should be identifying mechanisms by which religion benefits health.

One possible mechanism is that religious participation may promote good health habits. This is most evident in the Mormon faith, which prohibits smoking, alcohol, and

extramarital sex and provides guidelines for healthy living. Mormons, along with Seventh Day Adventists, who also have strict prohibitions, have a lower risk of certain negative health outcomes. The literature does indeed show that health habits partially mediate the effects of worship service attendance on many health outcomes, although the remaining impact is still significant when health habits are controlled. The mediation is most evident in cross-sectional studies. There is potential for research in this area, comparing health behaviors of specific congregations based on individual priorities placed on health promotional activities and the subsequent outcome, considering of course that health behaviors may have an impact many years from the time they are assumed (George et al., 2002).

Regular participation in religious organizations clearly provides greater access to social support, also a contributor to positive health outcomes. The multidimensional nature of social support makes this a complex area of study. Along with support, religious participation is associated with increased self-esteem, self-efficacy, and mastery, all three of which are also associated with better health (Cohen & Koenig, 2003; George et al., 2002).

Another potential mediator of the association of religion and health is positive psychological state. According to Cohen and Koenig (2003), there is robust evidence that a positive world view may have positive health consequences. In a classic study, Peterson, Seligman, and Vaillant (1988) analyzed the essays of almost 100 male Harvard graduates from the classes of 1942-1945. Physicians rated the health of these men 20-30 years later and found that those with more pessimistic styles had poorer health, even after controlling for health status at the time of writing. These findings are similar to the Nun Study findings in which investigators reviewed the autobiographies of 180 nuns 60 years after they were written. Those nuns in the top quartile of expressed positive emotion had a 2.5 times lower risk of mortality than those in the bottom quartile. Significantly, unlike most studies, the nuns had similar living conditions (i.e., convents), nutrition, and access to health care (Danner, Snowden, & Friesen, 2001). Finally, in more than 800 studies that have examined religious involvement and mental health, the overwhelming majority show that involvement is associated with greater well-being, life satisfaction, self-esteem,

purpose and meaning in life, hope and optimism, and marriage stability, and lower rates of depression and substance abuse (Van Ness & Larson, 2002).

In a follow-up to their 1997 study that identified that weekly religious attenders had lower mortality than those who attended less frequently or not at all, Strawbridge, Shema, Cohen, and Kaplan (2001) tested the hypothesis that frequent religious attendance resulted in improved health behaviors, mental health, and social interaction. Again, the investigators utilized data from the Alameda County Study, which tracked behaviors and health outcomes of a community sample of 6,928 adults between the ages of 17 and 95 years old for over thirty years, with baseline data collected in 1965, and follow-up data collection in 1974, 1983, 1994, and 1995. For the follow-up study, the investigators considered 2676 individuals who were 17 to 65 years old at initial survey. Findings included that weekly attendance was associated with greater success in smoking cessation, becoming more physically active, combating depression, increasing number of personal relationships, and marrying. For women, but not for men, there was an association with stopping heavy drinking (Strawbridge, Shema, Cohen, & Kaplan, 2001).

Reindl-Benjamins and Brown (2004) examined religious salience and denomination on the use of six forms of preventive health care: flu shots, cholesterol screening, breast self-exams, mammograms, pap smears, and prostate screening. Investigators considered the possibility that religious groups may encourage health practices including prevention; they may facilitate prevention by providing social support, transportation, financial support, or actually offering the services themselves. Data came from the Assets and Health Dynamics Among the Oldest Old survey (AHEAD), a nationally representative longitudinal study of non-institutionalized individuals born before 1924. Investigators completed two rounds of surveys – one in 1993 and one in 1995, with the age range of participants being 70 to 103 years old, grouping religious affiliation into four categories: Protestant, Jewish, Catholic or none. Ninety percent of respondents reported religion is very or somewhat important in their lives. Results indicated that levels of religious salience and denomination predicted preventive health care utilization (Reindl Benjamins & Brown, 2004).

The cumulative data suggest that the process of statistically correcting for the impact of positive behaviors when considering the association between religious

participation and health outcomes fails to consider that religious involvement may be mediating these behaviors, thereby underestimating that association (Strawbridge et al., 2001).

Impact of Functional Impairment on Participation in Religious Activities

As noted earlier, there is evidence that increased stress, especially health-related stress, is associated with an increase in turning to religious coping (Ellison & Taylor, 1996; Ferraro & Kelley-Moore, 2000; Koenig, Cohen et al., 1997). However, there is also evidence that individuals with significant functional impairment attended religious services less frequently than those without impairment, although use of religious media did not decline (Hays et al., 1998; Idler & Kasl, 1997). Decline in religious attendance may be more significant with an increasing number of impairments and conditions (Benjamins, Musick, Gold, & George, 2003). Religious attendance, however, is only one measure of religiosity, and studies have shown no decline in other religious participation with increasing disability. In a study using data from the New Haven site of the Established Populations for Epidemiologic Studies of the Elderly (EPESE), Idler, Kasl, and Hays (2001) examined self-reports of attendance at services, self-ratings of religiosity, and strength and comfort felt from religion for respondents who did and did not die within 12 months following an interview. They found that although attendance at religious services declined among the near-deceased, overall involvement, including feelings of religiousness and strength and comfort received from religion remained stable or increased throughout the last year of life (Idler, Kasl, & Hays, 2001).

Intercessory Prayer

Another area of study within religiosity and health is the effect of intercessory prayer on health outcomes. Palmer, Katerndahl, and Morgan-Kidd (2004) conducted a randomized trial on the effects of remote intercessory prayer on problem-specific outcomes and functional status in a group of community dwelling adults. They found that prayer intervention appeared to reduce an individual's level of concern about the outcome of a particular life problem only if the subject initially believed the problem could be solved.

Perhaps the most significant information gleaned from this study is the difficulty in research on intercessory prayer. The authors acknowledged that it is impossible to assure a control group because it is unknown whether others outside the study were praying for the subjects. Additional prayer for the experimental group would only be significant if there were a "dose response" to prayer. The authors also identified possible concerns about the ethics of praying for someone without permission, but one that could be eliminated by getting permission from both the control and experimental groups (Palmer, Katerndahl, & Morgan-Kidd, 2004).

In a major study published in the American Heart Journal, investigators considered 1802 patients undergoing coronary artery bypass graft surgery, randomly assigned them to one of three groups, and received permission for Christian intercessory prayer from all participants. A traditional study group and control group received or did not receive prayer without knowing their group assignment and a third group received prayer and were aware of their status. Although no difference in complication rate was seen between the first two groups, the group cognizant of receiving intercessory prayer had a higher incidence of complications (Benson et al., 2006).

Research Challenges

The complexity of research in the area of religion and health presents conundrums as to whether the mechanisms can ever be truly determined. In addition to the fact that we cannot randomly assign people to levels of religious involvement, it may be impossible to assess the level of meaning that individuals place on religious observance. Great heterogeneity exists in people who profess religious and spiritual beliefs, and certainly in those who attend religious services. As a person of deep faith, it is my belief that literally every action I take is in some way tied to my beliefs and my journey in a personal relationship with God – one that I cannot imagine a way to express in discrete measurable terms.

Suggestions by some investigators of considering objective measures including observations of actual practice was intriguing, but I am uncomfortable with how that can be accomplished. Measuring virtues such as forgiveness, altruism, and hope as an indication of religiosity (Powell et al., 2003) seems to miss the point that these may be based on religion or spirituality, or they may also be based on other motivations,

including fear, or simply culture. Even if we could measure these virtues, I do not see the significance or importance of this measurement.

It is noteworthy that the vast majority of studies are based on Judeo-Christian faith traditions, and in fact even among that tradition, most subjects are Christian and Caucasian Americans. Levels of religiosity vary by culture as do attitudes toward aging and support offered to elders. Cohen and Koenig (2003) identified a major difference in beliefs about religiosity between Jews and Protestants. To distinguish, Judaism is both a religion and an ethnic group. Jews assume an underlying belief in God, but do not require a certain belief system for Jewish identity. Doubt is an acceptable emotion, and Jews are encouraged to wrestle with the meaning of sacred text. People who consider themselves religious Jews often base this assertion on frequency or traditional nature of religious practices, rather than on beliefs. Protestant faiths are more dependent on beliefs for identification. In a related series of studies, Cohen, Siegel, and Rozin (2003) found that Jews based self-rated religiosity only on religious practice, while Protestants believed religious beliefs and religious practices made unique contributions. When asked to rate the importance of practice and belief in defining religiosity, Jews rated practice first, and Protestants rated belief more important than practice (Cohen, Siegel, & Rozin, 2001).

Summary of Religion and Spirituality

Overall, limitations in studies not withstanding, there is ample evidence that religiosity/spirituality is associated with positive health outcomes in a majority of the studies completed. There is also evidence that religiosity and spirituality are important to individuals, and it is reasonable to believe that to truly examine health and well-being, we should now consider a biopsychosocial and spiritual approach. In response to this recognition, professional organizations began acknowledging the need for greater sensitivity and better training of health professionals in the area of religion, spirituality, and health. These included the American Psychiatric Association in 1989, the American Psychological Association in 1992, the Accreditation Council for Graduate Medical Education in 1994, the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) in 1996, the American Academy of Family Physicians in 1997, the American College of Physicians in 1998, and the Association of American Medical

Colleges in 1998.(Larimore, Parker, & Crowther, 2002). These calls have been largely ignored until very recently.

Physician Attitudes, Behaviors and Education in Spirituality and Health

In a call to action for physicians, Koenig (2004) summarized the literature on religion and mental health through 2000. He noted the association of religiosity with less depression and quicker recovery from depression; lower suicide rates; less anxiety, greater well-being, hope and optimism; more purpose and meaning in life; less substance abuse; greater marital satisfaction and stability; and higher social support. Positive effects noted in these studies may independently contribute to the influence religion has on physical health. In another report of available studies, he found positive physical health benefits including better immune function, lower death rates from cancer, less heart disease or better cardiac outcomes, lower blood pressure, lower cholesterol, and significantly longer life. Since 2000, additional studies showed positive effects of religion, especially for individuals with chronic illness and greater extent of disability. Nevertheless, even in the southern United States, with the highest prevalence of reported religiosity, fewer than ten percent of physicians regularly address spiritual issues in patient care. Barriers identified included lack of awareness of research, discomfort, perception of inadequate time, and concern about going beyond their scope of expertise (Koenig, 2004).

These barriers are not insurmountable. Education is readily available in the literature, and medical school curricula are increasingly including spiritual aspects of patient care. Medical school educators have recognized that addressing spiritual and religious needs is a critical component of patient-centered care. The assessment of these needs for all patients admitted to inpatient hospitals, long term care facilities, and home health agencies is now a requirement of JCAHO (Koenig, 2005). Culturally competent health care delivery demands such consideration. With respect to time, guidelines exist that allow for efficient spiritual history taking as part of a comprehensive patient assessment. Finally, with respect to scope of practice, as with any specialty area, physicians are encouraged to refer to experts such as pastoral counselors and religious leaders as integral members of the health care team.

The position linking spirituality and medicine is not without opposition (Berlinger, 2004; Lawrence, 2002; Scheurich, 2003). Scheurich (2003) calls for a "separation of church and medicine" arguing that a religion-neutrality values assessment is appropriate as part of person-centered care and expressing concern when physicians blur the lines by praying with patients or exalting religious participation. Berlinger (2004) shares the concern regarding inclusion of spirituality in health care. Despite the attempt to avoid promoting religion, inclusion of spirituality in the physician - patient relationship raises concerns that a physician consciously or subconsciously may convey ideas about right versus wrong religion. This is especially alarming due to the power imbalance of the relationship. She suggested that it was of greater importance to honor the humanity and dignity of each individual patient by improving the overall quality of care provided. Lawrence (2002) also opposed the marriage of spirituality and medicine. Noting the stunning inflation of physicians' duties and the complexity of the topic, he posits that it is ridiculous to believe that physicians will have time to address this issue appropriately. He argued that physicians should not act in the role of screening healthy versus non-healthy religious beliefs and certainly should not encourage or discourage any beliefs.

Nursing Attitudes, Behaviors and Education

Unlike physicians, nurses have a long history of espousing that spiritual care is part of holistic patient care. Florence Nightingale considered spirituality an intrinsic and critical component of health and healing, and there is evidence of inclusion of this dimension of care in nursing educational programs established in the 1870s (Macrae, 2001). Somehow, this focus was lost in modern nursing education. Meyer (2003) suggests that one reason for the move away from discussions of spirituality in nursing education is the Supreme Court ruling in 1962 regarding separation of church and state resulting in an attempt by public institutions to avoid "supporting religion". Another is the emphasis on seeking credibility for nursing practice as a research-based science, including the development of nursing theories. Finally, the current health care focus on technology and on the business of health care has led nursing educators to prepare students for the market they will face – one that includes shortening the lengths of

hospital stays, assuming care for a larger number of patients, and delegating much of personal care to less qualified providers (Meyer, 2003).

In current practice, however, the rules seem to be changing. Both the International Council of Nurses (2000) and the American Nurses Association *Code for Nurses* (2002) include statements about nurses' responsibility to promote respect for an individual's religious and spiritual beliefs during care delivery (Cavendish et al., 2004). Beginning in 2000, compliance with the JCAHO requirement to consider religious and spiritual needs of all patients admitted to inpatient hospitals, long term care facilities, and home health agencies has fallen largely to nursing staff. Nevertheless, the literature suggests that nurses rarely address spiritual issues and report feeling unprepared to do so (Cavendish et al., 2003; Cavendish et al., 2004; Highfield, Taylor, & Amenta, 2000; McEwen, 2004, 2005; Meyer, 2003; Narayanasamy, 1999; Tuck, Pullen, & Wallace, 2001).

In a systematic review of the nursing literature from 1995 through 2005, McEwen (2005) reports widespread agreement that spiritual care is an integral component of high quality nursing care, and is a requirement, rather than an option. The American Association of Colleges of Nurses identified spiritual care as an integral component of nursing education, and that graduates should anticipate, plan for, and manage spiritual needs of the patient and caregivers (American Association of Colleges of Nursing, 1998). The National Council of State Boards of Nursing notes that the national nursing competency exam contains questions that test knowledge in the area of spirituality and health.

The nursing literature includes a multitude of instruments for assessment of the role of spirituality in patients' lives, yet nurses often feel unprepared to assess and develop interventions. Barriers identified include the belief that it is not a nursing responsibility, personal embarrassment, discomfort or uncertainty with their own spirituality, and discomfort dealing with conditions most often related to spiritual distress (death and dying, suffering, grief). Knowledge barriers identified include lack of knowledge about the spiritual or religious beliefs of others, mistaking spiritual needs as psychosocial needs unrelated to religious or spiritual issues, insufficient education, and limited availability of nursing theories and interventions. Situational issues such as

insufficient time, constraints placed by employers, and environmental distractions are also identified as limiting attention to spirituality (McEwen, 2005). These barriers may not be present in the practice of FCNs, who practice outside the traditional health care environment, who have a strong grounding in their faith, and who have a specific interest in linking spirituality to health and well-being.

Faith Communities and Health

President George W. Bush's January 2001 Executive Orders established a White House Office of Faith-Based and Community Initiatives, a center within the department of Health and Human Services and centers in the Departments of Justice, Housing and Urban Development, and Labor and Education with the goal of removing barriers to faith-based involvement in these agencies. His order recognized limitations of government to fill important roles in the health of individuals and communities and the belief that delivery of services rooted in moral values may be appropriately delivered in partnership with the faith community (Isaac, 2003).

The faith community has historically been a facilitator of health and healing. In the twelfth century, health care was listed first by Maimonides on his list of the ten most important communal services that had to be offered by a city to its residents. (Mishneh Torah, Sefer Hamadda IV:23). In more modern times, health ministries, which may include professional parish nurses, have emerged within faith based settings to promote health, including access to care (Anderson & Young, 1988). Byron Johnson, Director and Distinguished Senior Fellow at the Center for Research on Religion and Urban Civil Society estimated that just the larger faith-based organizations provide $20 billion of privately contributed resources to social service delivery for over 70 million Americans annually (Johnson, 2002)

Faith communities are the most significant membership organizations in the United States, with 64% of Americans reporting membership. Older adults are especially likely to be affiliated, as are members of minority populations (Winseman, 2005). Faith communities, including clergy and laity, welcome and have already assumed important health promotion roles, including visitation programs for home-bound or hospitalized elders, exercise programs, congregant meals, and health promotion activities (Cnaan,

Boddie, & Kang, 2005; DeHaven, Hunter, Wilder, Walton, & Jarett, 2004; Hale & Bennett, 2003; Johnson, 2002; Sheehan, Wilson, & Marella, 1988). Although literature describing programs and outcomes is extremely limited, there is evidence that some health promotion programs can result in reduced cholesterol and blood pressure, increased fruit and vegetable consumption and reduced weight, increased use of mammography and breast self-exam, increased knowledge about prostate cancer, increased readiness to quit smoking, and measurably improved mental health (DeHaven et al., 2004).

Faith Community Nursing

In the 1970s, Faith Community Nursing, a specific faith-based initiative, grew out of the work of Granger Westberg, a Doctor of Divinity. The initial model, supported by a grant from the Kellogg Foundation, established holistic health centers for medical and faith-based professionals to deliver holistic care. Although these centers proved to be too costly, the role of nurses as a link between the two communities provided a model for the current and more cost-effective parish nursing programs. The International Parish Nursing Resource Center was developed to facilitate, educate, and support nationwide endeavors and serves as a resource for information about parish nurse education and programs (Nelson, 2005). FCNs now work in all mainline denominations throughout the United States, Canada, Australia, and Korea (McDermott, Solari Twadell, & Matheus, 1998).

Faith Community Nursing is a specialty practice area within nursing. According to the Faith Community Nursing Scope and Standards of Practice (ANA, 2005), the FCN is knowledgeable in professional nursing and spiritual practices. In addition to the preferred level of a Bachelor's degree in nursing, the FCN is educated in the professional role of faith community nursing and in the spiritual beliefs and practices of a faith community. Education is available in nursing programs at undergraduate and graduate levels, though not all parish nurses have formal training. Approximately 100 FCN Basic Education programs affiliated with the International Parish Nurse Resource Center exist in the United States. Programs generally require the nurse to have been in practice for three to five years prior to enrollment.

Westberg (1990) identified four major roles of parish nurses, including educator, counselor, referral agent, and advocate/facilitator. His survey of 109 parish nurses revealed that 15% of their time was spent on home, hospital, and nursing home visitation; 14% on health teaching; 11% in telephone consultation on behalf of congregants; and 10% each on health screening; and health counseling. FCNs may organize support groups and serve as community liaisons and role models while helping congregants access existing services and/or encouraging others to offer support (Anderson & Young, 1988). They may serve as a complementary resource to provide critical linkages among individuals and families, the health care community, and other community resources, promoting mutual responsibility for healthy outcomes (Schank, Weis, & Matheus, 1996; Swinney et al., 2001; Weis & Schank, 2000).

The roles of the FCN are consistent with the American Board of Nursing Scope and Standards of Faith Community Nursing Practice (American Nurses Association & Health Ministries Association, 2005) including holistic assessment with a particular emphasis on spiritual beliefs and practices, diagnosis through analysis of data, outcomes identification, and implementation. Specifically within the area of implementation, standards include coordination of care delivery within the faith community, advocacy within the health care system, health promotion, and consultation to influence and enhance the plan to "facilitate change in support of health, healing and spiritual well-being." Other standards include ongoing evaluation and collaboration with others within the family, faith community, and health care community (American Nurses Association & Health Ministries Association, 2005). These standards are consistent with assisting older people in navigating the very complex systems that contribute to their overall health. The FCN, not bound by setting of care delivery, will likely follow congregants throughout the continuum of care, often playing a pivotal role in care coordination (Nelson, 2001; Nelson, 2005).

Four different support models are described in the literature (Miskelly, 1995; Solaritwadell & Westberg, 1991). They are the *institutional/paid model* in which the nurse is employed by a health care entity or community agency which contracts with faith communities; the *institutional/volunteer model* in which the nurse volunteers his or her time, but there is supervision and some financial support from a health or community

entity; the *congregational/paid model* in which the nurse is employed and supervised by the faith community; and the *congregational/volunteer model* in which the nurse volunteers time and is supervised by the faith community. In 2000, approximately 55% of parish nurses were volunteers and most worked in the congregational model.

Regardless of the model, the role of the FCN is largely defined by the needs of the community. Describing a church community in urban Wisconsin, Miskelly (1995) demonstrated how a needs assessment could be utilized to develop a faith community based health promotion plan to assist in meeting state and national health objectives. She found that 76% of 170 respondents believed they maintained satisfactory relationships with health professionals, and 82% perceived themselves as effective users of the health care system. In their sample of congregants of a large urban parish in Massachusetts, Swiney, Anson, Wonka, Maki and Corneau (2001) reported older adults have difficulty advocating for themselves in the current health care system and concerns including financial needs, living wills, and prescription drug interactions (Swinney et al., 2001).

Evaluation of FCNs has been limited to their role in health promotion and disease prevention, based on a community health approach. They have had positive impacts in reducing cardiac risk factors, increasing preventive screenings such as mammograms, and an increased sense of self-confidence in health care decisions. Acosta et al. (1999) reported significant increases in visits to church center health clinics, including a 91% and 87% increase in two churches visited mostly by older women. A study of a regional parish nurse network in south-central Minnesota found that facilitating early access to care and supporting caregivers in care provision for community-dwelling elders resulted in substantial Medicare cost savings and improved quality of life (Brudenell, 2003).

