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Faith Community Nurses' Impact on Family Caregivers

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IMPACT ON FAMILY CAREGIVERS

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Abstract

Title: What are the most compelling ways that faith community nurses support family caregivers?

Background: The need for family caregivers will rise exponentially in the United States in the coming decades as older adults live longer lives and often with two or more chronic illnesses. Faith community nurses are uniquely positioned through their trusted presence in faith community settings to provide this support to family caregivers.

Purpose: Family caregivers provide vital care to senior adults that our healthcare systems cannot absorb. Faith community nurses (FCNs) support family caregivers connected to their faith communities in tangible ways to strengthen the growing phenomenon of family caregiving in our country. Review of the literature identifies the supportive roles of the faith community nurse in enhancing the quality of life for family caregivers and care recipients throughout their caregiving journey.

Theoretical Framework: Pearlin's (1995) intervention strategies across the caregiving career offers the following roles: Role acquisition, role enactment and role disengagement. FCNs offer impactful interventions in each caregiving role to support the family caregiver.

Results: Sixteen articles identified for review were analyzed from both nursing literature and literature from related disciplines.

Conclusions: The literature identifies general themes including presence, practical help via education, health system navigation, and support throughout the caregiving journey. Faith community nurses build deep and trusting relationships with caregiving families in their faith communities and as such are able to leverage more positive, impactful, and lasting outcomes.

Implications for Research and Practice: Small sample sizes offered positive outcomes demonstrating the need for additional research with larger and more diverse samples to strengthen findings. The emerging role for FCNs in transitional care will grow as caregiving family's move from acute to transitional and home care settings. The FCN can facilitate these transitions to improve outcomes for family caregivers and care recipients.

Keywords: Family caregivers, care recipient, faith community nurse, parish nurse, older adults, chronic illnesses, whole person care, Pearlin's intervention strategies across the caregiving career, transitional care, quality of life, presence.

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Chapter One: Introduction

"There are only four kinds of people in the world:

Those who have been caregivers,

Those who are currently caregivers,

Those who will be caregivers,

And those who will need caregivers,"

— Rosalynn Carter (as cited in Snelling, 2012)

There is an emerging health care phenomenon on the horizon with the potential to influence multiple sectors of society and all dimensions of these selected individuals who are functioning as family caregivers. As senior adults in America live longer while managing two or more chronic diseases, the current healthcare system will not sustain itself under the demands generated by this growing segment of society (Gaugler, 2017). Family caregivers are increasingly called into family caregiving to provide a myriad of care services to older relatives, most of which they find themselves unprepared to embrace.

Most family caregivers do not plan or prepare for this role. It is often thrust upon them following a health care crisis or other significant lifestyle event. Life altering living situations suddenly reprioritize the lives of family caregivers in unintended ways. Family caregivers find every aspect of their lives can shift in a moment, or over time as a loved one's illness lingers, often depleting their financial and physical resources. Examples include altered daily routines, changes in employment status, progressive social isolation, and less attention to their own health needs.

"Experts have estimated that the economic value of services provided by family caregivers is in in excess of $375 billion annually. This figure is equivalent to the total expenditures of Medicare in 2005," (Rosalyn Carter Institute for Caregiving, 2010, p. 5).

The nursing profession must rise to this challenge by intentionally bringing the family caregiver into the circle of their caring for the aging loved one/care recipient. Just as the tip of an iceberg is only visible above the water's surface, the needs of family caregivers as they care for older adults in the years to come represents the portion of the iceberg currently submerged below the surface. While the nursing approaches to this issue may differ in various health care settings, nurses of the future will likely care for caregiving families in increasing numbers in the decades ahead regardless of the healthcare delivery setting.

Specifically, this paper addresses the professional nursing specialty practice of faith community nursing, exploring how family caregivers can access and leverage a kaleidoscope of resources through this unique and impactful role of professional nursing practice.

Statement of Purpose

The purpose of this capstone project is to examine the phenomenon of family caregivers in America, caring for adults aged 65 years and older in a home setting, who have two or more chronic diseases. The unique challenges related to maintaining a healthy quality of life during the family caregiving trajectory and an examination of how faith community nurses can best support family caregivers as they weave their way through the multi-faceted health care system and the larger community is proposed.