Additional studies have indicated that FCNs effectively facilitate home health care, access to well-elderly clinics, and immunization (Hughes, Trofino, O'Brien, Mack, & Marrinan, 2001). Weis and Schank (2000) described the establishment of various community partnerships to meet the goals of *Healthy People 2000*. Anderson identified the importance of access in her interviews with 25 parish nurses representing a variety of mostly Christian faiths, sizes of congregations, and models employed. She noted that parish nurses bridged medicine and religion to connect with people, representing health

as a multidimensional construct which encompass social and spiritual concerns along with the traditional biomedical approach (Anderson & Young, 1988).

Wallace et al. (2002) examined clients' perceptions of FCNs through an ethnographic study of interviews with care recipients in two congregations in Southeastern Appalachia, one predominantly African American and one primarily Caucasian. Major themes that emerged included the availability and approachability of FCNs, the integration of spirituality and health, and their focus on helping individuals help themselves. Importantly, clients perceived that they retained the primary responsibility for their own health and wellness but were empowered by their relationships with the FCN. Through their interactions with FCNs, patients gained a better understanding of medications and treatment regimens, greater adherence, healthier choices, and increased mobility (Wallace, Tuck, Boland, & Witucki, 2002). Another study of clients' perceptions identified the importance of trust, comfort, and the FCN's ability to respond to questions (Chase Ziolek & Gruca, 2000).

The literature supports that faith community nurses are more likely to include spiritual interventions in their practice than other providers, one of their primary foci (Brudenell, 2003; Buijs & Olson, 2001; Tuck, Wallace, & Pullen, 2001; Weis & Schank, 2000; Weis, Schank, Coenen, & Matheus, 2002). Through collaboration and consultation with others, FCNs may open the door to inclusion of this important dimension in health care, either through direct communication with health care providers or through empowering patients to demand such inclusion.

Conclusion

In conclusion, the aging of America has become a major topic of concern from social, economic and political perspectives. The financial impact of providing care for the aging population is largely borne by society through Medicare, Medicaid, and Social Security taxes and therefore affects local, national, and international levels, both in the form of taxation and in the costs of goods and services. That older people are also an excellent source of social, intellectual, and financial wealth is often overlooked.

The health and well-being of elders will have a huge impact on the future of the United States. The current trend of decreasing disability rates in successive cohorts of

elders seems to be slowing, but dramatic increases in rates of obesity in current and future elders suggests that prevalence of chronic conditions and disability will actually increase.

The current system to facilitate health is fragmented and fails to deliver optimal care to all individuals, especially older adults. Much of the failure is related to poor coordination of care both within the formal medical care system and between this system and the social care system, a vital partner in efforts to maximize individual and population health. Attempts at coordination are in large part limited by the complexity of the current medical care delivery system and the separation of medical and social health systems. Despite clear evidence that the majority of older people in the United States describe religion and spirituality as important in their lives and that there is an association between religiosity / spirituality and health, current health care delivery rarely addresses this domain, representing yet another fissure in addressing health and well-being from the holistic perspective endorsed by the World Health Organization. As noted previously, faith communities play an important role in the United States, and one that is often associated with trust. Faith communities are ideally positioned to contribute to the health and well-being of congregants and to provide linkages among individuals and/or communities and the health resources available through the medical and social support systems, thus providing a continuum of care that is currently largely absent (Boland, 1998; Swinney et al., 2001; Wallace et al., 2002).

Incremental changes in health care delivery have resulted in some improvement in the health and well-being of Americans; however, there are still important efforts to be made. A complex system with multiple stakeholders, many with conflicting interests, contributes to making major improvements unlikely in the near future. Assisting older people to navigate the existing system has tremendous value.

Having personally participated in altering outcomes for individual elders by assisting in system navigation and resource identification, I am acutely aware that such an approach can be highly effective. Teaching each older person the requisite knowledge and skills is not a realistic goal. Assigning an individual advocate to each individual would dramatically increase the cost of care. However, in a critical role for many Americans, FCNs can provide a potential solution based on their health system and medical knowledge, along with connections to individuals with specific needs. FCNs

have the added value of a natural inclusion of the spiritual dimension in health care. This partnership may well change the lives of elders and their families and contribute to an understanding of how we need to change systems to fit the "whole person".

Chapter Three - Methods

This study explores the knowledge base and practices of faith community nurses (FCNs) in meeting care coordination needs of older adults and identifies a model of gap-filling by FCN health care delivery. Three objectives and three phases structure the study. In Phase I, a survey was sent to FCNs in Kentucky in order to gather information on their background and activities. Qualitative data were collected in Phase II, in order to understand the meaning and guiding principles behind FCN service provision through in-depth interviews with 15 FCNs. In Phase III, in-depth interviews (n=6) were conducted with congregant recipients in order to understand services received from the recipients' perspective. The study design and related documents were approved by the Medical Institutional Review Board of the University of Kentucky through the Office of Research Integrity on January 10, 2007.

The Phase I survey results were analyzed using SPSS version 15.0 for descriptive statistics (e.g., means and cross tabulations). The Phase II and III interviews provided qualitative data that I analyzed using standard qualitative methods (e.g., constant comparison) (Denzin & Lincoln, 2005; Soderquist, 2005; Stauss & Corbin, 1998). Upon saturation and identification, I verified these themes with FCN educators and coordinators in order to validate my findings.

Research Participants and Procedures

   Phase I

Study Participants

The target population included people in Kentucky who had served as a FCN for at least one year. Because a comprehensive contact list of FCNs serving Kentucky did not exist, I recruited participants from a variety of sources. Initially, I made contact with three educational programs in Kentucky affiliated with the International Parish Nurse Resource Center located in St. Louis, Missouri. Representatives from the programs provided names of other key leaders throughout the state. The Office of Church and Health Ministries of Norton Healthcare in Louisville, Kentucky, provided a registry of FCNs affiliated with their program and included me in a consortium of FCN

Coordinators newly convened to begin sharing information. Three of these coordinators provided contact information or agreed to forward the survey to other FCNs. I was invited to an annual Faith Ministries meeting at Somerset Regional Hospital in Somerset, Kentucky, at which I met additional FCNs and obtained more contacts. A contact with Health Ministries Association, a national organization of professional and lay people involved in the integration of faith and health, led to an announcement of the study to members in a monthly email newsletter. The email announcement resulted in only one FCN meeting inclusion criteria; however, two FCNs from other states agreed to participate by reviewing the survey and providing input prior to administration. Through these efforts, I gathered contact information for 176 unduplicated names. A total of 10 email contacts and 12 postal contacts were returned as undeliverable, leaving a total of 154 potential participants.

Instrument Design

In developing the content of the survey (Appendix A), I first considered the existing literature on FCN practice, including the *Faith Community Nursing: Scope and Standards of Practice* of the American Nurses Association and Faith Ministries Association (2005). I compared available information about FCN roles to literature about the current health care delivery system, with a focus on service gaps that affect older adults. These gaps were identified through the holistic lens of health as described by the World Health Organization (1946), using the ICF Model and the social-ecological approach as guiding theories. For demographic content, I sought information to garner a clear picture of the people serving as FCNs without unduly adding to the burden of the survey (Dillman, 2007). Because the contact information included a combination of traditional mail addresses and email addresses, I utilized mixed mode surveys – paper and two forms of electronic instruments.

I used a modified, tailored design method as described by Dillman (2007) to enhance the aesthetic appeal, readability, and navigability of the survey. I grouped questions in a logical sequence based on topic, using bold characters, shading, and varying font size to assist with question clarity and navigation. Grouping the questions into sections allowed FCNs to consider only those pertinent to them based on prior responses.

Following the introduction, there were four sections to the survey instrument. Section A consisted of categorical and continuous scales to gather information about the individual and faith community. Categorical questions included level of nursing education, gender, personal faith, racial/ethnic background, religion, type of FCN education, relationship with faith community (e.g., volunteer or paid), and county of faith community. Continuous questions included duration of practice as a nurse and as a FCN, age, size of congregation served, hours per week served as a FCN, and ages of congregants served. Section B was one open-ended question asking the respondent to describe the major roles played in service to his or her faith community. In Section C, FCNs were asked categorical questions to describe their interactions with individual congregants; and in Section D, a series of response grids allowed the FCN to identify type of information obtained during histories and assessments performed. The survey concluded with two open-ended questions: one asking respondents to identify agencies or organizations to which they had referred congregants in practice, and a final response area for any additional information the FCN wanted to share.

For the on-line version, MRInterview software allowed the inclusion of imbedded navigation in the survey design. I used a consistent question order and altered wording of the questions only minimally to reflect the mode of response required because this differed among the software, form, and paper versions. Because in the other two formats respondents were able to skip questions they preferred not to answer, I allowed this feature in the on-line version, with the exception of questions essential for the study. The "form" version of the electronic survey and the paper booklet survey were nearly identical with the exception of having indicators for cursor placement when selecting or entering responses in the form version and scrolling through screens instead of turning pages.

Pilot Testing

Four FCNs who did not meet eligibility requirements for the study reviewed the instrument and provided feedback. I modified the survey in response to their feedback with one exception. One of the four reviewers objected to the first question including the category "other" in response to "I am a(n) RN, ARNP, Other". She correctly counseled that FCN is a specialty practice within nursing that has the minimum requirement of

being a professional nurse, thus excluding anyone who was not a registered nurse (RN) or advanced registered nurse practitioner (ARNP). However, other reviewers and other FCN consultants to this project suggested that there were many people self-identified as FCNs who did not meet this requirement. Because so little is known about FCN practice in Kentucky, I kept this option in the survey to identify the extent of this trend.

Procedure

I contacted individuals for whom email addresses were available via the internet and asked them to complete the survey. I provided an introductory letter (Appendix B) that explained the purpose of the study and the required elements of consent. Consent was evidenced by completion and return of the survey. Recipients sent a separate email message to me if they wished to receive results of the completed study. Study participants could complete the survey in one of three formats (e.g., on-line completion, off-line completion using a Microsoft Word form, or printing the survey and completing it by hand).

Option one, the on-line survey, used MRInterview, a survey software package available at the University of Kentucky through the Center for Statistical Computing Support (SSTARS). This software allows design and deployment of an online survey using SSL (Secure Sockets Layer) protocol. Participants could click on a link imbedded in the introductory email message and then complete and submit the survey. The last question of the survey asked about willingness to participate in Phase II. If the answer was yes, subsequent screens had questions about contact information.

There were advantages to Option One for both participant and researcher. First, the format was aesthetically pleasing, as graphics and color were employed throughout. Second, the survey design allowed participants to navigate the survey based on responses to prior questions. Rather than directing respondents to skip questions, they simply never appeared in the survey. Responses to certain questions were required before respondents could continue. Required questions were identified by a red symbol [»], and the need to complete these questions so labeled was explained in the instructions. The screen identified the existence and location of any missing responses before respondents moved to the next page. If a respondent found any of the required questions objectionable, she was unable to complete the survey. A final advantage of this completion method was

that, once data were collected electronically, they were easily downloaded to SPSS or another statistical analysis software package.

The major disadvantage to the MRInterview software was that, once a respondent began the survey, she had to complete and submit it before closing the web browser. If a participant closed the survey or the internet connection was lost prior to submission, all responses were lost. I explained this problem in the introductory email message so that FCNs could select the survey completion method most suitable to their schedules. Allowing individuals to stop and return to the survey was an option in MRInterview; however, it required assigning a log-in and password to each individual participant. My method of distribution of the survey made such assignment impractical. Another disadvantage was that a participant could not identify how many questions were left as she or he progressed through the survey. I added broad statements, including the number of sections to the survey, but time to complete the survey varied considerably based on individual responses.

The second option for survey completion was an attached version in Microsoft Word Forms format. This format allowed a respondent to select boxes in multiple choice questions and type responses to short answer or numerical questions. Participants could start and stop the survey at their convenience. There were detailed instructions on how to save the survey and then send it as an attachment to an email address especially designated for the survey. For confidentiality, messages were accessed by a University of Kentucky graduate research assistant who had completed HIPAA training and was approved as part of the IRB application. She printed the anonymous surveys and gave them to me. This format allowed participants to complete the survey in stages, view it in its entirety, and gauge its length. The main disadvantage was having to save and attach the survey to send it to a specified email address. In two cases, respondents returned the survey to the investigator's email address, thus creating the potential for responses to be linked to an individual. To correct this problem, I printed the survey and pooled the hard copy with the other surveys received in the same format. Other disadvantages were that data had to be hand-entered for analysis and that some respondents failed to indicate their willingness to participate in the interviews.

A third option was to print the "Form" version of the survey, complete it by hand, and fax or mail it back to the investigator. For ease of response, a fax coversheet and a mailing label were also included as an attachment. Advantages and disadvantages were similar to those described earlier for completing the form by computer. A potentially unique advantage was easier survey completion by those not comfortable using the computer. The major disadvantage was any expense incurred by the respondent to return the survey.

Survey Distribution and Follow-Up

I used a four phase survey method to enhance response rate. I sent an initial email message, followed by three follow-up email messages (Appendix C). I sent the first reminder three weeks after the initial request, a second reminder two weeks later, and then a final plea 10 days later. I embedded the survey link and included attachments in each but changed the message slightly each time.

Approximately half of the FCN's contact information did not include email addresses. For FCNs without email addresses, I conventionally mailed a packet with the same cover letter describing the study as discussed above, a paper copy of the survey in booklet form, a self-addressed postage paid envelope for survey return, and a separate postage paid postcard asking the respondents their willingness to participate in the interview and their desire to receive study results. I sent postcards for the first two reminders and a letter as a final request. I did not include additional copies of the survey though I provided a toll-free number to allow recipients to request a new survey if needed. In two cases, FCNs contacted me to request a new copy of the survey.

Phase II

Sample

The target population for Phase II included persons who were practicing FCNs for at least one year and who serve a population at least 40% of whom were older adults. FCNs who indicated a willingness to participate in a personal interview and who met the specific inclusion criteria that also included serving individual congregants as part of their role and practicing in Kentucky were selected based on my interest in obtaining geographic diversity (i.e., rural versus urban as well as regions of the Commonwealth),

diversity in ethnicity, faith, and size of communities served, and paid versus volunteer status. I interviewed a total of 15 FCNs, at which point I achieved the desired diversity of participants (i.e., paid and unpaid, urban and rural, Caucasian and African American, from large and small congregations) and was not gaining any new information from the interviews. Although all of the FCNs who responded and thus all who were interviewed are Christian, churches included Baptist, Catholic, Church of Christ, Episcopal, Methodist, Presbyterian, and Seventh Day Adventist.

Procedure

I communicated, either by email or telephone, with each of the FCNs using their preferred method to discuss the second phase of the study and choose a time and location of convenience for the interviews. The majority of interviews were conducted in the participant's home or church, with one in the public library and two in local restaurants.

Following introductions, I explained the study, responded to questions, had participants sign the informed consent document (Appendix D), and provided a copy of the consent form for the individual's records. I then explained the interview protocol. Upon approval, I audiotaped each interview (Appendix E), which ranged from 40 to 90 minutes, and also took notes to supplement the tape. At the conclusion of each interview, I explained that the study design also included interviewing clients of the FCN who were 65 years old or older for whom services were provided for at least one month. I discussed issues related to inclusion criteria, including cognitive capacity, and I provided flyers to FCNs to distribute to appropriate congregants. The flyers, approved by the IRB, included a brief introduction to the study and a toll-free number to ask further questions about participation (Appendix F). The FCN determined the cognitive capacity of the client based on her professional assessment and ongoing client relationship and then allowed the congregant to determine interest in being interviewed.

Phase III

Sample

In Phase III, I interviewed client congregants in order to understand the role the FCN played in their health and to identify any unmet health needs. Congregant

participants were encouraged to contact me directly after receiving a recruitment flyer from their FCN. A total of 6 people agreed to participate, and I interviewed all of them.

Procedure

I conducted semi-structured interviews using a format similar to Phase II. I met each person in her or his home or church, introduced myself, explained the study, and completed consent documents (Appendix G). Upon approval, each interview was audiotaped (see Appendix H for Phase III Interview Guide). Interviews varied in duration from 20 to 90 minutes.

Data Management and Analysis

Survey Data

As previously noted, I used MRInterview software to compile the data from participants who completed on-line surveys. I entered data from the other forms of the survey instrument manually into a Microsoft Excel spreadsheet. I double entered the data to ensure accuracy. I then transferred both data sets to SPSS software for statistical analysis and used means, standard deviations, and cross-tabulations to analyze the descriptive questions of the study. Cross-tabulations allowed separation of data based on whether or not FCNs served individual congregants, as well as comparison of Phase II participants to the larger group of Phase I participants. Narrative data, including specific roles served and referral to outside agencies, were manually counted and categorized. The count and categorization were confirmed by my Dissertation Chair.

Interview Data

Either a research assistant under my supervision or I transcribed each survey tape verbatim after each interview. I de-identified transcriptions by replacing names with pseudonyms and removing the names of churches. I then compared the taped interview and my hand-written notes to each transcript, correcting any errors and adding my observations of non-verbal communication. Data were kept secured in a locked file in the primary investigator's office. All audiotapes will be destroyed within one year of the completion of this study.

Data Analysis

Qualitative research is a systematic and reflective process for development of knowledge, permitting research to be driven by the data obtained in order to build a holistic picture of phenomena experienced (Malterud, 2001). In this study, the survey data provided information about characteristics of FCNs and their congregations along with descriptive information about current practices; however, the interview data provided the meaning behind these practices.

Phenomenological Approach

Because I desired to gain an understanding of the meaning of faith community nursing to the FCNs and to their care recipients, each from their own point of view, I used a phenomenological approach to analyze the data (Denzin & Lincoln, 2005; Domholdt, 1993). Such an approach recognizes that individuals view the world based on their own unique history and situation. Characteristics include attentiveness, empathetic understanding, and the suspension of preconceptions during the interviews. These provide a window for interpretation of the conceptual world constructed by each individual about her or his experiences (Bailey, 1997). Careful analysis of first-person narrative descriptions allows the researcher to draw meaning from the subjectivity of experiences as lived by each individual. In this study, the semi-structured interviews in Phase II and Phase III allowed each participant to provide his or her perspective, while also allowing some structure for comparison of experiences and meanings.

Levels of Coding

I used open coding (Strauss & Corbin, 1998) to identify and label events or phenomena from the stories of the participants. This involved line-by-line analysis to fracture the data by allowing identification of individual concepts or phenomena. Next, I grouped the identified concepts into categories and through an iterative process of re-reading the transcripts. I refined these categories across all transcripts. The initial categories identified included faith connectedness, current practice, gaps, interactions with others, and personal factors. Each of these categories had subcategories. For example, subcategories for interactions with others included faith community leaders, care recipients, other congregants, and health and social service providers. Many

subcategories included their own subcategories. For example, health and social service providers included interactions on the individual level and on the institutional level.

During the next phase, axial coding, I re-grouped the discrete concepts and linked them together according to commonalities among the codes (Strauss & Corbin, 1998). I considered the results in light of the research questions and identified six broader themes, along with sub-themes, based on the data. These themes, *a strong grounding in faith, a sense of congregational family, reliance on general nursing assessment skills (rather than formal assessment), intentional empowerment of congregants to meet identified needs, performance of bridging roles, and shared challenges,* are described in detail in Chapter Four.

In a final selective coding step, I compared the themes and sub-themes to the roles of FCNs as defined by the International Parish Nurse Resource Center, and to the Nursing Intervention Classifications (NIC) (Burkhart & Androwich, 2004; Coenen, Weis, Schank, & Matheus, 1999b), an established system for classifying nursing interventions. The core concept that emerged set the groundwork for integration of the ICF and social ecology models to explain FCN practice.

Verification of methods was provided by Pamela Teaster, Ph.D., my Dissertation Chair and an experienced qualitative researcher. Dr. Teaster and I coded three interviews independently and then compared our work to help me identify initial codes and categories in the data. Dr. Teaster then reviewed the themes, sub-themes and narrative support to assure consistency and coherency.

Validity and Reliability - Trustworthiness

Validity of this study was enhanced by the rigor of data collection, management and analysis. Triangulation of methods, including multiple sources of evidence and verification of draft findings with members of the Kentucky FCN Coordinators Consortium, contributed to internal validity (credibility) of the results. Linkage of study results to prior research on the role of FCNs contributed to external validity (transferability) (Portney & Watkins, 2008). The roles and scenarios described by the FCNs demonstrated consistent themes among the interviewees and analysis continued until data saturation was reached, with no new categories identified. Meaningful quotations provided "thick descriptions" to represent and confirm the identified themes

(Mellion & Tovin, 2002) and FCN coordinators confirmed that data and themes were consistent with their own experiences. Subsequent to analysis and theme generation, the data were compared to prior research on the role of FCNs as categorized by a standardized classification system utilized in nursing practice.

Reliability was strengthened by the consistency of questioning and analysis, the guidance of an experienced qualitative researcher for analysis of interview transcripts, and by guidance from the FCN Coordinators who reviewed drafts of the survey and interview guide.

Researcher Preconceptions – Phase II and III

Qualitative research requires that the researcher identify inherent biases that may inadvertently influence data gathering and analysis. I conceived this study based on my academic preparation, prior professional life, and experiences with fragmentation of the current health care system, specifically the way older adults are treated. I have extensive experience as a health care provider and administrator. That background, together with my review of relevant literature and theory and gerontology training, helps me recognize how the health care system can and should work to achieve optimal patient outcomes. Also, as a person of strong Jewish faith, I believe that spirituality is a significant component and determinant of health. The growing body of literature linking spirituality and health, described earlier in this dissertation, may, in fact, understate this connection due to challenges in measurement of religiosity and spirituality.

An additional potential bias is my rehabilitation background. As a physical therapist, I observe signs of potential functional decline as a matter of course. This automatic behavior may include the recognition of impaired balance in a person who reaches for furniture when walking, or weakness in a person who has slight delay in rising to stand. I have knowledge of resources that may help slow or reverse this decline, and I know the importance of preventive intervention.

In the next chapter, I present results of the study. These results include a description of FCN respondents and the services they offer to their congregations followed by an in depth consideration of their specific practices in serving individual congregants and the meaning and impact of these interventions. Next, I present themes

and sub-themes identified from the in-depth interviews with FCNs and their care

recipients and a comparison to existing FCN standards.

Chapter Four - Results and Analysis

This chapter describes findings from all three phases of my research in the order in which I obtained the data. I describe characteristics of the FCN respondents, including demographics, education, and major activities reported by all respondents. Based on the data from those FCNs who reported serving individual congregants, I present findings regarding client assessments and personal interventions. The chapter concludes with findings from my interviews with FCNs and their care recipients.

Phase I Survey Results

The purpose of this phase was to gather information about FCNs currently practicing throughout Kentucky and the congregations they serve. I sought a picture of the demographics of the individuals and communities, as well as the services provided within these relationships. The study population included 176 unduplicated potential contacts obtained from the FCN educators in Kentucky. Of these, 10 email surveys and 12 postal surveys were returned as undeliverable (n=22). Nine respondents said that they were not practicing FCNs, resulting in 145 FCN contacts. Of the 145, a total of 60 surveys were returned, for a 41% response rate based only on the known contacts and an acceptable rate of return in social science research (Kaplowitz, Hadlock, & Levine, 2004; King, Pealer, & Bernard, 2001; Price, Murnan, Dake, Dimmig, & Hayes, 2004). Of the 60 responses, 33 were completed using on-line completion, five used the off-line Microsoft Word form, and 22 used the paper version.

FCNs from 21 counties, representing rural and urban areas throughout the state, responded to the survey. The majority of respondents were from Jefferson County (38%), a direct result of the contact list compiled by the FCN Coordinator from a Louisville hospital. Figure 4.1 illustrates the geographic diversity of respondents. There was one respondent from Northern Kentucky, three were from Eastern Kentucky, eight from Western Kentucky, thirty-four from Central Kentucky, and fourteen from South-Central Kentucky. One FCN did not include her county of residence.
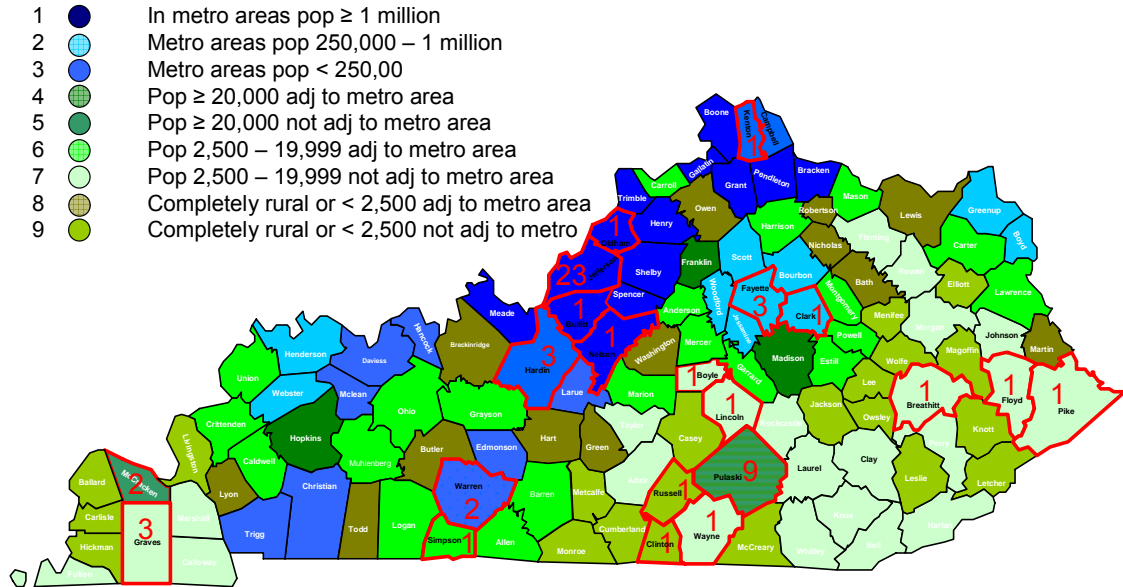
1. In metro areas pop ≥ 1 million
2. Metro areas pop 250,000 – 1 million
3. Metro areas pop < 250,00
4. Pop ≥ 20,000 adj to metro area
5. Pop ≥ 20,000 not adj to metro area
6. Pop 2,500 – 19,999 adj to metro area
7. Pop 2,500 – 19,999 not adj to metro area
8. Completely rural or < 2,500 adj to metro area
9. Completely rural or < 2,500 not adj to metro

Data Source: Rural-Urban Continuum Codes, USDA, revised 2003

Adapted from map prepared for UK Center for Rural Health by Elmer Whitler and Tena Smith

Figure 4.1 Survey Responses by County

Demographics / Characteristics

Table 4.1 provides demographic information for the 60 FCNs who responded to the survey. All were women who ranged in age from 32 to 87 years old, with a mean age of 57 years (S.D. 11.1). Of those who provided information about race, fifty (87.7%) were Caucasian and seven (12.3%) were African American. The overwhelming majority of respondents were registered nurses. Although three LPN respondents (5%) were not FCNs as defined by the ANA Scope and Standards of Practice (American Nurses Association & Health Ministries Association, 2005), they self-identified as FCNs for purposes of the survey, and I included them in Phase I analysis. All of the FCNs had been practicing nurses for more than five years, with the majority practicing for more than 20 years. Only half had been practicing as FCNs for more than five years. All nurses identified their religion as being some form of Christianity.

Table 4.1 *Phase I Demographics*

Age	n	Percent
31-40	3	5.0
41-50	10	16.7
51-60	24	40.0
61-70	14	23.4
71+	6	10.0
Not reported	3	5.0
Race		
African American	7	11.7
Caucasian	50	83.3
Not reported	3	5.0
Nursing Education		
RN	52	86.7
ARNP	5	8.3
LPN*	3	5.0
Duration of Practice as Nurse		
< 1 year	0	0.0
1 – 5 years	0	0.0
6 – 10 years	3	5.0
11 – 20 years	13	21.7
> 20 years	44	73.3
Duration of Practice as FCN		
< 1 year	5	8.3
1 – 5 years	25	41.7
6 – 10 years	21	35.0
11 – 20 years	7	11.7
> 20 years	2	3.3

Phase I FCN Practice

Seven respondents (11.7%) reported having no specific training for their role beyond their regular nursing education, 30 (50%) attended a formal program accredited by the International Parish Nurse Resource Center, 19 (31.7%) attended organized continuing education courses, and seven (11.7%) received informal training by another FCN.

Table 4.2 *Phase I FCN Practice*

Denomination	n	Percent
Baptist	18	30.0
Episcopal	2	3.3
Methodist	5	8.3
Non-Denominational	3	5.0
Presbyterian	3	5.0
Roman Catholic	17	28.3
Unitarian Universalist	1	1.7
Other	11	18.3
Size of Faith Community		
< 100 members	8	13.3
100 – 300 members	21	35.0
301-599 members	11	18.3
600 – 1000 members	10	16.7
> 1000 members	10	16.7
Hours Worked by Volunteer FCNs		
0 – 10 hours per week	48	88.9
11 – 20 hours per week	6	11.1
> 20 hours per week	0	0.0
Hours Worked by Paid FCNs		
0 – 10 hours per week	0	0.0
11 – 20 hours per week	4	66.7
> 20 hours per week	2	33.3

Fifty-four (90%) reported that they serve as volunteers; six (10%) said that the faith communities they serve pay them. As expected, paid FCNs tended to spend more average hours per week in their FCN role than volunteers, with all paid FCNs and only 11% of volunteer FCNs spending at least 11 hours per week working.

Specific roles (Figure 4.2) reported by the 60 FCN respondents were categorized according to the expected roles of FCNs as reported in the literature and included in standard FCN educational curriculum established by the International Parish Nurse Resource Center (American Nurses Association & Health Ministries Association, 2005; Holstrum, 1999). Because descriptions of activities made it difficult to differentiate between these two roles, I combined health advocate and referral source, as advocacy roles identified were for the individual rather than related to health policy. Health education was identified as a role by the women more than three times as often as any other.
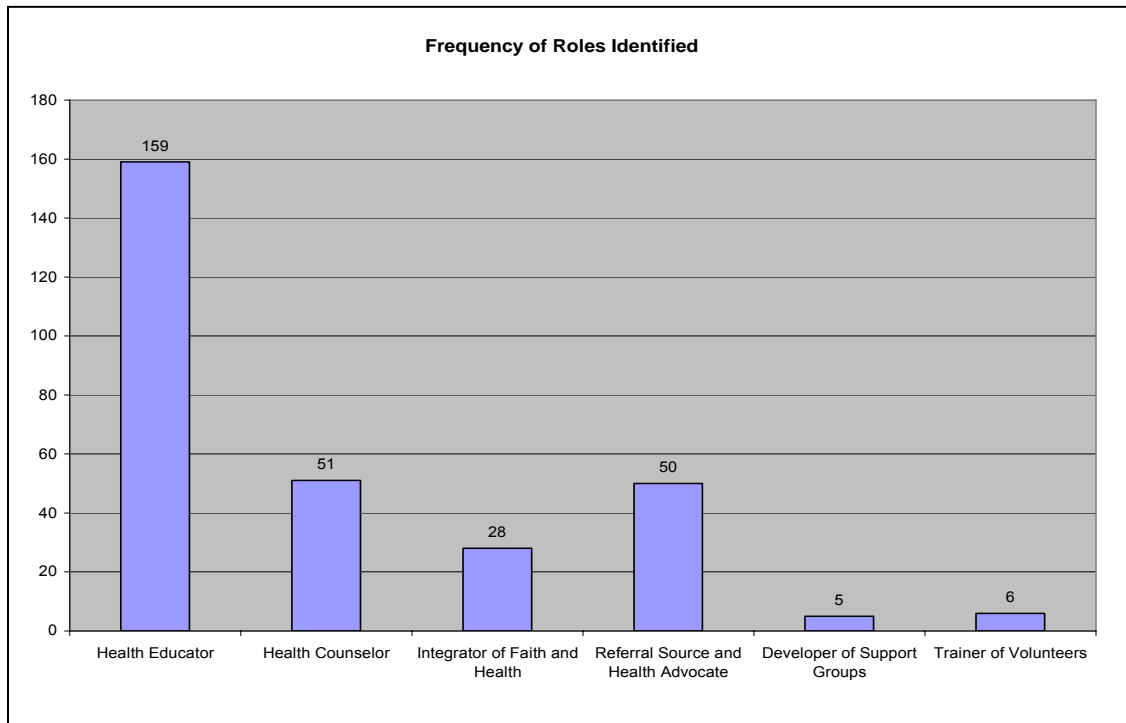
Figure 4.2 Roles Identified by FCN Respondents

Congregant Interactions

Twenty-three of the FCNs (38.3%) provided services, including those identified above, but only in group settings. Thirty-seven (61.7%) of the FCNs included individual patient contacts as part of their practice. Locations for these contacts included the faith community (60%), the individual's home (24.3%), hospital (11.4%), nursing home (7.6%), and assisted living community (5.4%).

The information obtained by FCNs during history taking for new clients varied widely (Table 4.3). Medical history, name of health care providers (HCP), and social support available were always or often obtained from nearly half the recipients. History of urinary incontinence and history of falls, both significant issues in geriatric care, were always or often obtained from 40% of care recipients. Status of preventive health screens, which is important in all age groups, was always or often assessed in only 30% of cases reported. Fifty-seven percent always or often checked for signs of potential abuse or neglect.

Table 4.3 *Information Obtained During Intake*

Frequency of Obtaining Information	Always/Often %	Occasionally %	Rarely/Never %
Signs of Abuse/ Neglect	56.8	13.5	29.7
Medical History	48.6	18.9	32.4
Name of Healthcare Provider(s)	48.6	10.8	40.5
Social Support Available	47.2	19.4	33.3
Current Medical Treatment	43.2	16.2	40.5
Current Medications	43.2	18.9	37.8
Spiritual Beliefs and Needs	43.2	21.6	35.1
Financial Needs	43.2	32.4	24.3
Work History	43.2	37.8	18.9
Urinary Incontinence	41.7	25.0	33.3
History of Falls	40.5	21.6	37.8
Health Insurance	40.5	32.4	27.0
Use of CAM*	29.7	37.8	32.4
Preventive Health Screens	29.7	45.9	24.3

* Complementary and Alternative Medicine

As with patient histories, patient assessments varied widely, with very few formal assessment tools being utilized. Figures 4.3 and 4.4 display the likelihood of formal or informal assessments conducted in key areas that are addressed in traditional nursing assessment. FCNs reported always or often using informal assessments of these areas in approximately half of their encounters, though formal assessments were rarely utilized.
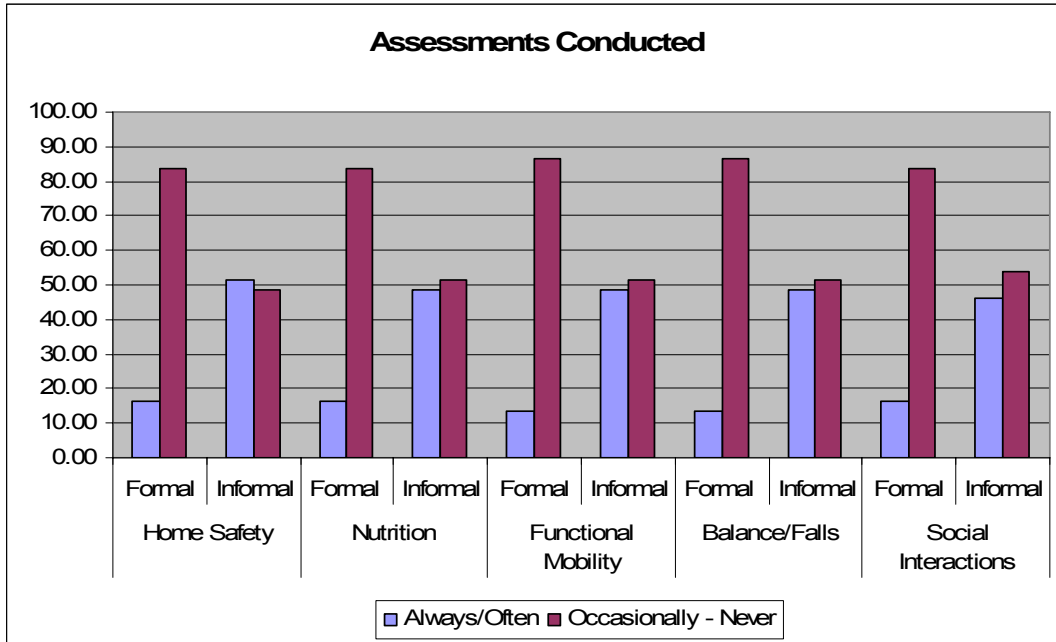
Figure 4.3 Formal and Informal Assessment of Key Areas
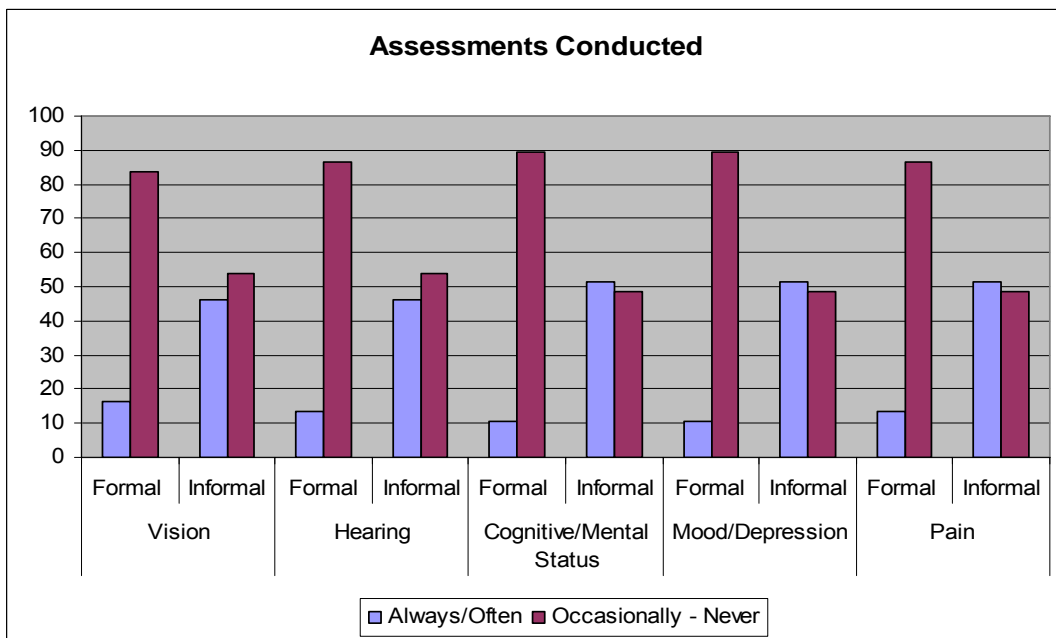

Figure 4.4 Formal and Informal Assessment of Key Areas

Twenty-nine of thirty-seven FCNs who work with individual congregants (78%) reported referrals to community agencies, including Alzheimer's Association, American Cancer Society, Meals on Wheels, the local Health Department, Hospice, and Adult Protective Services. The most frequent referral was for home health services.

Phase I Summary

The 60 FCNs who responded to the survey represented all four regions of the state – Eastern, Western, Northern, and Central Kentucky – a range of rural and urban counties, and diverse denominations of churches of varying sizes. The most prevalent roles identified by the FCNs were those of health educator, health counselor, and referral source/advocate. Forty percent of respondents did not serve individual congregants, but instead performed activities for the congregation as a whole, such as teaching educational classes and writing articles for the church bulletin. For those FCNs who did serve individuals, there was no consistency identified in the history information obtained from clients during intake, although observing for signs of abuse or neglect was always or often included by a majority of respondents. Assessments conducted by the FCNs rarely included any formal assessment instruments or surveys; however, informal assessments were always or often completed in many key areas such as home safety, functional mobility, pain, mood, and mental status approximately 50% of the time.

Phase II Results – FCNs

The purpose of this phase of the research was to gain a deeper understanding of the FCNs and the roles they played within their congregations, including their motivations and the meaning they placed in their practice. I selected 15 participants from the Phase I respondents who indicated a willingness to be interviewed. All FCNs interviewed had been practicing FCNs for at least one year, and they represented diverse faiths, geographic regions, and races to the extent possible.

Phase II Socio-demographic Information

Nearly three-quarters of the FCNs interviewed were between 51 and 70 years of age, with a mean age of 60.5 (S.D. 9.9). A third were Roman Catholic and nearly all were Caucasian (Table 4.3). One LPN respondent was included because she was the only African American FCN who agreed to be interviewed, although as previously noted, she is not technically a FCN as defined by the American Nursing Association.

Table 4.4 *Phase II Demographics*

Age	n	Percent
31-40	0	0.0
41-50	2	13.3
51-60	5	33.3
61-70	6	40.0
71+	2	13.3
Race		
African American	1	6.7
Caucasian	14	93.3
Nursing Education		
RN	14	93.3
ARNP	0	0.0
LPN*	1	6.7
Duration of Practice as Nurse		
11 – 20 years	4	26.7
> 20 years	11	73.3
Duration of Practice as FCN		
1 – 5 years	5	33.3
6 – 10 years	9	60.0
11 – 20 years	1	6.7
> 20 years	0	0.0

Phase II FCN Practice

As in the Phase I respondent group, the majority have been in nursing practice for more than 20 years and in FCN practice for fewer than 10 years. Their congregations include between less than 100 members and approximately 20,000 members. Twelve of the 15 (80%) serve as volunteers.

Table 4.5 *Phase II FCN Practice*

Denomination	n	Percent
Baptist	1	6.6
Episcopal	1	6.6
Methodist	3	20.0
Non-Denominational	3	20.0
Presbyterian	1	6.6
Roman Catholic	5	33.3
Other (Seventh Day Adventist)	1	6.6
Size of Faith Community		
< 100 members	1	6.7
100 – 300 members	4	26.7
301-599 members	2	13.3
600 – 1000 members	3	20.0
> 1000 members	5	33.0
Hours Worked by Volunteer FCNs		
0 – 10 hours per week	9	75.0
11 – 20 hours per week	3	25.0
> 20 hours per week	0	0.0
Hours Worked by Paid FCNs		
0 – 10 hours per week	0	0.0
11 – 20 hours per week	2	66.7
> 20 hours per week	1	33.3

All women serve predominantly Caucasian congregations, with the exception of the one African American FCN who agreed to be interviewed and who serves a congregation that is 85% African American. Most of the FCNs were from Jefferson County (n=6), with two each from Fayette and Graves, and one each from Campbell, Nelson, Oldham, and Pulaski Counties.