Qualitative Question

What are the most compelling ways a faith community nurse (FCN) supports family caregivers?

Appropriate Evidence Demonstrating Need for Critical Review of a Nursing Problem

According to the Family Caregiver Alliance, "Nearly one out of every four households in the U.S. (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over (2016, p. 1). As older adults in society live longer often with multiple chronic diseases, the U.S. health system will stretch in unprecedented ways. Family caregivers provide a crucial role by caring for loved ones at home. The potential for improved quality of life for the care recipient and cost savings to the family are major factors that inform family caregiving decisions.

In their 2012 study, Caregiving in Context, Wilder Research (2012) states:

> The age wave is beginning. More than 78 million baby boomers in America are poised to enter retirement age. Even in this healthiest of older generations, many older adults will rely on substantial help with everyday life in their later years. One of the most important challenges of our time for families, communities, and government leaders, is how to best prepare for and provide that help. (p. 1)

Significance to Nursing

This age wave, or graying of America as some have called it, poses critical challenges to our society, our health care system and to the profession of nursing. Regardless of the nursing practice arena, most nursing roles will interface with a caregiving family with increasing regularity in the coming years.

Preparing to meet the challenges these families face in a variety of clinical and community settings offers a clarion call to the profession of nursing for the decades ahead to

both improve care transitions and to care well for the family caregivers. While each nursing specialty area will need to address this within their own framework, the focus of this project is to view family caregiving through the lens of faith community nursing.

Faith community nurses (previously known as parish nurses), are uniquely poised to offer a personal connection with the caregiving family as both a professional nurse and a trusted representative of a faith community who has additional skills in spiritual care and often pastoral care training. As a purposeful blend of nursing and ministry, faith community nursing, is recognized by the American Nurses Association (ANA) and the Health Ministries Association (HMA), as a nursing specialty practice with its own Scope and Standards of Practice (2017). Intentional care of the spirit is central to the practice of faith community nursing and the seven identified roles can offer deep impact into the life of a caregiving family.

Originally called Parish Nursing, this specialty practice began with Lutheran General Hospital Chaplain and Pastor, Rev. Dr. Granger Westberg, who noticed the unique contribution nurses made to patient care by offering a bridge between the sciences and the humanities (Westberg, 1990). Westberg noted that nurses were often at the bedside with the patient after the physician came in to deliver difficult news and nurses were in a position to help the patient process news of a new diagnosis along with its ramifications.

In the late 1970's, Westberg developed wholistic health centers in churches comprised of a physician, a counselor, and a nurse with the goal of addressing the various dimensions of parishioners in a congregational setting. The model enjoyed initial success, but was not financially sustainable, and from this model, the role of the parish nurse remained.

> The theological concept of personhood and life in the Old and New Testaments implies an understanding of health that is more than purely the absence of specific physical or mental ailments. It encompasses community wellbeing, peace, justice, forgiveness, service with God, and others, purpose, identity, the ability to give as well as to receive, to use one's gifts, to be able to pray and to worship God, to choose good and to resist evil, to care for the environment, and to enjoy God's creation. This is whole-person health, or "wholistic health" (the w differentiates it from the new age concept of holism), and should underlie and direct the Christian approach to health provision. (Wordsworth, 2016, p. 107-108)

From these insights, Westberg developed the parish nursing role as a way to place a nurse on the pastoral staff of six local churches around Lutheran General Hospital in Park Ridge, Illinois in the mid-1980s. Westberg charged parish nurses with helping parishioners understand how their faith and health were interrelated. Health promotion, health education, screenings, support groups and a listening presence from the parish nurse were a few of the early roles identified.

The parish nurse role expanded quickly, with early efforts in rural Iowa and surrounding states. Lutheran General Hospital launched a National Parish Nurse Resource Center with resources and a curriculum for parish nurse education and preparation. By the mid-1990s parish nursing grew across the nation and up to 1,000 parish nurses attended the now annual Westberg Parish Nurse Symposiums in the Chicago, IL area (Westberg Institute for Faith Community Nursing, formerly the International Parish Nurse Resource Center, 2001).

Seven roles were identified for the professional specialty practice of parish nursing; integrator of faith and health, health educator, personal health counselor, referral agent and

liaison, health advocate, developer of support groups, and coordinator of volunteers. Using this framework, parish nurses could combine professional nursing practice with spiritual care within the context of their own congregation or faith community to identify and meet these unique needs. (ANA & HMA, Scope and Standards of Practice, 2017).