Phase II

Kentucky County Classification
Rural-Urban Continuum Codes
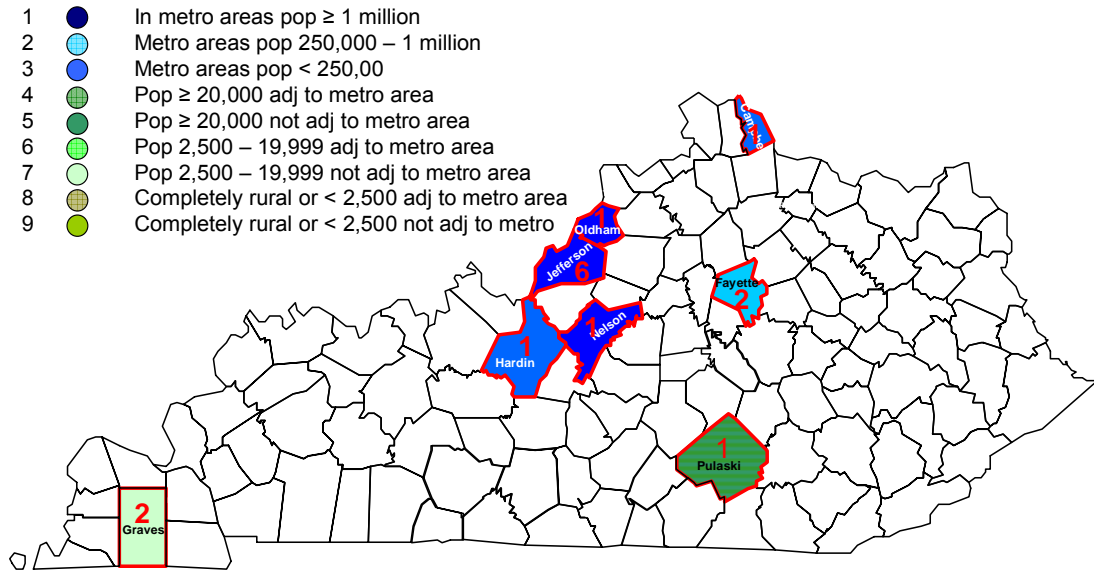
1	●	In metro areas pop ≥ 1 million
2	●	Metro areas pop 250,000 – 1 million
3	●	Metro areas pop < 250,00
4	●	Pop ≥ 20,000 adj to metro area
5	●	Pop ≥ 20,000 not adj to metro area
6	●	Pop 2,500 – 19,999 adj to metro area
7	●	Pop 2,500 – 19,999 not adj to metro area
8	●	Completely rural or < 2,500 adj to metro area
9	●	Completely rural or < 2,500 not adj to metro

Data Source: Rural-Urban Continuum Codes, USDA, revised 2003

Adapted from map prepared for UK Center for Rural Health by Elmer Whitler and Tena Smith

Figure 4.5 Interviewed FCNs by County

I contacted each FCN by telephone to schedule a private interview session. At that time, I briefly explained the format of the interview, and we agreed on a mutually convenient time that would allow at least two hours for the visit. I completed the informed consent procedure and obtained permission to audiotape before beginning each interview.

Phase II Themes

When I began this investigative journey, I was cautioned by Sister Beatrice Keller, a key leader in FCN education and practice in Kentucky, that, "If you know one faith community nurse, you know one faith community nurse." The diversity she suggested was consistent with my findings. Nevertheless, interviews, which were between one and two hours in duration, revealed six main themes: *a strong grounding in faith, a sense of congregational family, reliance on general nursing assessment skills (rather than formal assessment), intentional empowerment of congregants to meet identified needs, performance of bridging roles, and shared challenges.* Each theme also contained related sub-themes, supported by excerpts from the participants' interviews.

For ease of identification, I used pseudonyms for each participant, selecting those pseudonyms in the spirit of each participant's name.

Theme 1: Strong Grounding in Faith

As expected, all of the FCNs clearly identified the presence of faith in their lives and their roles within their congregations. This included their motivation for entering faith community nursing as well as many of the practices they employed. By their choice, I met most of the FCNs at their homes or in their church offices to conduct the interviews. I was immediately struck by the sense of spirituality in the environments that each chose. The women's spirituality was most evident by the presence of religious artifacts or the placement of a bible in a place of apparent regular use, such as beside a comfortable chair. In four homes, specific areas, including two indoor sitting areas and two yards seemed as sanctuaries based on built and natural environments. In many cases I felt that I was in the presence of holiness throughout the interview. The women exuded spirituality in their manner, especially the tone of their voice, their posture, and their words. They freely expressed their faith in their explanations that they were called by God to share their gifts. Laura, aged 63, clearly believed in this call:

> The Lord knocked me over with a brick and said this is what He wanted me to do. It was unbelievable… I was sitting at my desk at work in front of a computer… and up pops on my computer, "I am able to accomplish the two things I love most in the world – the Lord and nursing." I finished my business and closed my computer and I was obsessed with it. I didn't even know what parish nursing was and it was all… I knew… I just knew that this is what the Lord wanted me to do with the rest of my life… It's just what I'm supposed to do. I love this church, I love these people, and I truly love the Lord. And I know that this is where He wants me.

Krista, aged 66, noted,

> If you have a profession, you just owe it to your faith community to give of yourself. You know, the Lord gave you a talent; you are called to share it.

Colby, aged 52, described serving as a FCN as directly related to her faith.

> Having a life-long commitment to church and church service, it was a good way to use my unique gifts and talents in order to give back to my congregation

Several FCNs identified the importance of sharing their faith with those they serve. Claire, aged 64, described the reward in "bringing people to a higher level in their faith."

> This man that I've been visiting said that he feels that he has grown closer to God during his illness… When we go to the hospital, we see people who may be Catholics, but might not have been practicing Catholics, and the reward of bringing them (pause) I hate to say back into the church - that's not it, but where they wanted to be at that point.

Faith Rituals: Prayer, Communion, Prayer Chains, Prayer Quilts

Most of the women referred to the inclusion of prayer in the healing relationship. Anne Marie, aged 79, enjoyed the freedom to include religion in her nursing role and to pray with people of common faith:

> And of course, working for the state all these years, you know, we wouldn't dare mention anything pertaining to religion… I wouldn't have thought of praying with the patient—out loud that is— of course, there was a lot of prayers, but not out loud. And I wouldn't have even thought about mentioning the church or anything to a patient… And it's so nice to minister to your congregation that you know are on the same uh... line of thinking that you are.

Their grounding in faith was also evidenced by the fact that faith rituals, such as communion or prayer chains, were identified as a way many FCNs initiated contact with a given congregant in need. In some cases, Eucharistic Ministers (i.e., a member of the laity who has been authorized by church clergy to administer and distribute communion) would refer the FCN to a person whom they had visited and had brought communion. In other instances, FCNs themselves regularly brought communion to individuals in the hospital, nursing facility, or home. An ongoing caring relationship was built from that initial contact. Six FCNs described active prayer chains in their congregations, a ritual in which members pray for the health and well-being of specific congregants and notify other members to do the same, through a telephone tree

Despite a clear grounding in faith, the faith ritual of prayer was not always a part of interactions among FCNs and congregants. Though most nurses reported praying with congregants or reading scripture, two said they only pray if asked to do so. Two FCNs also initiated the distribution of prayer quilts to congregants in need, to serve as a tangible

expression of the prayers of the faith community. Anne Marie, aged 79, was visibly moved as she described her experience with this project.

> We just take (fabric squares) to a meeting, a women's meeting, and with floss. And, the women will say a prayer and tack a place in that square wherever they want to and sign their name and say a prayer for that particular person that's going to be get--We always know who they're for. The lady that we took the first one to was a nurse… And she just- I'd never seen anybody be so appreciative. She just loved that prayer square. And when I'd go to visit her after that, she'd say, she just made me feel so good. She'd say, "You don't know what that has meant." She said, "Whenever I just get a headache so bad I can't hardly stand it," she was dying with cancer. She said, "I just take that square and I feel those knots and I read those names and I pray for them." And I thought, Oh, here she's praying for all of us, and the whole purpose is for us to pray for her.

Personal Growth Through Service

Several women sensed that their own faith grew through service as an FCN. For example, Jenna, aged 57, noted surprise in changes she has experienced over her ten years as a FCN.

> I think that when I look back over the years, the part of it that I never would have guessed I would have enjoyed—in fact I would have guessed I never would have ever wanted to do this—is to be a worship leader… I was terrified to do that. And now I really enjoy it. The function of it is it puts the nurse in front of the congregation. They feel comfortable. They know who she is. I've been identified. You know, it makes me accessible. But it also has just grown my faith and made me feel a true part of the church team.

Most women spoke of their personal satisfaction when providing service to their congregations in spiritual terms. Although only a few were paid for this role, even those nurses worked far more hours than the number for which they were being paid. All of the women believed they had been called to the mission of serving their congregations. Anne Marie, aged 79, had practiced nursing for 55 years and had been a FCN for the past ten years:

> I think I could say unequivocally that it is the most rewarding thing that I have ever done, especially and not got paid for. You know, honors professionally and all are nice and very welcome. You know, and they make me feel good. But there, there's something about doing parish nursing. You're doing it for the Lord. And it seems like there's just something much more rewarding about that, you know.

Integrator of Faith and Health.

Most of the women felt called by their own faith to serve in this specific way, and most of them bring prayer or faith through religious rituals into the healing relationship when congregants are ill or in distress. However, although all of the FCNs said that their major focus was health promotion, only four FCNs overtly mentioned faith in the context of motivating congregants to develop healthier lifestyles. According to Marcia, aged 60, a Seventh Day Adventist:

> Seventh Day Adventists have been involved in health as a part of faith for a long time. Right… no smoking, no caffeine, no pork, pepper … it's right there in the bible. I don't know why people don't understand that God put that there for a reason. Back in the 1850s Kellogg – did you know they were Seventh Day Adventist? The Lord gave her the health message and as a church, we became healthier by following the bible… The Holy Spirit is working through me … knowing that I have skills that can help someone be stronger in mind, body and spirit.

Sheila, aged 64, noted that her church hosts a weight-loss program called "Thin Within" that is based on biblical teachings about health, and another FCN reported helping coordinate an annual retreat that focused on health of mind, body, and/or spirit.

Three FCNs coordinated walking programs using figurative journeys to important sites in the bible. As an example, congregants walked independently and reported their mileage to the FCN, who kept track of the congregation's "progress" on their way to Bethlehem. In one case, the entire group walked together and included topical activities based on their figurative location along their journey, such as belly dancing in Morocco. This same congregation walked in silence one of the days while praying for congregants who had requested it. In these latter examples, faith was directly linked to the activitybut was not necessarily the motivation.

Although FCNs may either serve their own congregations or may be placed in other faith communities, all of the FCNs served their own churches. Their shared faith, shared membership, and shared history with the other members contributed to their motivation and their acceptance within the church family.

Theme 2 – Congregational Family

The role of the FCN as a member of the congregational family was perhaps best exemplified by Colby, aged 52, who described a commissioning service that was held for her in her church. The service included responsive readings and intentionally selected hymns. The elders in the congregation "lay on hands" to make her faith community nursing role more visible, "to lift it up as a ministry within the life of the congregation." A sense of integration within the congregational family is also evident in how FCNs interact with their congregation members on a regular basis whether in church or when absent. Laura, aged 63, described her simple practice of being aware of a congregant's presence. Each member is important in the life of the congregation and to the FCN in particular.

> If people that have come to church like every Sunday for the last 5 years and all of a sudden 3 weeks have gone by and this person hasn't been here, I call them. Just to say, "Are you okay? We've missed you. You know, just wanted to check."

The theme of congregational family resonated with two FCN roles reported in the literature and identified in Phase I, Trainer of Volunteers and Developer of Support Groups. In almost all cases, FCNs mentioned their reliance on other members of their faith communities to help with functional support of ailing congregants such as cooking meals, transporting congregants to appointments, or performing errands. Several FCNs also relied on members of Sunday school classes, who served as immediate family members within the larger congregational or extended family. Frequently, they used the term "church family" to describe these relationships. Two FCNs described numerous support groups including grief support, caregiver support and groups for people with various chronic conditions. In one of the churches, there is a weekly "Soul Care" meeting in which members or prospective members are encouraged to come to learn of the many support groups available to help and to be screened for needs that may require referral for individual counseling. The FCN is present to assist with screening and directing people to the appropriate support.

Theme 3: Reliance on General Nursing Assessment Skills

Within the congregational family, members have important roles and FCNs, while part of the congregational family, are also distinct within it. Their special skills as nurses allowed them to meet various health needs within the specific scope and practice established by the ANA. Only two FCNs used formal instruments on a consistent basis to assess congregants' needs. The rest relied on general nursing assessment skills and active listening to determine what intervention may be appropriate. In fact, although all of them kept records of interactions, it was important to them that these records not be documented using a medical model. Claire, aged 64, described how the simple act of sitting and taking a blood pressure reading can open the door to deeper conversation.

> We do a monthly health screening. We don't call it a health screening to the people as they come in, but it turns out to be that. I think people are more willing to come in if they think it's just to have their blood pressure taken, but then they share their story.

In addition to blood pressure screens, an informal assessment can be obtained by being acutely aware of a congregant's environment and relationships. Marcia, aged 60, described the informal assessment she completes each time she goes to visit a congregant.

> Sometimes I go into a home and do an assessment and … you know nurses are really good at assessment. I can just walk in and see what kinds of things a person might… well… I am just used to going in and looking around and figuring out what might be wrong. It might be just picking up obstacles laying around a house… it might be answering questions about medicines… it might be just praying together. It would be a scan of the house environment… I may help determine whether the person can really safely stay in the house.

Even in these trusted relationships, congregants may not be forthcoming about particular issues of concern. Charlotte, aged 42, explained how she might find out more details about needs that she suspects, but that the recipient may be reluctant to share.

> I might ask them if I could bring up some milk or something before I go there… Sometimes, that's just an excuse for walking over to the refrigerator, and seeing what's in the refrigerator. You know, nursing assessments are always made for the environment, and we will go in, and sometimes I'll call the children, and I'll say, "You know, I was visiting, and I'm so afraid that she's gonna fall. And, would you mind if we went in there, and kind of tidied up some, or moved her furniture around a little bit." Especially if they have fallen in the house...You know, we go out there, and we'll just kind of assess that. Just little things that can mean a lot.

Once such information is known, the FCN can begin to use her skills to develop a plan to help the congregant.

Theme 4 – Intentional Empowerment

Whether working with individuals or with groups, the FCNs recognized the importance of empowering members to help themselves and each other. Each of the FCNs clearly identified their role based on the established Scope and Standards of Practice for FCNs (American Nurses Association & Health Ministries Association, 2005). They stressed that their focus was on wellness rather than on a traditional nursing model of treatments and interventions and that this was often difficult for congregants and health care providers to understand. Jenna, aged 57, summarized it as "getting the faith community to claim its healthiest self."

> I usually try to find the resources for (congregants) and get them going… I don't want someone to rely on me 100% of the time… They get to a place where they have to take care of (their problems).

Part of getting members to take control of their health is educating them about their rights to make decisions and then helping guide and reinforce them as they take initial steps. In a few cases, FCNs described situations in which health care providers made recommendations that conflicted with the desires or values of the individuals. In such cases, often the congregant needed to discuss the specific situation with a person who was both knowledgeable and trusted. Deirdre, aged 71, relayed several stories of congregants who simply needed reassurance that they were making sound decisions about their own health care.

> There's Carla and Bob, and they both have health problems. He's going to be 90 … and she's in her 80's. And he has Parkinson's and he's in a motorized vehicle now and she fell and broke her hip about … 2 years ago. And ever since then she's had some mobility problems… and a wound that doesn't heal. They have a caregiver that comes in—2 caregivers … for 22 hours a day. This is sort of funny. And I started talking to her, about it. But she says, "We never have any just private time when it's just us!" And so from 3 to 5 every day, it's their private time. And it's cute. 'Cause they're both in their recliners and … I guess it's just so, it isn't always caregivers listening in on everything.
>
> The agency, they said, "We think this is dangerous. We don't think you should be doing this—that you should be alone for those two hours."

And she says, "What do you think?" See, that kind of thing, they'll bounce off of me. And I said, "Carla, I know what that means to you. And I don't think you're going to die in two hours, seriously. If that's, yo—if that means that much to you, then you do that for yourself." I just think, you know, if that two hours in a 24 hour period give her joy — If I really think it's too dangerous for them, I will tell them. But I would still say, "But the final decision is yours."

She also described a congregant who developed a serious post-surgical infection that required a long-term residential stay in a nursing facility, followed by outpatient therapy.

I also helped her to become her own best advocate. That if she needed to challenge personnel who were not washing hands or not giving her the care she needed in the hospital or in the nursing home— that she could speak up. (pause) That she would challenge the doctor if there were things that she didn't understand, because she was another one of those—she's sort of that generation where, "Well, the doctor said it." And I think, "Come on! That doesn't mean you can't ask a question or he's always right!" And, you know, and I would try to do that kindly. But I always tried to get her to um, stand up for herself, you know, in a real way. And she often would say, "I learned so much from you and how just to, you know, approach things, how to speak up when I needed to speak up."

In a story from Charlotte, aged 42, a woman wanted to allow her husband with Alzheimer's disease to return home instead of staying in a nursing facility. She was even more determined to do this when he wandered from the facility in an attempt to go home himself. With the support offered by her FCN and congregational family, she was able to keep him home for over a year, until he had to return to a facility for the last few weeks of life.

Also in the area of empowerment, many FCNs noted the importance of encouraging people to follow health recommendations. They asked congregants how a new medication may be working, checked vital signs for patients taking blood pressure medication, or checked in after a hospitalization to see if the discharge plan has been effective. The theme of empowerment overlaps the previously mentioned FCN roles of health educator, health counselor, and health advocate. The FCN helps educate patients about their rights and options, counsels them as they make health decisions, and empowers them to advocate for themselves, providing support as needed.

Theme 5 –Bridge Across Expanses

The complexity of the existing health system presents challenges to even empowered congregants, and the FCN is often regarded as a trusted resource to help with

system navigation. The importance of fidelity was emphasized by many of the FCNs in their assumption of this role. The nurses are considered trustworthy by congregants, both because of their role in the faith community and because they have proven themselves in established relationships. They are considered trustworthy by health care providers by virtue of being one of them. This unique position of trust enables the FCN to serve as a vital bridge across many domains.

A Bridge Between Congregant and Family

According to the 2000 Census report, 31% of adults aged 65 and older in Kentucky lived alone (Wan et al., 2006). Given the geographic mobility of younger generations, this often means that older adults are living alone without close relatives nearby to participate in their lives. Several FCNs described their role in these cases as being a vital link for families. This was a major focus for Jenna, aged 57.

> I think one of the most helpful things currently given the way um demographics are—I can be a wonderful conduit between the person and long distance relatives. On the phone or even with email. You know I can keep them up on mom and dad … I can be their eyes and ears…I can say now's the time for you to come home, or um you've really got to take the car keys away. You know, that kind of thing that they aren't here to do and um it's been very helpful. Finding them resources that—I don't make the decisions for the family but I'll say, "Here's what's available for you that you may not know about."

In other cases, even when families are nearby, immediate members may not recognize signs of functional decline that may be easily observed by the FCN. In such cases, the FCN is able to mobilize other family members and assist them in obtaining proper care for their loved one. Jenna provided this scenario as well.

> I can give you an example of a woman that actually had family in town and one Sunday I went to bring her flowers that had been given in honor of her husband and she hadn't been coming to church and when she opened the door it was very clear to me that she had Parkinson's. Nobody who saw her on a regular basis picked up on it. Four daughters that were living in different towns … and I called them and said, "I'm going to take your mom to the doctor." … She did have— she was sort of half way into her Parkinson's disease. Um... she no longer should live alone, so we had to change residences. Finally, we got her on medication and… made other recommendations

In another case, distance was not a factor, but rather, the difficulty of initiating the conversation. Paula, aged 69, described the case of a woman who was living with cancer

and still receiving chemotherapy, which made her ineligible for Hospice. She facilitated a conversation between this woman and her husband that the wife dearly wanted but felt unable to initiate.

> … and we talked, and she had admitted to me that it wasn't workin'—the chemo wasn't workin – but her husband wouldn't talk about it. And, you know, we—we sort of came to the conclusion there that maybe she needed to stop…um…I can explain to someone the benefits of having hospice as opposed to trying to hang on with the chemo… Sometimes families have to give the patient permission to die

Paula went on to describe teaching the congregant's husband how to use a form of Eastern medicine along with a visualization of being held in Jesus' arms in order to connect with his wife in a physical and supportive way as she was living the last days of her life.

> It was just perfect. I thought and the husband said to me later, and the family, I mean they still go on about it. The husband said to me that that was the first and only time that he was offered any kind of tool to make him feel that he could help her. You know, he felt useless. He felt hopeless.

A Bridge Between Congregant and Family and Health Care Providers

In addition to linking congregants and families, all nurses related stories in which they facilitated interactions among congregants and families and health care providers. Specifically, FCNs believed that they could serve as a liaison to enable people to get better care. The role of interpreter was also frequently described, either explicitly or through stories of intervention. Jenna, aged 57, is one of many FCNs who accompany congregants to medical appointments.

> I have frequently gone to the doctor with somebody and sat there with them so that I can hear the diagnosis and then interpret to the family. The same thing is— uh goes with the discharge plan of the hospital—you know that—the wife or husband is kind of rattled and they're not really hearing things and I'll ask for them or I'll say, "That won't work in this case. And I've been in his home and I know what it looks like and it doesn't fly," so you know just to be there along side 'em.

Laura, aged 63, finds that congregants rely on her as mediator and interpreter whether or not they have already been to visit their physicians.

> You know, they ask me all kinds of questions about, "I have this pain right here," and you know, 98% of the time I say, "I think you should see your doctor." You

know, but they come to me first. They could have been to the doctor and they still come to me and say, "Okay, what are they talking about?" With some of the elderly people, I have gone to their doctor with them, just so I could explain to them what this man said after we leave. Or at least say, "I don't think she understood that."

There's been quite a few times that people have asked me to go with them (to the doctors appointment) just so I can … interpret what the doctor is saying to them. You know, they talk in medical-ese and nobody really knows what they're talking about unless you're a medical person.

Beyond this interpreter role, there are times when FCNs reported that they had to initiate tough conversations on behalf of health care providers, just as described earlier with respect to such conversations among family members. Charlotte, aged 42, shared one example.

I will just tell the family what to anticipate… I mean, I'm not the one who says "Grandma's dying," but – but I'll be the one again with the tough questions and they'll say, "Well, the doctor said this, and the doctor said this," and I know what the doctor's trying to say, but he's not saying that. And so, I'll say, "Well, you know, this doesn't really look good." Or I may say, "If she were to die from this …" and I'll open up that door.

In other cases, routine screenings or conversations led to the discovery of serious medical conditions that needed attention. The FCNs then referred, or sometimes even pressured, the congregant to seek medical attention. Almost all of the FCNs reported that one of their regular activities was blood pressure screenings on Sundays and that these screenings served as a way to begin conversations that went far beyond blood pressure. Frequently, such conversations grew into long-term counseling sessions in order to help older congregants understand their chronic conditions, help caregivers identify their own needs, and guide people to additional resources.

A Bridge Between Congregant and Family and Health and Community Resources

FCNs clearly serve an important role in letting people know about available resources in the community. Many reported providing referrals to home health agencies, adult day care, social service agencies, and equipment companies. There are also long-established support groups such as those run by local chapters of the Alzheimer's Association and the Muscular Dystrophy Association that FCNs suggest to appropriate congregants. Specifically, there was a sense that their older congregants were a

generation of individuals "fiercely independent and either not informed about community agencies or not as willing, maybe, to ask for help." Elders often erroneously believe that all services are need-based, even when not the case. One FCN remarked, "You know, in a simpler time, we didn't have to know that kind of stuff." Charlotte, aged 42, had similar interactions with families.

> I have family members who come in and share things that's going on in their families, seeking help because they don't feel comfortable talking with their doctor, and they don't know where else to go. And, that's really where a lot of community resources and advocacy fall into place with that.

Several FCNs reported informal networks among nurses from various denominations in the same geographical area, through which they share knowledge and equipment from their respective loan closets. In some cases these networks were facilitated by local hospitals that employ FCN Coordinators; however, some were spontaneously formed by individual FCNs. Charlotte, aged 42, contacted the churches in her region and convened a group to share resources and to provide support one another.

A Bridge Between Congregation and Community

A final bridge is that of mobilizing citizens of the faith community toward social action. Many of the FCNs described connecting their congregations to the larger community through coordination of civic activities, including blood donations, walks for various causes, or wellness clinics that are open to the community at large. "We have a lot of people that are very civic minded. It's sort of their Christian way they can express God's love." In two cases, this role was extended to include influencing the faith community to become active in public policy. Paula, aged 69, described this as "faithful citizenship".

> I tie that in with good citizenship, and that's how we're called to be present and do God's work is often through other people. It may even be the government. I spend a lot of time responding to Senators and things like that. And that's what we're asked to do. … It's social justice. I was thinking in terms of providing clothing for the poor and things like that… but you gotta get out there and say "it's time to vote."

This theme again seemed to overlap with many of the seven FCN roles reported in the literature. By serving as a bridge among congregant, family, faith community, health

care providers and the larger community, FCNs serve as health educators, health counselors, referral agents, and health advocates.

Theme 6 – System Challenges

The final theme from the interviews is that of common challenges. Based on their experiences, FCNs identified challenges including privacy restrictions, fragmentation of the system, communication gaps, quality lapses, high cost of care, and availability of resources. Additionally, most women mentioned that they wished they could do more for their congregations.

Almost every FCN specifically mentioned changes due to privacy restrictions imposed by the Health Information Privacy and Accountability Act (HIPAA), as interfering with their involvement with congregants. Although FCNs used to call the hospital regularly to see if any church members had been admitted, such information is no longer available to them. FCNs and pastors encourage families to notify the church when a congregant is admitted to the hospital or has other needs; however, this is not always done and thus patients are missed. This knowledge was clearly important to the FCNs, especially when they learned that congregants had unmet needs or were hurt by the absence of their faith family. One FCN from a very small congregation had HIPAA waivers signed by her congregants so that if they needed her assistance in an emergency, she would have the authority to get involved in their care.

The fragmentation of the current health care system was regarded as particularly challenging to older congregants. Several FCNs specifically noted having to assist congregants in navigation among various doctors and settings. Colby, aged 52, was especially poignant in her description:

> I think the system is more unwieldy and more complicated than ever. I think that they cannot navigate the system because they cannot figure it out. And they do not know where to go for help. These are well-educated people. They're proud. They feel that they should be able to get it. They've always been able to take care of their own personal affairs, and they just can't—they can't figure this out. They have the access, they have the means, they have the education, and they have the personal resources, but because it is so complex, they don't even — they can't — they don't even understand the language.

Communication gaps were identified as coming both from the patient and family and the providers. Marcia, aged 60, identified a common trend amidst her older congregants.

> The biggest thing is … some people never question the doctor. Just never question anything at all… go along with whatever whether they understand it or not. …Or if somebody has told them something and they didn't understand it, they just nod along as if they did… I wish I could convince people and families to ask questions… And a lot of doctors just want to get them out of their office and get on to the next patient so they don't really even check to be sure someone understands… Of course, a lot of people would just nod even though they hadn't the slightest idea what was said… We would need to educate older adults about what they deserve and should demand.

Charlotte, aged 42, identified the lack of communication from the provider to the patient as a key area of gap-filling that she is able to fill.

> I really feel like I—the faith community nurse fills in some of those gray areas. That, that, physicians don't have time to sit down, and explain all of this. Their nurses don't have time to sit down and explain this. And, patients don't ask for an explanation. They shake their head, and they say, "Okay," and then they leave, and they say, "Let's go over to the church."

In these cases, FCNs again stressed the importance of empowering congregants and families to ask questions – mostly through coaching them and providing specific questions to ask of their physicians or of other members of the health care team. Such empowerment was clearly more prevalent than intervention by the FCN with the provider, although most held that as an option if necessary. They voiced recognition of the importance of helping people gain control over their own health.

Within the area of advocacy, respondents were also acutely sensitive to the current state of hospital care and conveyed the importance of being especially vigilant in that environment. The FCNs alerted congregants and families about assuring that providers washed their hands, checking medications, and being proactive in discharge planning. Marcia, aged 60, described the general state of care.

> So often people don't get good care in the hospitals anymore. I like to be a liaison between the person and the health care team if that is okay with the person and family.

Colby, aged 52, had clearly given this issue considerable thought.

What I find is the health care system does not do an adequate job of informing patients, family, as to time of surgery, time that they might be in surgery. And that all increases a level of apprehension. And it, it also, I see that it creates an adversarial role. The families are not trusting of what is being done. They think it is more being done to their family member rather than for their family member. That's something that the hospitals really need to work on.

The cost of health care and inadequate availability of resources were also of great concern to the FCN respondents. They reported that even with Medicare Part D, many older congregants were unable to afford needed medications and that many of their congregants were reluctant to access assistance programs. Educational programs to assist congregants in selection of Medicare Part D plans as well as "brown-bag pharmacy days" in which pharmacists were brought in to review prescriptions and advise congregants about potential adverse drug interactions were common. Lack of transportation resources was a major concern, and many FCNs relied on other members of the congregational family to help congregants get to medical appointments or to help a congregant visit a spouse who was hospitalized or in a nursing facility. Even when public transportation was available in the community, FCNs reported that such services were often unreliable and difficult for people to utilize for timed appointments. Another common concern was the insufficient number of adult day care centers and quality residential nursing facilities. Perhaps of greatest concern for the FCNs was inadequacy of reasonably priced home care services for older congregants who did not have family available to help. Members of the congregational family were willing to assist on a short-term basis, but long-term solutions were difficult to obtain.

Finally, as identified earlier, 80% of the women interviewed volunteered their services as FCNs, often in addition to working as a nurse in another environment. Most echoed a sense expressed by Carla, aged 54, who stated, "We really could be utilizing the captive audiences that we have to do more education or prevention" or Kelly, aged 61, who stated, "We haven't even tapped into all of the things we could be doing." The sense that they are not doing enough was definitely not consistent with congregants' opinions that were obtained in the third phase of this study; however, it was a consistent thread in many of the FCN interviews.

Phase II Summary

Despite the independence and diversity of the FCNs interviewed in this phase, several common themes emerged from their interviews. As expected, their own faith was the primary motivation for entering FCN practice. Faith rituals were commonly part of their interventions with individual congregants; however, health promotion was rarely linked to religion in educational programs, screenings, or literature in church bulletins. Rather, the church seemed to serve as a venue for health promotion activities, much as any other community may serve. The FCNs' dual role as a member of the congregational family and a health professional allowed them to develop close healing relationships with individuals and to empower the care recipients to take greater control of their health. Often, this was done by facilitating communication among the many people and organizations of influence within the set of nested interactive systems that contribute to health as described by the social ecological perspective. The FCNs also described common challenges to providing care, including regulations, system complexity, communication gaps, high cost, declining quality, and access to care. They all had the sense that they were not doing enough for their congregational family, a sense that was not shared by their care recipients interviewed in Phase III.

Phase III Results – Congregant Care Recipients

Phase III provided the all important perspective of the older congregant recipients, the focus of the FCNs' work. Six congregants volunteered to be interviewed. They included one couple, both of whom had a relationship with their FCN, one congregant who had received services in helping with his wife who died of Alzheimer's disease and with his own complicated medical problems, one congregant who had received care for herself over many months, and one who had received assistance with caring for her husband. A final congregant was in the unique position of having received care from the FCN in his church and serving on the health ministry team in his role as a retired pastor. Three of the recipients were male, and three were female.

The themes that emerged in their interviews reinforced several of the themes identified by the FCNs. Faith participation and faith rituals were important to all of the congregants interviewed. There was also a sense of trust that was based on their personal

relationship with the FCN as a member of their congregational family. This trust allowed them to accept and even ask for advice for health needs. Another common theme was continuity. The care recipients valued the sustained relationships with their FCN, when they had needs and when they had recovered, in all environments. These themes were consistent with three themes identified by Wallace et al. (2002): being available, integrating spirituality and health, and helping us help ourselves, and with distinctive qualities of trust, comfort, and responding to questions identified by Chase-Ziolek and Gruca (2000).

Theme 1 – Personal Faith

All of the congregants expressed strong personal faith. All six attended church and Sunday school weekly, unless they were too ill to go, and each mentioned participation in other church-related activities on a regular basis. It was evident that the church was integrated as a part of their daily lives. They appreciated that when they were ill, contact with the FCN generally involved prayer, and they fervently believed that faith had an impact on their health.

> I remember wheeling myself into the bathroom, and closing the door, and saying, "God, I want to get well." And, you know, like I needed a blessing, or something. I mean, I—and I am a praying person. I pray everyday, but I didn't—I didn't. Other people had to do it. I—I just wasn't feeling it was working for me. I don't know what it was. But, when Deirdra would visit, and pray (for me) … it was fine. I even had a friend who is a doctor. And, I don't even know what type of faith – religion she is, but she came to visit me, and asked me if it was okay if she did a laying on of the hands. And, I said, "Of course."

Not surprisingly, Bob, the retired minister said,

> I don't know of anything any better than to point back to what God has told us about the Holy Spirit's work and how God wants (us) to be a well person

Four of the congregants independently described their FCN as a blessing from God and noted that her help had a major impact on their health care experiences.

Theme 2 – Respect and Trust

The most salient theme identified was the respect and trust held for the FCN and the sense of support felt through this relationship. Congregants reported being able to ask the FCNs anything at all and knowing that they would get accurate answers that they

could understand. They were certain that the FCN cared deeply about their health and the health of the congregation, both of which were appreciated. They also confirmed the themes of empowerment and serving as a bridge as identified in the FCN responses. Sam, a widower who received assistance for his wife and for himself, described his experiences.

> After I got sick, she [FCN] was, um, very supportive. Was able to get me advice—help me understand, that—if I had some problem that I didn't understand, or some description, or something like that—well, she was able to get—give me the advice, and what—help me with that. She was a go-between, between me and the nurses and the doctors, and all that. Because she understood what they were saying and I didn't. I could trust her.

The husband and wife expressed their trust by consulting their FCN about most things.

> He coded. That was the time and of course he was in there with all the tubes and then you know all of that kind of stuff—didn't really know what was going on. But she just appeared and—you know. So, I don't know--we just talked. Yeah, it was scary seeing him go in and I was in there when the doctor came in and started doing that (indicating chest compressions), til they said, "Hey you don't need to be in here."

> I run it all by her now though—when I'd come in for our exercise, I come in and then I'd relay, I wasn't worried about me I'd relay about him. "Now, he's doing this and he's doing this." And his blood, you know, protime. "He's—it's too high." So, we you know—I kind of consult her on all of his doins' and his medications from week to week Well, I think she probably knocks some edges off… And you know where it's more palatable and actually more understandable.

Another woman described scenarios in which her FCN prepared her for situations she had not anticipated in bringing her husband with Alzheimer's disease home from a nursing facility, issues about which she would not even have known to ask.

> Things I never even thought about… I never thought my husband couldn't find the bathroom when it's right there in front of him. It's unbelievably hard. (She helped) prepare me for that. I felt free… I could ask her anything and she covered it… she covered it all. Anything I wanted to know, I could ask Charlotte.

The sense of trust in the FCN was largely due to their established relationship; however, the church itself was also held in a position of trust. One congregant expressed her wish that more health and social services could be provided by the church community, because she was certain they would be of higher quality.

You know, I wish our church had a nursing home. Wouldn't that be great?
Senior adult housing would be wonderful, too. And you know there's gonna be
more of us according to what I read in the paper. And we'd rather be paying the
church than someone else… Well, I think uh probably we'd have maybe better
care. Don't you think a possibility of better care? Because the nursing homes
have to take whoever they can get. Now there's some wonderful people though
that waited on me. I don't mean to say there isn't, but I think… there are too
many patients for the number of people. I think (the church staff) would care…be
concerned. In fact those people who didn't wouldn't stay very long.

Theme 3 – Continuity

A third theme that emerged was the fact that the FCN followed the congregants
throughout entire episodes of care and through several environments of care. Rather than
being explicitly identified as important, such stories typically included, "and then when I
moved to …" This sense of continuity was very comforting to the congregants and their
families. In two cases, the FCN visited with congregants in the hospital, then in skilled
nursing facilities where each of them had gone for treatment of a post-operative
complication, then at home after discharge, and finally, back in church as they were able
to return. In all of the other cases, there were at least two environments of interaction.
The congregants reported that the FCN was "always there when I needed her." Sheila,
one of the congregants with the post-operative infection described the course of her
health care experience.

How I met Deirdra is she came to visit me in the hospital…And, stuck—stuck
with me through the whole thing, and I—I—it was the first major illness that we
had—my husband and I had…and we were really very ignorant. And, because of
her, she spoon-fed us through this thing. And, she—she made it a lot easier than
it could have been. Because she---she gave us information, and um, ca—because
we didn't know what to…You know, we'd never done it, and—and, in the
nursing home, she was right there. … Then (when I went home) she would call,
and she would come by and visit me.

This continuous presence is more of what is expected from a family member than
from a health care provider, and it was clear that all of the congregants interviewed had
come to feel that their FCN was indeed a member of their family. This is consistent with
the FCN theme of congregational family, which was further supported by the
congregants' stories of visits, prayers, and functional assistance provided by other

members. When asked if it made a difference that her FCN was a member of her church, Sheila, a woman who had a year-long illness from which she is still recuperating, said

> It is, because I knew— I would continue to see Deirdra, and if it was somebody outside of the parish, then I wouldn't. All of us—all of the people in that congregation who have—who have had her blessings, and her—the benefit of her being a parish nurse…—just to say, if you haven't done it, you can't imagine what it's like.

Phase III Summary

Each of the care recipients interviewed had experienced both an intense episodic interaction with his or her FCN, and an ongoing relationship. This relationship was built initially by virtue of a common congregational family but has evolved to be a deep partnership that directly impacts each individual's health decisions. Faith, trust, and continuous presence were the threads in what one FCN described as the tapestry that emerged.

Chapter Summary

Data obtained through the three phases of this study reinforced each other in providing an understanding of current FCN practice in Kentucky. Findings were further validated by the FCN coordinators who served as consultants to me throughout this process. They believed the themes were consistent with their own experiences as FCNs and reflected what they heard from others in Kentucky and through national organizations.

Despite significant differences among FCNs and their congregants, it is clear that the seven major roles of FCNs included in the literature are being practiced to some extent by all of them.   As in prior studies, both FCNs and their congregant recipients valued their affective relationships, especially the inherent trust and continuity over time and believed they added to effectiveness (Chase-Ziolek & Iris, 2002). The themes were also consistent with the strengths of faith communities identified by Gunderson (1997), including being present in the lives of members, accompanying them on their life journey, having the ability to connect individuals to resources and to frame the meaning around any efforts that are made, providing a safe place or sanctuary amidst an environment which may otherwise seem hostile, having the power to pray together, and

having a different sense of time based on continuity. As in other studies, the practices and themes identified fit Nursing Intervention Classifications, including active listening, emotional support, spiritual support, presence, health screening, teaching, counseling, support system enhancement, decision-making support, and referral (Coenen, Weis, Schank, & Matheus, 1999a; Weis, Matheus, & Schank, 2001; Weis & Schank, 2000).

The final chapter is a discussion of these findings in light of the International Classification of Functioning Disability and Health model and the social ecological perspective previously described. I will identify strengths of current practices and opportunities for improvement that may allow FCNs to have an even greater impact on the health of their faith communities and individual congregants.

Chapter Five - Discussion

This study was designed to explore the knowledge base and practices of FCNs in Kentucky in meeting care coordination needs of older adults and to identify a model of gap-filling by FCN health care delivery. Although limited research exists examining interventions employed by FCNs and the meaning of practice to the FCN and to the congregant recipient, prior research has not considered these issues in the context of the current health care delivery system.

Findings from this study suggest that FCNs in Kentucky often identify and fill significant gaps in health care for older adults. They do this through all seven roles identified in the nursing literature for FCN practice (i.e., health educator, health counselor, integrator of faith and health, referral source, health advocate, developer of support groups, and trainer of volunteers) either at a congregational level, an individual level, or both. Spirituality was clearly significant for both the FCNs and those they served, and prayer and other faith rituals were an integral part of the relationship, especially during illness. Because they are trusted by the people they serve, FCNs are often sought by congregants to answer questions, interpret medical information, and assist with interactions among the many people and organizations involved in health care delivery. The stability over time of the FCNs in the lives of their congregations was also regarded as important to the relationship, as congregants counted on FCNs' presence through their transitions in health and health care environments.

Findings also revealed that there is little planning or coordination of FCN efforts to maximize resources or outcomes. Although they spoke of receiving strong congregational support, with the exception of receiving regular assistance from others to conduct blood pressure screenings, very few had organized systems to match congregants to needs. Most FCNs relied on their general observational skills in determining congregant needs rather than using a standardized assessment instrument. This may result in missed opportunities to improve the health and well-being of their congregations.

FCNs are deeply committed to their work, and they often regard themselves as an army of one. With limited time available, especially because most serve only part time in

their role, better mobilization of congregational resources would add to their effectiveness.

Emergent Models of FCN Roles

FCN Impact Through the Lens of the ICF Model

Consistent with the World Health Organization vision and definition, health must be viewed as a complex state dependent on individual health conditions along with contextual factors including personal and environmental factors. Conditions of body structures and functions are manifest at the level of the individual in terms of activities that can be accomplished and resultant participation in desired life roles. As identified in this study, FCNs are able to influence the individual at all levels of the ICF model. An opportunity exists for FCNs to contribute to better health and quality of life for their congregants through screening, health education, risk identification and counseling, advocacy, and referral for intervention when indicated.

Body Structure and Function

Almost all FCNs offered blood pressure and heart rate monitoring on a regular basis. They interpreted medical information given to congregants by other health care providers, including laboratory tests and diagnostic procedure results. Some conducted health fairs to screen for conditions such as diabetes and peripheral vascular disease. Also at this level, however, formal assessments of areas including vision, hearing, cognitive and mental status, mood, and pain were rarely conducted. Informal assessments of these areas were completed only about half the time. Questions about geriatric syndromes such as urinary incontinence and history of falls rarely or never were asked by more than a third of FCNs, and status of preventive health screens was not a priority. Lack of attention to these critical areas seems a missed opportunity, as there are many simply administered tests and scales that would provide valuable information, especially in the context of healthy aging. Early identification of signs of impairment or functional decline allows prompt referral and intervention and thus reduces the risk of serious adverse outcomes that could affect an individual's length and quality of life.

Activities and Participation

As members of a congregational family, FCNs have opportunities to observe congregants in diverse environments. Data show they used general observational skills to identify difficulties with balance, nutrition, social engagement, and self-care. As astute observers, their nursing knowledge and focus were valuable in identifying problems that may be missed by family and friends. Because of the trust inherent in their relationships, congregants may be more likely to address such concerns identified by their FCN, and FCNs felt free to follow up with congregants to determine if they had sought medical evaluation. FCNs also influenced congregations to remove architectural and other barriers to participation for people with various impairments, thus having a direct impact on inclusion within faith community activities.

Contextual Factors

Ongoing relationships that FCNs had with their congregants as members of the congregational family allowed them to be more aware of personal and environmental contextual factors contributing to overall health. Although some older adults have primary care physicians who make efforts to learn about these contextual factors, such relationships between patients and physicians have become less common due to shorter duration of physician visits in the current health care environment. Findings from this study also identified the many layers of environments that must be considered within the contextual factors that impact individual health. The social ecological perspective provides a framework for consideration of this additional complexity.

FCNs in the Social Ecological Perspective

A growing body of research in behavioral medicine and health promotion is based on the social ecology theory (Grzywacz & Fuqua, 2000; McLeroy, Bibeau, Steckler, & Glanz, 1988; Smedley & Syme, 2001; Stokols et al., 2003). As previously mentioned, this perspective considers the interaction among characteristics of each individual and those of the nested systems making up his or her environment. Consideration of these human and environmental factors are essential to understand health, to prescribe treatment, and to design community interventions (Grzywacz & Fuqua, 2000).

Ecological theorists suggest that certain behaviors, roles, or conditions within an individual's life may exert a disproportionate influence on his or her life situation and thus may be viewed as "high-impact leverage points" for potential intervention (Stokols, 2000; Stokols et al., 2003). With an understanding of the leverage points, interventions for health promotion can be targeted to achieve their greatest impact. Simply identifying factors within the micro-, meso-, exo-, and macrosystems that serve as leverage points is incomplete, however, without considering mediators in the relationships (McNeill, Wyrwich, Brownson, Clark, & Kreuter, 2006). Through the interviews with FCNs and their congregant recipients, it became clear that FCNs serve as a mediator at all levels.

Figure 5.1 represents the nested environments specifically related to health and health behaviors. Those closest to the individual, with the most direct impact on his or her daily life, are represented at the microsystem level. These people may be family, friends, or others who share a common personal environment and often provide direct care with respect to health needs. Given the data indicating importance of faith to the majority of older Americans (Ehmann, 1999; McCullough et al., 2005; Winseman, 2005), the faith community is identified as a high impact leverage point at the mesosystem level.

Faith communities are uniquely positioned to cooperate and provide mutual support, given the foundations of most faiths and the shared values of members. Such support is especially important because of the increasing ethnic diversity in our nation that is not similarly matched by a diversity of health care providers. Faith communities generally share or have a greater appreciation of the diversity represented in their congregations, and they also reflect values of the community. They often provide emotional support, encouragement, and prayers and may also serve in the role of extended family. The health care system, including both medical and social systems, forms part of the exosystem. The level of accessibility to needed services varies substantially based on location and ability to pay, and thus may or may not be available to a given individual. Finally, the macrosystem refers to the highest social level including social norms, cultural ideology, and social policy. As depicted, FCNs traverse all of the nested environments in their interactions with their congregations.
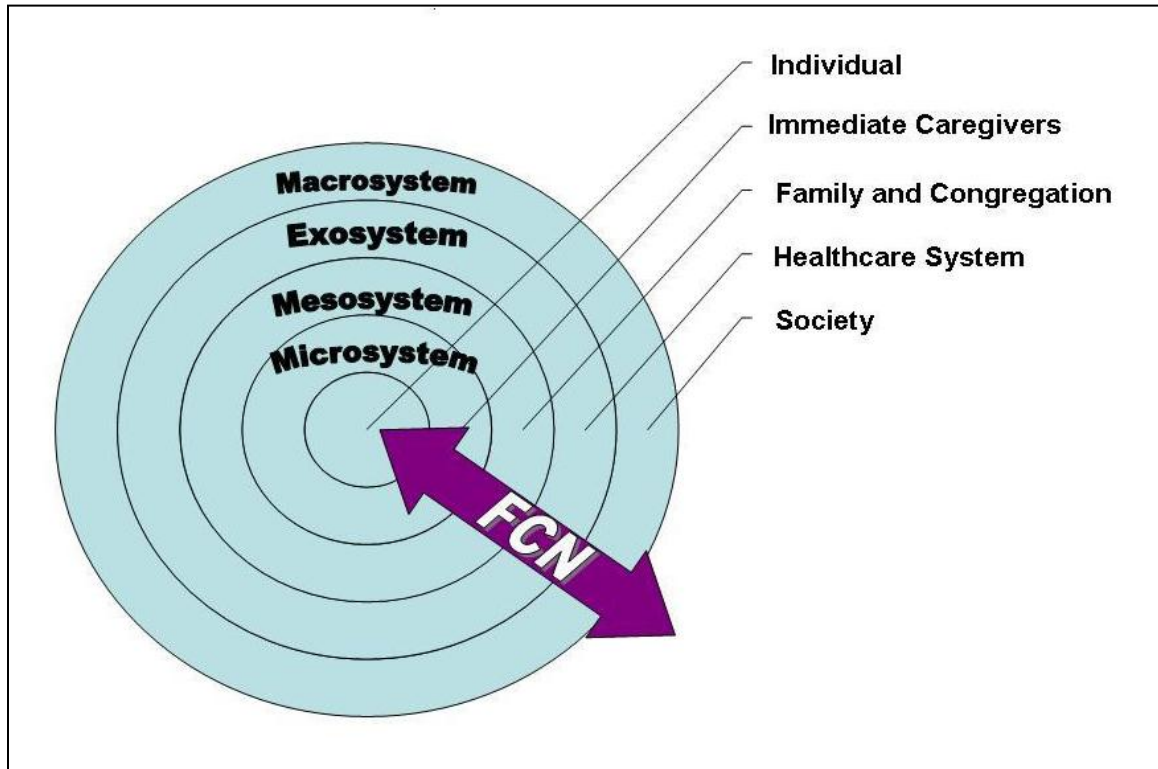
Figure 5.1 Social Ecological Perspective of the Faith Community and Health

Expanded ICF - Social Ecological Model – FCNs as Health Navigators

Based on the perspectives of the FCNs and their congregants, results of this study provide a more detailed view of how the FCN has an impact at each of the nested environmental levels (Figure 5.2). First, the ICF model is enhanced by considering all of these environments as playing a role in contextual factors that affect body structure and function, activities, and participation. Societal constructs and policies influence the health care system, which in turn influences each community and its members, which then influence the health of the individual as explained by the ICF. It became clear that as a FCN touches each of the environments, she connects them in a way that changes the relationships among and between them, thereby changing the environments themselves. This is explained through several of the themes identified in the interviews, including a strong grounding in faith, congregational family, intentional empowerment, and bridging across expanses.
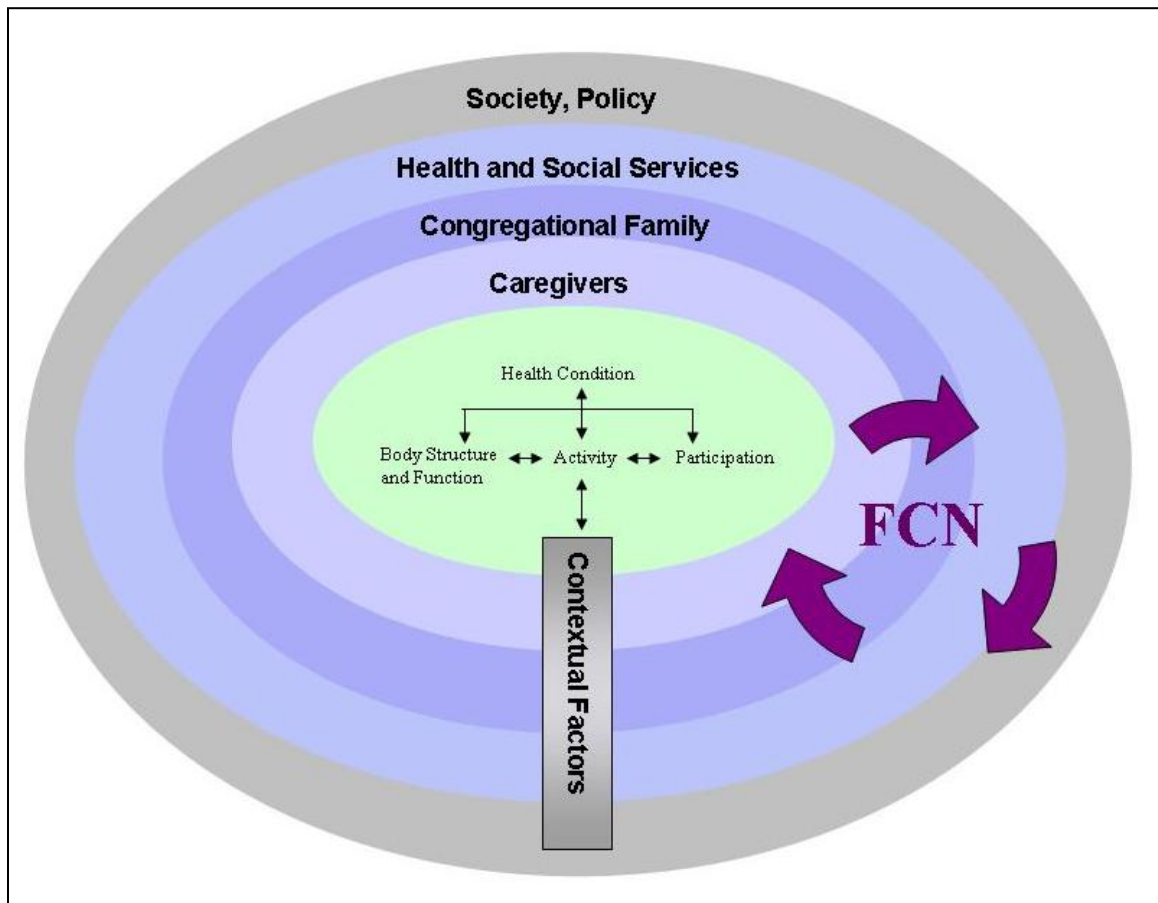
Figure 5.2 Expanded Social Ecological Perspective – FCN and Health

Individual Level

FCNs are in the unique position of understanding the individual, often based on longstanding relationships as a member of the congregational family. They hold an inherent position of trust and are able to serve as health counselors, educators, and advocates, and also to serve as a bridge between the individual and others involved in his or her health care. Furthermore, FCNs explicitly integrate faith and health through prayer and other faith rituals, strengthening individual resolve as congregants face threats to their health. Ultimately, as FCNs empower congregants, the congregants themselves change in the way they interact within the larger environments of care.

Microsystem – Establishing the Immediate Environment

Similarly, the FCNs have established relationships with families and significant others who create the immediate environment for individual congregants. This allows the FCN to support caregivers, to facilitate difficult conversations among congregants, caregivers, and other providers, and to empower caregivers who act on behalf of an individual in need. From the health promotion perspective, if people in close regular contact are educated together about healthy behaviors and choices, they are more likely to incorporate and reinforce these behaviors for the entire group, thereby creating a healthier environment for everyone at the microsystem level.

Mesosystem – Convening the Congregational Family

At the mesosystem level, FCNs have the power to convene the congregational family to mobilize members to support individuals and families in need, again serving as a bridge. They can also play a key role in guiding their faith communities in health directed initiatives. The faith community serves as an important setting to assess individual health needs and to educate people regarding self-directed health behavior. Blood pressure screenings conducted by almost all of the FCNs is an example of such use of a leverage point in an individual's life, as is the health educational material prepared by FCNs for their church bulletins. Support groups within the faith community, likewise, could have a very significant impact on health behavior.

On a broader scale, by educating key decision-makers in the faith community, FCNs may influence their congregations to adopt "other-directed" health behaviors, actions that influence the health and well-being of their own communities as well as the general public. Examples include FCNs who encourage congregations to serve healthy alternatives at all social gatherings that involve food or FCNs who promote the importance of routine health screening through established communication networks. Based on their strong grounding in faith, FCNs can encourage their faith communities to explicitly include the spiritual link to health behaviors as part of their culture and religious education, thereby laying the foundation for improved health for the entire community.

Exosystem – A Bridge Among Actors

As educated health care providers, FCNs are knowledgeable about health and the health care system and can create a bridge among individual, family, providers, and community resources, thereby enhancing interactions at the exosystem level. As identified in the study, FCNs often serve as interpreters allowing patients to better understand their conditions and empowering them to make decisions about their own care. Providers thus interact with people who become partners in their health care, enhancing adherence to negotiated care plans as well as improving the resultant health outcomes.

As described in Chapter 2, there is evidence that religiosity and spirituality are linked to positive health outcomes and that religiosity and spirituality are important to a majority of Americans. In response to this evidence, major professional associations including the Accreditation Council for Graduate Medical Education, the Association of American Medical Colleges, and the Joint Commission on the Accreditation of Healthcare Organizations have called for greater attention to religion, spirituality, and health (Larimore et al., 2002). Nevertheless, the literature also indicates that most providers do not yet include such considerations in their provision of care.

Barriers identified include discomfort, perception of inadequate time, and fear of exceeding their scope of expertise (Koenig, 2004). These barriers can be overcome through involvement of FCNs as part of the team. If a provider identifies spiritual distress as interfering with an individual's health, he or she can refer the patient to the patient's FCN, who can provide direct support or referral to an appropriate faith community leader. In this way, the provider and the faith community can work together to facilitate whole person health.

Macrosystem – Engaging in Faithful Citizenship

Finally, on the macrosystem level, FCNs mobilize their congregations to engage in faithful citizenship by advocating for better health insurance coverage or greater access to public health resources in their communities, ultimately impacting the well-being of society. These societal changes have a direct effect on the health and social systems, the congregation, and on the individuals throughout all environmental levels.

Study Limitations

As with all research, there are several limitations to this study. These include issues related to sampling, survey design, response bias, and investigator characteristics.

Study Population

Because there is no registry of FCNs in Kentucky, the population consisted of FCNs known to FCN coordinators and educators throughout the state. This omitted a group of nurses who serve their faith communities in some capacity, perhaps with formal training from outside Kentucky or without formal training or recognition. Nurses without specific education would not qualify as FCNs according to the American Nurses Association standards; however, they may be offering vital services to their congregants that are unrecognized by the study.

All FCN respondents in this study were women. Because the initial mailing list of potential participants was overwhelmingly female, it is possible that the sample is a true reflection of the gender of FCNs in Kentucky. According to the Kentucky Board of Nurses, more than 90% of nurses in the Commonwealth are female. Women are known as nurturers and caregivers and may also be more likely to assume the role of FCN in addition to their employed nursing role.

Due to the nature of qualitative research, the relatively small respondent pool means that the findings are not applicable to all FCNs. Furthermore, because all of the respondents were of various Christian faiths, the findings are not necessarily applicable to FCNs of other religions. A survey published in February 2003 revealed that 84% of Americans consider themselves Christian, and among those 57 years of age or older, 93% reported they are Christian (The Barna Group, 2003). This percentage is estimated to be even higher in Kentucky (Grammich, 2004). Nevertheless, FCNs are represented in all major religions and these findings do not reflect that diversity.

Survey Design

The survey design was lengthy and may have intimidated some respondents, especially as FCNs are often volunteers. Although the 41% response rate was acceptable for social science research, a higher response rate may have provided more varied responses. FCNs who were willing to complete the survey may be different from those

who declined. Additionally, because the survey was anonymous, there was no way to follow up with respondents to substantiate or clarify any responses that were unclear.

Response Bias

In Phase II, there may be differences between behavior reported in the interviews and actual behavior. Moreover, because the survey and interviews represented a retrospective snapshot rather than a longitudinal view, there could have been omissions or inaccuracies. Because congregant participants in Phase III were notified of my study by the FCNs who serve them, it is likely that those with positive feelings about their FCNs self-selected.

Investigator Characteristics

Finally, my own personal characteristics may have biased my view. As a person of strong faith, I may be more likely to seek the good in faith community interventions and to engage more easily in conversations grounded in faith than others who are less involved or do not have a particular faith. For those FCNs who asked about my faith and learned that I am Jewish, it is possible that they filtered some of their responses due to their perception that I may not understand their religious motivation.

Implications and Future Directions

Considering the role of FCNs within the expanded social ecological framework provides a valuable model to guide analysis and to frame recommendations for role refinement and expansion. Through fully appreciating their importance in touching all of the nested environments affecting health and wellness, FCNs may be better able to organize congregational support to impact even more lives. Ultimately, such an approach has the potential to significantly improve the quality of life of older adults at little to no financial cost and may in fact save money through better individual health and decreased utilization of health care services. Furthermore, recognizing that FCNs affect experiences of their congregants as well as surrounding environments suggests an even broader potential impact on society.

Empowered individuals who take a more proactive approach to health and wellness, including changing health behaviors, obtaining health screenings, and adhering

to negotiated health regimens are likely to be healthier, thereby reducing the demand on our overtaxed system. Assisting with appropriate navigation of the health care system, especially during transitions, is likely to result in less duplication of service, fewer medical errors, and greater satisfaction with care (Coleman, 2003; Tsilimingras et al., 2003). As identified in the literature, inclusion of religion and spirituality also positively influences health outcomes (Koenig, 2004; McCullough, Hoyt, Larson, Koenig, & Thoresen, 2000). Improved health will likely result in fewer activity limitations and greater participation of older adults in life roles they find meaningful. During times of illness, increased support of the faith community relieves other caregivers of excessive burden, thereby contributing to the health of families and communities and reducing the burden on employers of family members missing work. Support of the faith community nurtures individuals and families in ways that traditional health and social systems do not, providing added value at no cost.

The confluence of several factors makes this a pivotal time to engage in this discussion. There is growing recognition that the U.S. health care system is failing to meet its potential, particularly in meeting needs of a rising number of older citizens. These failures include inadequate attention to health promotion and disease prevention, a complex medical care system that tends to focus on individual organ systems rather than whole person health, and dramatically rising costs of care that jeopardize the solvency of the Medicare system. Innovation, which remains a strength of the U.S. health care system, allows many people to live longer than ever before, but with chronic conditions managed by high cost medications and technology. Although historically, long-term care has been provided by families rather than the health or social systems, demographic trends such as aging baby boomers and the geographic mobility of their children translate into a larger number of older adults living without family members nearby to provide this care. As further evidence of the realization among the public and the relevance of a political economy perspective, during this presidential election year, health care is among the top issues of concern to the populace.

At the same time, there is a growing awareness among faith communities of the changing demographics and the need to minister to older congregants. Making facilities accessible for individuals with activity limitations allows them to maintain participation,

and considering their preferences of service and music encourages continued presence. However, the role of social justice within faith communities mandates a more comprehensive focus on health and well-being of their congregants. In a national sample of 349 pastors representing more than 80 Christian denominations, there was strong support of congregational health ministries (CHM). Pastors with CHMs were more involved with health promotion and disease prevention than those without CHMs, and those without CHMs acknowledged the importance of congregational health involvement and expressed willingness to become involved with CHMs (Catanzaro, Meador, Koenig, Kuchibhatla, & Clipp, 2007). In a survey of more than 6000 congregations conducted by the National Council of Churches USA, a majority reported providing some sort of health ministry services, including direct health care services, health education, and health advocacy (Lindner & Welty, 2007).

Coinciding with this awareness is the growing recognition on the part of policy-makers that broad-based community action is necessary to improve the health of individuals and communities. Through initiatives such as Healthy People 2010, national, state, and local governmental agencies are urged to partner with each other and with private and public organizations and individuals to reach specific objectives for the health of the nation. Because FCNs already have experience at all levels throughout the nested environments of their congregants with specific reference to health, they are poised to lead the faith community in a partnership for a healthier America.

National Initiatives

Partnering for Health Promotion

There are many organizations at the national level with a focus on mobilizing government agencies, businesses, health professionals, and communities to heighten the priority of health promotion activities in policy and practice. These include the Healthy People initiatives, the Coordinating Center for Health Promotion (CoCHP) of the CDC, the Office of Disease Prevention and Health Promotion of the Department of Health and Human Services (DHHS), and the Council of State Governments. There are also organizations specifically focused on the involvement of faith communities in health promotion. These include the Carter Center's Interfaith Health Program (IHP), created in

1992, which conducts an annual Institute for Public Health and Faith Collaborations, and the DHHS Center on Faith-Based Initiatives established by President Bush in 2001 as part of the White House Office of Faith-Based and Community Initiatives (Isaac, 2003). Partnership for Prevention, a national membership organization of businesses, nonprofit organizations and government agencies seeks to make prevention a national priority. This organization is among many who have developed comprehensive, evidence-based guides to encourage engagement of diverse communities in health promotion activities (National Association of Chronic Disease Directors, 2005; National Commission on Prevention Priorities, 2007). Information abounds, along with suggestions for engaging community partners that include faith-based groups.

FCN Networking

With specific reference to FCNs, two major organizations provide networking and information sharing on a national level. The first is the International Parish Nurse Resource Center, which, as previously mentioned, has established the learning curriculum used in most formal FCN educational programs. It has an annual meeting attended by hundreds of FCNs who then return to their communities to enhance their individual programs.

Health Ministries Association (HMA) is a diverse support network of professionals and lay people who share the common objective of developing programs in their communities that integrate care of the body, mind, and spirit. Although HMA partnered with the American Nurses Association in the development of the FCN Scope and Standards of Practice, they are not focused solely on FCNs, but rather on health ministries of all kinds. Through their internet site, national meetings, and regional chapters, they provide members with comprehensive practical and educational information, links to other partners with similar interests, consultation, and research opportunities.

Denomination-Specific Organizations

Finally, several denominations have ongoing programs to support health ministries within their own communities. These include the Presbyterian Church (USA), Seventh Day Adventists, and the Roman Catholic Diocese. Such support generally

includes networking, sharing models of care, educational programs, and in some cases, grants for program development.

Need for Further Application

Clearly, there are ample resources available to facilitate more widespread implementation of faith-based health initiatives. However, as self-described armies of one, the FCNs in this study indicated that their priority was attempting to meet the identified and individualized needs of congregants. Many were aware of resources available and occasionally utilized some of the educational materials, but there was no sense of a common purpose or of a commitment toward a unified agenda for change. Furthermore, their focus included, but was not limited to health promotion activities. Given the number and diversity of faith communities and the differences in state policy, health care needs, and resources, it is likely that a local focus would be more effective than national efforts to achieve greater involvement of the faith community in the health of their congregations.

Kentucky Initiatives

The FCN Coordinators Consortium formed in 2007 and created a vision of establishing a health ministry in every faith community in Kentucky. Members of this group have relationships with several major health care and educational institutions within the state, and the Kentucky Department of Health Promotion and Disease Prevention has contacted the group with an interest in understanding potential partnerships toward a healthier Kentucky. Results of this study of the practices of FCNs in Kentucky may help guide and strengthen such partnerships and provide avenues for outcome assessment and best practice modeling.

The study also identified potential opportunities for enhancement of the role played by individual FCNs in their own faith communities in Kentucky. Increased focus on the faith–health connection, engaging more of the congregational family, using comprehensive screening tools, and strengthening and operationalizing the various bridges among environments of care all lead to suggestions for program development.

Increase Connection Between Faith and Health Promotion

Among the most salient themes identified by both FCNs and their congregants was a strong grounding in faith. Recognition that the faith community is a high impact leverage point can encourage FCNs and others working with them to more directly and explicitly link faith to health. Judeo-Christian tradition teaches that life is a gift of God and that each individual is a steward and trustee of God. Preservation of health is an act of worship in that we are preserving the instrument through which we serve God (Sherwin, 2003). The FCN can engage faith community leaders to include this linkage in regular messages throughout the year and can help mobilize the community from congregational leaders through educators through volunteers who prepare meals, to become messengers of healthy behavior at the important mesosystem level.

Enhance Sense of Congregational Family

FCNs should expand their capabilities by partnering with others within their congregational family in the formation of a health ministry. Members of faith communities often seek ways to use their time and talents to serve others but may not come forward until needs are identified. Given their knowledge and skills, FCNs make ideal coordinators of such a ministry for matching talents to needs. Although some FCNs are part of such a health ministry, this appeared to be the exception.

FCNs can enlist assistance to perform a gap analysis, considering the difference between needs of the congregation and services already delivered. Conducting such an assessment from the perspective of the ICF model of health would necessarily include consideration of the contributing personal and contextual factors from a holistic perspective. Results would likely identify needs that could be met by members with skills in health care, legal services, social services, advocacy, education, and financial services. A small committee led by the FCN can triage individual congregant's needs and then facilitate contact with an appropriate faith community member to assist individuals and families, thus expanding the reach of the ministry at microsystem and mesosystem levels.

Supplement General Assessment with Comprehensive Screening Tools

Although the FCN may be somewhat unique in her observational skills and thus not feel the need for formal instruments to assess congregants' health status, developing a comprehensive screening tool for administration by others would allow more congregants to be reached and identify more needs for triage. The FCN and other health professionals within the congregation can then be engaged to facilitate interactions with the health care and social service delivery systems at the exosystem level, with an ongoing focus on empowering congregants to become their own advocates. Specific needs for older congregants include screens for geriatric syndromes and preventive interventions such as pneumonia vaccination and annual flu shots. Partnership for Prevention has identified substantial savings in reduction of lost lives and of cost of care based on increasing utilization of preventive services (National Commission on Prevention Priorities, 2007).

Enhance Ability to Bridge Across Expanses and Individual Empowerment

With respect to the theme of bridging the expanses experienced in health care, the most dangerous chasm to close seems to be that of transitions in care. The prevalence of care transitions for older adults in 2000 was estimated by Coleman (2003) to include an average of over 400 ambulatory visits, 300 emergency department visits, 200 hospital admissions, 46 skilled nursing facility admissions, and 106 home health care admissions per 1000 persons. Potential points for breakdown during transitions include preparing the patient and family, communicating vital elements of the plan of care, reconciling medication regimens across settings, patient transportation, completion of follow-up care, and the presence of advance directives across settings (Coleman, 2003). The FCNs' continuous presence throughout transitions of care was identified by both FCNs and congregant recipients as being of critical importance.

A transition program such as that developed by Coleman et al. is particularly appropriate for FCNs to incorporate. This plan is based on development of a personal health record to facilitate productive provider–patient interactions across settings. It includes a problem list, medications, allergies, and list of red flags for completion. Also included is a transfer checklist of activities to accomplish before discharge from an inpatient environment and space for the patient to record questions and concerns.

Together, patient and caregiver maintain the record and update it with the assistance of a transition coach. A transition coach encourages patient and caregiver to access the health care system with a goal of empowering and educating older patients to meet their health care needs across all environments. (Coleman et al., 2004; Parry, Coleman, Smith, Frank, & Kramer, 2003). This simple plan formalizes what the FCN is already doing in many cases and encourages even greater patient and family empowerment. This program, or a similar organized approach to assisting in transitions, would be an excellent adjunct to the informal system currently in use by most FCNs in Kentucky, resulting in decreased medical errors, improved outcomes, and decreased burden of care for individuals and families.

Challenges for Future Practice and Research

Along with the great potential for expanded FCN practice to significantly improve the health and quality of life of older adults are several challenges to large scale implementation. These include the lack of a statewide network of FCNs, an aging FCN workforce, and the difficulty in outcome measurement to demonstrate FCN effectiveness.

Lack of Statewide Network

The number of FCNs in Kentucky is unknown, and there is no central repository of contact information for those FCNs who are known. This awareness deficit serves as a substantial barrier to any coordinated efforts to impact practice. It could be easily resolved by the Kentucky Board of Nursing gathering this information at the time of licensure renewal. Once FCNs are identified, the FCN Coordinators Consortium can partner with other community agencies and educational institutions to serve as a statewide clearinghouse for initiatives. Best practice models may be shared, and faith community leaders may be more fully engaged to guide communities toward what Jenna, aged 57, described as "getting the faith community to claim its healthiest self." Once the value of FCNs is recognized, a more concerted effort to meet the vision of a health ministry in every congregation in Kentucky can be realized.

Aging FCN Population

The aging of the current pool of FCNs and the potential this may have for long-term sustainability of programs is one that must be addressed, because there does not seem to be a cohort of FCNs to take their place. A concern was first identified by the FCN Coordinators Consortium and was reinforced in my analysis. The mean age of the FCNs in this study was 57. Many nurses are nearing retirement age and may be able to devote more time to their faith communities; however, to serve as a FCN, they must retain their nursing license and should also retain professional liability insurance.

Costs for these requirements may discourage FCNs from continuing to practice, because most FCNs are not paid for their services. Health care institutions that support FCN practice, many of which are represented in the FCN Coordinators Consortium, already provide free continuing education, and so this licensure requirement can be met at no cost. However, concern about the fee to the State Board of Nursing remains. Given potential cost savings from keeping even one Medicaid recipient out of a nursing facility for several months (Rydholm, 1997), it is reasonable for the state to waive licensure fees for those FCNs as well as other health care providers whose sole practice is volunteer work in service to the health of their communities. With further evidence of the cost effectiveness of FCNs in health promotion and disease prevention, funds should be identified to provide professional liability coverage through the faith communities served or through another agency.

Another factor relating to the aging FCN population is a general lack of awareness of this specialty area among most practicing and newly graduating registered nurses. Those FCNs who serve as community health preceptors for nursing education programs often found that the nursing students were completely surprised by the experience and valued it greatly. Unfortunately, only a very limited number of students are reached. The FCN Coordinators Consortium has established relationships with most of the nursing education programs in Kentucky and should endeavor to assure that faith community nursing is discussed within the curricula.

Outcome Measurement

Evidence of improved quality of life, better health outcomes, and of cost effectiveness can only be obtained through data collection and analysis. Unlike academic and some public institutions, faith communities are not familiar with outcome measurement and tend to consider attention in this area as taking away from their true mission. Johnson (2002) undertook a systematic review of all available evidence on faith-based organizations, examining journal articles, books, chapters, dissertations, and technical reports to search for effectiveness data and even calling large faith based organizations. He found that the overwhelming majority of faith communities neither produced studies nor requested that they be done (Johnson, 2002). We must convince faith communities that the belief that they are doing the right thing is not enough and that outcome measurement will enable them to use resources to effectively meet their mission. Without measurement and analysis of outcomes, it is possible that inappropriate or duplicative services will be offered or opportunities for greater impact will be missed, despite good intentions. This is another area in which partnership with educational and community organizations is essential.

Future Research

Testing the expanded social ecological model of FCNs and health should be conducted for FCNs of diverse faiths and practices throughout the country. If validated, the model may provide a guiding framework and common language for collaboration among FCNs, faith communities, and the many public and private entities united by the mission of improved health for individuals and communities.

In order to expand the reach of FCNs in health care navigation and health promotion, we must first identify and address any additional barriers that may exist. These may include statutory, regulatory, and policy barriers in addition to simple misconceptions. Ways to accommodate retaining and expanding the explicit grounding in faith while still meeting requirements for participation in grant funding and governmental programs should also be sought. The Kentucky Office of Faith-Based and Community Initiatives may be a resource; however, with the recent change in state government, the position has been vacated and is not expected to be filled.

At our most recent meeting in January 2008, the FCN Coordinators Consortium shared the sense that there is ample information available for program implementation, but little to identify which specific strategies might be most effective in the various regions they serve. Because each of the members is associated with either a health care institution or an educational institution, we agreed to identify high impact needs and then identify potential interventions. The Kentucky Institute of Medicine's recent report, *The Health of Kentucky* (2007), which includes objective data and resource information about risk factors and disease outcomes for each of Kentucky's counties (Kentucky Institute of Medicine, 2007) will be utilized as a resource. The report also includes suggested interventions by measure (i.e., diabetes, obesity, smoking), that may be valuable for consideration in the area of health promotion. Assisting the Coordinators Consortium in selecting interventions and designing outcomes studies to test the interventions would be a powerful next step. Such research may be best accomplished through a partnership with the Kentucky Institute of Medicine. It should include consideration of health behaviors, health outcomes, quality of life, health care resource utilization, and financial and human resource costs. Because the major health concerns in Kentucky, including diabetes, obesity, inactivity, and heart disease are also national concerns, findings from this research may be easily expanded to have a national impact.

Finally, although the majority of Americans report membership in a faith community, reaching those who are not members may also be possible using a similar approach within any tightly integrated group. The expanded model would provide a valuable framework to consider other high-impact leverage points and individuals who may serve as facilitators. With specific reference to older adults, senior living communities, or even groups of friends, may enlist knowledgeable community health promoters to enhance the health of their communities, without adding substantial cost to our overburdened system.

Conclusion

The current condition of health care in the United States does not live up to our expectations. This may be built in part on the perception that health is something we "get" instead of something we "do". This misperception is supported by a medical

industrial complex that has proven slow to adapt in large part because, as explained by political economy, health care is another market commodity.

In reality, the vast majority of health <u>care</u> is provided by the individual him or herself, within unique nested environments that provide varying levels of support. This is especially true for older adults, of whom over 80% are living with at least one chronic condition. Such conditions require ongoing lifestyle modifications based on understanding and valuing of what is required and an ongoing environment that facilitates health. The health care system is only one part of this environment. Although efforts to change the system itself must continue, re-examining health as envisioned by the WHO, "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity," guides us to solutions from individuals and their communities. FCNs can play a major role in this important change of focus, particularly given the current fiscal climate.

Robust evidence demonstrates the importance of faith and faith communities to the majority of older Americans, and in particular older Kentuckians. From a social ecological perspective, the faith community is clearly a high-impact leverage point for intervention. Moreover, the linkage between faith and health, often valued by individuals but overlooked by the traditional medical community, is easily enhanced.

FCNs in Kentucky play an important role in the health of their congregations, in large part due to their strong grounding in faith and their ability to bridge and connect all environments, from individual through macrosystem levels. Their focus on intentional empowerment and the continuity of their relationships as members of a congregational family strengthen their potential for meaningful improvement of the health experiences of their older congregants. Specific opportunities for refinement of current practice include enhancing engagement of the congregational family, strengthening the integration of faith and health in health promotion, and developing comprehensive screening tools specifically targeted to older adults. Challenges include the lack of a registry of FCNs in Kentucky, the aging FCN workforce, and the absence of a research infrastructure.

There is momentum for innovative change with respect to health and health care in the U.S. and in local communities. Concern about lapses in quality, medical errors, and fragmentation of care are well documented, with our current system unaffordable and

inefficient for many. This is especially true in Kentucky, where health rankings are among the worst in the country. Refinement and expansion of FCN practice throughout the Commonwealth will help Kentucky become an example for other states and improve the quality of life and health of its older adult population, both now and in the future.

Appendices

| Faith Community Nurse Survey |

JANICE KUPERSTEIN

UNIVERSITY OF KENTUCKY

GRADUATE PROGRAM IN GERONTOLOGY

You may type your responses directly into this form. To select a response, click in the option box. To unselect, click the same box again. To type narrative responses such as completing an "other" box or responding to a question, place your cursor in the highlighted area and type. When finished, move your cursor to the next section of the survey. SAVE THIS DOCUMENT TO YOUR COMPUTER. That way, you may start and stop the survey, and your work will be saved.

When you have completed the survey, save the document again and attach it in an email addressed to: FCNResearch@yahoo.com

Faith Community Nurse Survey

Section A: Background and your faith community

1 I am a(n)
- ☐   RN – Registered Nurse
- ☐   ARNP – Advanced Registered Nurse Practitioner
- ☐   Other

2 Highest academic degree earned **in nursing**:
- ☐   Diploma
- ☐   Associates degree
- ☐   Bachelors degree
- ☐   Masters degree
- ☐   Doctoral degree
- ☐   Other (please identify)

3 Other degrees or special certifications, if any:
Enter Here:

4 Duration of practice **as a nurse**:
- ☐   Less than one year
- ☐   1-5 years
- ☐   6-10 years
- ☐   11-20 years
- ☐   > 20 years

5 Duration of practice **as a <u>FAITH COMMUNITY NURSE (FCN)</u>**:
- ☐   Less than one year
- ☐   1-5 years
- ☐   6-10 years
- ☐   11-20 years
- ☐   > 20 years

6 Gender:
- ☐   Female
- ☐   Male

7 Age:

8 Personal faith affiliation:
- ☐   Baptist
- ☐   Episcopal
- ☐   Jewish
- ☐   Lutheran
- ☐   Methodist
- ☐   Non-denominational
- ☐   Presbyterian
- ☐   Roman Catholic
- ☐   Unitarian
- ☐   Other:

If this is not the faith of the community you serve, enter that faith here:

9   Ethnic/racial background:
☐   African American
☐   Asian
☐   Caucasian
☐   Hispanic/Latino
☐   Other:

10 Formal or informal FCN training and education:
☐   No additional specific training as an FCN beyond nursing
         education
☐   Informal training by another FCN
☐   Formal program accredited by the International Parish Nurse Resource Center
         (please explain below)
                         Duration of total FCN training in contact hours:
                         Organization(s) providing the education:

☐   Formal training through continuing education courses (please explain below)
                         Number of continuing education units:
                         Organization(s) providing the education:

11 Which of the following best describes your arrangement with the community you serve?
☐   I serve my community as a volunteer (please move to next question)
☐   I am paid for my FCN role (please continue below)
                 ☐ by the faith community
                 ☐ by a health care institution such as a hospital or group practice
                 ☐ by a health care payer such as an insurance company
                 ☐ other:

12 County or counties of the faith community or communities you serve:

13 Size of the congregation you serve. (If you serve more than one ***congregation, start with the congregation consuming most of your time***).
☐   < 100 members
☐   100 – 300 members
☐   301 - 599 members
☐   600 – 1000 members
☐   > 1000 members

        Including yourself, number of FCNs serving this faith community:

o   Approximate ethnic/racial distribution in this faith community:
         % African American
         % Asian
         % Caucasian
         % Hispanic/Latino
         % Other

If you serve more than one faith community, please continue. Otherwise, move to question 14

   o   Sizes of **the other** congregations you serve. *If you serve more than one <u>additional</u> congregation, please consider them in order of time commitment:*

<u>Second Faith Community</u>

☐   < 100 members
☐   100 – 300 members
☐   301 - 599 members
☐   600 – 1000 members
☐   > 1000 members

<u>Third Faith Community</u>

☐   < 100 members
☐   100 – 300 members
☐   301 - 599 members
☐   600 – 1000 members
☐   > 1000 members

   o   Including yourself, number of FCNs serving each of these **other** faith communities:

      ▪   Community # 2
      ▪   Community # 3

   o   Ethnic/racial distribution in each of these **other** faith communities:

      ▪   Community # 2
      ▪   Community # 3

14 Average number of hours spent per week as a FCN:

☐   0 - 10 hours per week
☐   11 - 20 hours per week
☐   > 20 hours per week

15 Based on the number of hours you spend each week, estimate the percent of time you spend in the following roles *(total should be 100%)*:

    % Community based activities (e.g., educational programs, group screenings, group classes, health fairs).
    % Working **with or on behalf of <u>individual congregants</u>** (e.g., visiting, making referrals, counseling)
    % Preparing articles for distribution (e.g., newsletters, bulletin)
    % Working with other members of the faith community to enhance health programming
    % Other

   <u>100%</u>

16 Considering all of your roles as a FCN, age distribution of members served (estimate using percent):

    % Children (birth – 18)
    % Adults (19 - 64 years old)
    % Older adults (65 + years old)

Section B: Major Roles and Activities:
Briefly describe your major roles as a FCN over the past 12 months. Include activities you participate in and activities you direct. When known, identify outcomes of specific interventions (e.g., number of people identified with hypertension who have received treatment).

Start typing here:

Section C: Your FCN Role with INDIVIDUAL CONGREGANTS:
(Working one-on-one with a specific individual or with others on behalf of this individual)
If your role at this time does not include any individual congregant interactions, please skip to the last page.

17 Approximately <u>how many</u> **individual congregant contacts** do you have each week? Consider contact WITH an individual congregant or ON BEHALF OF the congregant. Identify number in each gender and age category:
- o   Males   Under age 65
- o   Females   Age 65 and older

18 Of the individual contacts you make each week:
- o   What percent are by telephone or email?   %
- o   What percent are in person?   %
  OF THOSE IN PERSON, identify the percent that takes place in each location (***total should be 100%***):
  Faith community (e.g., church, temple)   %
  Individual's home   %
  Assisted Living   %
  Hospital   %
  Nursing Home   %
  Other   % Location(s):

19 How are referrals received or prospective care recipients identified? Estimate the percent referred each way:
  % Referred by self or family member
  % Referred by a health care provider
  % Identified independently by you or another FCN
  % Referred by a member of the faith community leadership
  % Identified by another member of the faith community
  % Other

20 If needed by an individual, what resources are available from the faith community you serve? Check all that apply:
  Financial resources
  Volunteers
  Prayer
  Other

21 Estimate the percent of congregants who receive intervention (direct or on their behalf):
  Once weekly or more   %
  One to two times per month   %
  One to two times per year   %
  One time interventions   %
  Other   %

Section D: Interactions with Older Congregants: Final section!

Consider interactions OVER THE PAST YEAR WITH CARE RECIPIENTS 65+. If your role does not include any individual interactions with this age group, please skip to the last page.

22 From the list below, identify the likelihood that you will obtain this information from most recipients as part of the intake process:

	5 Always	4 Often	3 Occa-sionally	2 Rarely	1 Never
Medical history	☐	☐	☐	☐	☐
Names of health care providers	☐	☐	☐	☐	☐
Current medical treatments	☐	☐	☐	☐	☐
Current medications	☐	☐	☐	☐	☐
Preventive health screenings status	☐	☐	☐	☐	☐
Spiritual beliefs and needs	☐	☐	☐	☐	☐
Complementary/Alternative treatments	☐	☐	☐	☐	☐
Family contact information	☐	☐	☐	☐	☐
Social support availability	☐	☐	☐	☐	☐
Work history	☐	☐	☐	☐	☐
Hobbies/Recreational activities	☐	☐	☐	☐	☐
Health insurance	☐	☐	☐	☐	☐
Learning needs and style	☐	☐	☐	☐	☐
History of falls	☐	☐	☐	☐	☐
Signs of potential abuse or neglect	☐	☐	☐	☐	☐
Urinary incontinence	☐	☐	☐	☐	☐
Financial needs	☐	☐	☐	☐	☐

23 In the area of **CARE RECIPIENT ASSESSMENT**, identify the likelihood that you will obtain the following information using an informal assessment (e.g., observation, asking questions), a formal published assessment (e.g., Mini Mental State Exam, Fear of Falling Inventory), or both. If a formal assessment is used, identify the instrument in the space provided:

	5 Always	4 Often	3 Occa-sionally	2 Rarely	1 Never
Home Safety Assessment					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Nutritional Status					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Functional Mobility					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Balance/Falls					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Social Interactions/Activities					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Vision					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Hearing					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Cognitive/Mental status					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Mood/Depression					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					
Pain					
Informal Assessment	☐	☐	☐	☐	☐
Formal Assessment	☐	☐	☐	☐	☐
* Tool(s) Used: Enter Here →					

24 For each element below, identify the likelihood that you will obtain this information from a congregant 65+ on **FOLLOW-UP VISITS**:

	5 Always	4 Often	3 Occa-sionally	2 Rarely	1 Never
Changes in medical condition	☐	☐	☐	☐	☐
Changes in social conditions or support system	☐	☐	☐	☐	☐
Changes in any treatments	☐	☐	☐	☐	☐
Activity restrictions due to illness or injury	☐	☐	☐	☐	☐
Falls	☐	☐	☐	☐	☐
Change in religious participation	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

25 Consider your **personal interventions with or on behalf of specific individuals** over the past year. Estimate the percent of time you spent in each of the following roles:

Screening for health conditions   %
Education regarding health conditions   %
Spiritual counseling   %
Psychosocial counseling   %
Referrals to established agencies or programs   %
Contacts with others on behalf of congregant (advocacy) %
Other   %

26 List agencies or organizations to which you have referred patients for services over the past year, and how often you have made such referrals:

Agency or Organization	How often have you referred?

If there is anything else you would like to tell us about your service as a FAITH **community nurse, please do so in the space below:**

Start here:

Appendix B – Phase I Survey Introductory Letter
_____

On Letterhead

You have been identified as a nurse who serves one or more faith communities as a Parish Nurse or Faith Community Nurse (FCN). You serve a critical role in helping people achieve a greater sense of health on the holistic level – including not only biomedical, but psychosocial and spiritual wholeness as well.

As a doctoral student in Gerontology at the University of Kentucky, I am studying FCNs to gain insight into the role you already play, to increase awareness of this nursing specialty in Kentucky, and to consider some best practice recommendations to expand your reach and effectiveness, particularly with older adults. For my research study to be meaningful, I need your help.

The attached survey should take approximately 20 minutes to complete and will give me a picture of your background, your congregation, and your current practice. There are no expected risks to the study. Completion of the survey, which is purely voluntary, will serve as evidence of your consent to participate in the study. Although there may be no direct benefit to you individually, it is my hope that my research will benefit FCNs and congregants through greater public understanding of the role played by FCNs in assisting older congregants.

All information will be kept confidential and used only in the aggregate. You will be asked to select a unique identifying number that is known only to you, in case you elect to participate in the second phase of the study. That phase involves an interview that I plan to conduct at a community location of your choosing. Information at the conclusion of the survey (a computer screen for on line surveys or an attached postcard for written surveys) will allow you to provide your contact information to participate in this follow up that provides additional insight into your work. A separate consent process will be conducted.

If you have any questions, please contact me:
 Email: jkupe0@uky.edu
 Phone: 859-323-1100 extension 80593 or 800-851-7512 extension 83510

As noted, your participation is voluntary and there is no penalty should you decline to participate. However, I truly appreciate your completion of the survey and welcome the opportunity to interview you at your convenience.

With sincere thanks,
(inserted electronic signature)

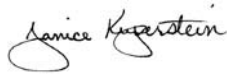Janice Kuperstein, PT, MSEd, Doctoral Candidate in Gerontology

Message 2
Two weeks ago, a packet was sent to you asking your help in completing a survey on your role as a Faith Community Nurse (FCN).

If you have already completed and returned the survey, please accept my sincere thanks. If not, please consider responding as soon as you can. Only through you sharing your experiences can we understand the diverse roles that FCNs (volunteer or paid) play in assisting congregants with health issues.

If you did not receive the survey or if it was misplaced, please call us toll-free at 1-800-851-7512 ext 83510 and we will send another one promptly.

I do so appreciate your assistance!

Janice Kuperstein

Janice Kuperstein
Doctoral Student in Gerontology
University of Kentucky

Message 3

Greetings:

Within the past two months, you should have received requests from me to participate in a study of faith community nurses (FCNs) in Kentucky. If you have already responded, thank you so much!

I am writing because every response is critical to the study and there are many outstanding. All responses help identify current practice, even if your activities seem limited. **If you have not yet completed the survey, please take time to do so.** Your response will help increase the usefulness and validity of this study. Your participation will help give an accurate picture of faith community nursing and its potential.

Some people have indicated that they should not have received the survey because they are not faith community nurses or they have not practiced faith community nursing for some time. If either of these cases applies to you, send me a message at jkupe0@uky.edu or by calling toll free at 1-800-851-7512 to let me know. I will remove your contact information from my data base.

If you need a new copy of the survey, or if you would prefer to take the survey on-line, please contact me as above, and I will send the appropriate information.

I would so appreciate you taking the time to respond if you have not done so already!

Blessings to you all,

Janice Kuperstein (signature)

Janice Kuperstein

Final Request

Greetings:

Over the past two months, I have sent you several mailings regarding my doctoral research on the activities of Faith Community Nurses. The purpose of my study is to gain insight into the role played by FCNs in Kentucky, to increase awareness of this nursing specialty, and to consider some best practice recommendations to expand your reach and effectiveness, particularly with older adults.

If you have already responded, please accept my sincere thanks. If you have not yet done so, there are still a few days left to help. I am sending this final request in the hope of capturing the vast diversity of FCN activity throughout Kentucky. I recognize that the survey is long, but any information you provide will contribute to recognition of the diversity of FCN roles and may lead to insights regarding untapped potential. Here is the link to the survey.

The following is a <u>secure site</u> through the University:
https://SSTARS.ad.uky.edu/mrIWeb/mrIWeb.dll?I.Project=FCN1
The Word version and letter about the survey are also attached.

If you believe the questions do not capture what you do, please let me know that as well – along with a description of your FCN education, how long you have been practicing, and a brief description of your faith community.

Your help would be so appreciated.

Thanks for all you do!

Consent to Participate in a Research Study

Faith Community Nurse [Phase II]

A Faith-Based Approach for Assisting Older Adults in Health System Navigation

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You have been invited to take part in a research study about your experiences as a faith community nurse. You are being invited to participate in this phase of the research study because you expressed a willingness to be interviewed during your completion of the survey phase (Phase I). If you take part in this phase of the study, you will be one of about 20 faith community nurses in Kentucky to do so.

WHO IS DOING THE STUDY?

The person in charge of this study is Janice Kuperstein, PT, MSEd, a doctoral candidate in the University of Kentucky Graduate Center for Gerontology and a faculty member with 10 years experience in the Department of Rehabilitation Sciences. Pamela Teaster, PhD, a faculty member in the Graduate Center for Gerontology will serve as her advisor.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to understand the experiences and the practices of faith community nurses serving older adult clients. A subsequent phase of the study will be conducted to understand the experiences and desires of older adult clients of faith community nurses.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

You have already completed the survey portion of this study and have indicated a willingness to participate in a more in depth interview regarding your work.   The interview will take place in a location of your choosing and will last approximately one hour.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to devote approximately one hour to be interviewed concerning your experiences as a faith community nurse. If there are any questions that you do not want to answer, you do not need to answer them. You may choose to end the interview at any time. The interview will be audiotaped and then transcribed to ensure an accurate record

of your thoughts; however, the tapes will be destroyed after transcription and no identifying information will be retained with the transcript. You will also be asked to distribute flyers to congregants you serve who meet inclusion criteria and may be interested in participating in the next phase of the study. The flyers will include contact information so the congregant can contact the investigator independently.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?

You should not take part in this study if you are not/ were not a faith community nurse who serves or served parishioners age 65 and older within the past year.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no expected risks from participating in this study. You may answer only those questions with which you are comfortable, and you may discontinue your participation at any time.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you will get any benefit from taking part in this study. Your willingness to take part will help to identify the role played by faith community nurses in assisting their congregants and may lead to the development of best practice recommendations which will be shared within the faith community nursing community.

DO YOU HAVE TO TAKE PART IN THE STUDY?

Your participation in this study is voluntary, and you may withdraw your participation at any time.

IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to take part in the study, there are no other choices except to not take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There are no costs associated with taking part in this study.

WHO WILL SEE THE INFORMATION YOU GIVE?
We will keep private all the research records that identify you to the extent allowed by law. Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

The survey will be kept in a safe place. Only the researchers will have access to these surveys. Once all the analysis are performed and writing is completed, the surveys will destroyed.

The audiotapes will be destroyed following transcription and appropriate tape review, and no personally identifying information will be included in the transcripts.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

CAN YOUR TAKING PART IN THE STUDY END EARLY?

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Janice Kuperstein, at 859-323-1100 ext 80593 or at jkupe0@uky.edu. If you have any questions about your rights as a research volunteer, contact the staff in the Office of Research Integrity at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428.

WHAT ELSE DO YOU NEED TO KNOW?

You will be told if any new information is learned which may affect or influence your willingness to continue taking part in this study.

_____   _____
Signature of person agreeing to take part in the study   Date

_____
Printed name of person agreeing to take part in the study

_____   _____
Name of [authorized] person obtaining informed consent   Date

_____
Signature of Investigator

Interview Guide – Phase II

1) When did you become a FCN? How and why did you become a FCN?

2) What type of support do you receive from the faith community in serving them? Do you get support from any other entities? If yes, what entities and what type of support?

3) Describe the major activities you have done in the past year in service to the congregational community as a whole. What have been the outcomes? Are you currently planning any new community interventions?

4) Tell me your major activities in service to individual congregants. How do you become involved with individuals and their families? What are their expectations of your role?

5) Do you interact with the church community on behalf of individual congregants? Do you encourage the congregant or family to do so independently? If so, describe examples.

6) Do you interact with the health care community on behalf of individual congregants? Do you encourage the congregant or family to do so independently? If so, describe examples.

7) Were there ever times that the health community and the faith community were at odds? What did you do? Please describe in detail.

8) Given adequate time and resources, what services would you add to what is currently offered to the congregation or to individual congregants?

9) Describe some scenarios in which your involvement with an individual congregant had a major impact on the quality of life of the congregant. What were the circumstances and what did you do for or with the individual or family?

10) Describe a time you felt frustrated in your efforts to assist a congregant. What were some of the barriers you experienced?

11) Especially with respect to congregants ages 65 and older, what gaps, if any, do you see in the health care system that you wish you could help fill? If any are identified, what would you need to fill those gaps? How does an FCN fill gaps?

12) Do you plan to remain an FCN? Why or why not?

Sample Scenario:
Ms. Jones is a congregant you have been seeing periodically in her home. She was recently admitted to the hospital for exacerbation of a chronic condition.

     Will you be aware of her admission and if so, how?
     Are you likely to visit her in the hospital? If so, what will your role be?

After 5 days in the hospital, Ms. Jones is nearing discharge.

     Will your role change at all with discharge approaching?
     Are you likely to do a home visit after discharge? If so, how soon?

Once at home, it becomes apparent that Ms. Jones and her family are having difficulty managing her care. Ms. Jones is alone during the day because her daughter and son-in-law both work. She is having difficulty getting out of bed and has already fallen twice, although thankfully she has not been injured. She takes the medications her daughter puts out for her, but it has become apparent that her memory is not quite as good as it used to be. Her daughter comes home during lunch to check on her, but this is not viable as a long-tern solution.

     What interventions, if any, will you propose for this family?

UNIVERSITY OF KENTUCKY RESEARCH

Volunteers Needed for Research Study on Faith Community Nurses Serving Older Adults

Researchers at the University of Kentucky Center for Gerontology are conducting a study to examine the role Faith Community Nurses play in assisting older people with using the health care system.

You may be eligible for this study if you:
- Are a man or woman who is 65 years old or older
- You have received services from a faith community nurse [parish nurse] for at least one month

Study time will be approximately an hour to an hour and a half. Participants will be interviewed in their homes or another setting of their choosing, regarding the role the nurse has played in their lives.

Please contact Janice Kuperstein, PT at **859-323-1100 ext 80593** or **1-800- 851-7512 ext 83510** for more information or email **jkupe0@uky.edu**

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UNIVERSITY OF KENTUCKY
An Equal Opportunity University

Consent Letter to Participate in a Research Study

Congregant Participants [Phase III]

A Faith-Based Approach for Assisting Older Adults in Health System Navigation

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?

You have been invited to take part in a research study about your experiences while receiving services from a faith community nurse. You have been invited to participate in this phase of the research study because you contacted the investigator saying you were willing to consider being interviewed. If you take part in this phase of the study, you will be one of about 5 to 10 people interviewed in Kentucky.

WHO IS DOING THE STUDY?

The person in charge of this study is Janice Kuperstein, PT, MSEd, a doctoral candidate in the University of Kentucky Graduate Center for Gerontology and a faculty member with 10 years experience in the Department of Rehabilitation Sciences.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to understand the experiences and the practices of faith community nurses serving older adult clients and the experiences of the clients being served.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?

The interview will take place in a location of your choosing and will last approximately one hour. If most convenient for you, the location may be your home or your house of worship or another nearby location.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to devote approximately one hour to be interviewed concerning your experiences receiving services from a faith community nurse and how these influenced your health and wellness. If there are any questions that you do not want to answer, you do not need to answer them. You may choose to end the interview at any time. The interview will be audiotaped and then transcribed to ensure an accurate record of your thoughts; however, the tapes will be destroyed after transcription and no identifying information will be retained with the transcript.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?

You should not take part in this study if you are not 65 years old or older. You should also not take part in this study if you have not received services from a faith community nurse within the past year.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no expected risks from participating in this study. You may answer only those questions with which you are comfortable, and you may discontinue your participation at any time.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

There is no guarantee that you will get any benefit from taking part in this study. Your willingness to take part will help to identify the role played by faith community nurses in assisting their congregants and may lead to the development of best practice recommendations which will be shared within the faith community nursing community.

DO YOU HAVE TO TAKE PART IN THE STUDY?

Your participation in this study is voluntary, and you may withdraw your participation at any time. Your choice to participate or not will not affect the services you receive from your faith community nurse.

IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to take part in the study, there are no other choices except to not take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There are no costs associated with taking part in this study.

WHO WILL SEE THE INFORMATION YOU GIVE?

We will keep private all the research records that identify you to the extent allowed by law. Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials. Your faith community nurse will not have access to any information about how you answered interview questions.

The audiotapes of your interview will be destroyed following transcription and appropriate tape review, and no personally identifying information will be included in the transcripts.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key. You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have been abused or you pose a danger to yourself or someone else.

CAN YOUR TAKING PART IN THE STUDY END EARLY?

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

WHAT HAPPENS IF YOU GET HURT OR SICK DURING THE STUDY?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Janice Kuperstein at 859-323-1100 ext 80593 or at 1-800-851-7512 ext 83510 immediately. It is important for you to understand that the University of Kentucky will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. This cost will be your responsibility. Also, the University of Kentucky will not pay for any wages you may lose if you are harmed by this study.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will not receive any rewards or payment for taking part in the study.

WHAT IF I HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Janice Kuperstein, at 859-323-1100 ext 80593 or at 1-800-851-7512 ext 83510. If you have any questions about your rights as a research volunteer, contact the staff in the Office of Research Integrity at the University of Kentucky at 859-257-9428 or toll free at 1-866-400-9428.

WHAT ELSE DO YOU NEED TO KNOW?

You will be told if any new information is learned which may affect or influence your willingness to continue taking part in this study.

_____   _____
Signature of person agreeing to take part in the study   Date

_____
Printed name of person agreeing to take part in the study

_____   _____
Name of [authorized] person obtaining informed consent   Date

_____
Signature of Investigator

Interview Guide – Phase III

Interview Questions – Phase III – Congregant Participants

1) What, to you, is a FCN?

2) How has the FCN helped you? How has the FCN helped you in ways that a regular nurse may not have?

3) I know that you have been visiting with your faith community nurse for at least a month and would like for you to tell me a bit about how this started and the different places you may have met with the nurse.

4) Would you describe for me what a typical visit might be like?

5) What are the most important things that the nurse does? Are there other things you wish could be done?

6) Please tell me a bit about your interactions with the health care system. Do you visit one or more doctors regularly? Other health providers? In general, how do you feel about these interactions? Are your questions answered?

7) Do you discuss visits to health care providers with your faith community nurse? Does he or she provide any assistance related to your health care providers or their recommendations?

8) Is there anything else you would like to tell me that I haven't asked you?

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INTERNATIONAL PEER REVIEWED:

Creating Meaning for Tough Issues: A Multidimensional Approach to Teaching   Mar 2006
End of Life Issues. Kuperstein, J, Kelly, D
> International SUN Conference on Teaching and Learning

Exploring Student Views on the Ethical Impact of Their Clinical Experiences   Sep 1997
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NATIONAL PEER REVIEWED:

Combining Your Passions: Partnering With Your Faith Community in Health   Feb 2008
Promotion and Professional Advocacy

Creating Meaning for Tough Issues: A Multidimensional Approach to Teaching   Apr 2006
End of Life Issues. Kuperstein, J
> Southern Gerontological Society

Assessing the Public's Knowledge of the Physical Therapy Profession   Feb 2004
> Roberts, H, Smith, G, Kuperstein, J.
> 2004 Combined Sections Meeting of the American Physical Therapy Association

Knowledge Acquisition in Administrative Issues: Application of the Tools   Jun 2003
and Techniques of Performance Improvement. Kuperstein J, English T.
> Annual Conference and Exposition of the American Physical Therapy Association

Advocacy in Physical Therapy: Your Profession, Your Responsibility   Feb 2003
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Effect of the Balanced Budget Act of 1997 on Functional Outcomes of Skilled   Jun 2002
Nursing Facility Patients with CVA
> Fawbush, J., Cory C, Adkisson I., McCollough R., Kuperstein J.
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Interventions for Children with Special Needs: A Multidisciplinary   Jun 2001
Service Learning Model for Educating Physical Therapy Students
Annual Conference and Exposition of the American Physical Therapy Association

LAMP Skills: Utilizing a Virtual Classroom to Create a Community of Learning   Feb 2001
During Clinical Internships. Kuperstein J, Malone T
> American Physical Therapy Association Combined Sections Meeting
> ***Recognized as Best Platform by the Administration Section of APTA***

An Analysis of Preprofessional Performance Data, Professional Performance   Jun. 2000
Data and Outcome Measures for Students in a Physical Therapy Program
Kuperstein J, English T.
> Meeting and Exposition of the American Physical Therapy Association

SELECTED PUBLICATIONS:

Creating Meaning for Tough Issues: A Multidimensional Approach to Teaching End of Life
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> Proceedings of The International Sun Conference on Teaching and Learning 2006

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An analysis of preprofessional performance data, professional performance data and outcome measures for students in a physical therapy program, Kuperstein J, English T
    Abstract - *Physical Therapy* Supplement May 2000

Exploring the ethical impact of clinical experience on physical therapy students Kuperstein J, Skaff KO
    Abstract - *Physical Therapy* Supplement June 1998

Exploring student views on the ethical impact of their clinical experiences Skaff, KO and Kuperstein, J
    Abstract - Australian Association for Professional and Applied Ethics 1997

Treatment and practical management of diabetic somatic neuropathy: a working philosophy for the forgotten complication of diabetes, Pfeifer, Beach, Jung, Kuperstein, et al
    International Diabetes Monitor, Vol 5, No. 1, 1993

Quality Resource Manual - From QA to CQI
    Kentucky Physical Therapy Association, 1992

BOOK CHAPTERS
Reimbursement Essentials. Kuperstein J in <u>Primer on Lymphedema Management.</u>
Prentice Hall, Upper Saddle River 2001, Chapter 6

Neurologic Implications for Rehabilitation of the Knee. Malone TR, Nitz AJ, Kuperstein J, Garrett W in <u>Knee Ligament Rehabilitation.</u> WB Saunders, Philadelphia 2000

EDUCATIONAL MULTIMEDIA
Documentation – Legal and Practice Issues – 2007 Update
    Kentucky State Board of Physical Therapy

Documentation – Legal and Practice Issues – 2006
    Kentucky State Board of Physical Therapy
    For use with credential-holders [PTs and PTAs] who violate KRS 327

Practice Act Refresher – 2006
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    For Jurisprudence Exam Preparation

<div align="right"><u>Janice M. Kuperstein, March 26, 2008</u></div>