In 2005, the American Nurses Association along with Health Ministry Association revised the original 1998 Parish Nurse Scope and Standards of Practice to further expand and define the scope of practice. At this time, leaders of these organizations recommended a change from parish nurse to faith community nurse as the overarching term for this area of specialty practice.

The rationale identified that while parish nursing began in Christian congregations, primarily, Lutheran, Catholic, Baptist, non-Christian, and faith-based sites expressed interest in parish nursing. Faith groups outside of the Lutheran and Catholic churches did not embrace the term parish. Additionally, in the southern U.S., the term 'parish' is synonymous with a geographical county, creating further confusion between county or public health nurses and parish nurses in those regions.

Formerly accepted terms such as parish nurse, congregational nurse (in Jewish synagogues), church nurse, or pastoral nurse are utilized in individual settings with the understanding that faith community nursing is now the professionally accepted umbrella term for the specialty practice (ANA & HMA, Scope and Standards, 2017, p.1).

"The primary focus of the FCN is the intentional care of the spirit, differentiating this specialty practice from the general practice of a registered nurse"(ANA & HMA. 2017, p.1). Faith community nursing has grown dramatically in recent years. The Church Health Center in Memphis Tennessee, which now houses the International Westberg Institute of Faith Community

Nursing, reports that there are over 15,000 Faith Community Nurses in the U.S. Many more are practicing in countries such as Canada, Australia, New Zealand, the UK, Swaziland, Pakistan, Israel, and South Korea (Church Health Center, 2014).

In the Twin City Metropolitan area of Minnesota, over 600 FCNs either practice independently on the staff of their faith communities, or connect through a health system based faith community nurse network that offers education, resources, and support to FCN's (Faith Community Nurse Network of the Greater Twin Cities, 2017).

The former HealthEast Care System, Allina Hospitals (Mercy & Unity), Fairview Hospitals, Lakeview Hospital in Stillwater, MN, Lyngblomsten Senior Care in St. Paul, ElimCare Senior Living, based in Eden Prairie, MN, TRUST, Inc. in southeast Minneapolis, and Park Nicollet in St. Louis Park have long-standing parish or faith community nurse networks.

The Faith Community Nurse Network of the Greater Twin Cities launched in 2005 with coordinators from local health system based networks partnered to offer quarterly educational symposiums, two Foundations of Faith Community Nursing Preparation Courses each year, opportunities for research, and a library of resources through the Hennepin County Library System. Hennepin County offered funding and structure to identify local FCNs and meet their ongoing educational needs (Faith Community Nurse Network of the Greater Twin Cities, 2017).

Today, Faith Community Nurses are embracing their roles in the transitional care process, as patients move quickly between hospital based observation care or inpatient admission status to transitional care facilities and back home (FCN Scope & Standards, 2017). The significant contributions of Dr. Deborah Ziebarth identified this transitional care role through her dissertation and prolific written work on faith community nursing. Ziebarth recently published a

manual to train faith community nurses to build effective transitional care skills to join the national effort to reduce the rate of preventable hospital readmission rates (Ziebarth, 2015).

Faith community nursing also supports the Healthy People 2020 Goals:

> Attain high quality, longer lives free of preventable disease, disability, injury, and premature death. Achieve health equity, eliminate disparities, and improve the health of all groups. Create social and physical environments that promote good health for all. Promote quality of life, health development and healthy behaviors across all life stages. (Paapas-Rogich, & King, 2014)

In summary, faith community nursing is a continuously evolving professional nursing specialty practice that builds on the foundation of professional registered nursing education and experience to prevent, promote and protect the health of populations organized in faith-based organizations across the nation and around the world. The third edition of the FCN Scope & Standards, 2017, reflects the incorporation of Healthy People 2020 initiatives and the 2010 Institute of Medicine report on the future of nursing mandates to be reflected in faith community nursing practice. Finally, faith community nurses need to maintain growing competencies in both faith community nursing practice and spiritual care expertise as recommended by the faith community where they serve.

Conceptual Model

The model chosen for this literature review is the Pearlin Stress Model (Aneshensel, Pearlin, Mullan , Zarit & Whitlatch, 1995). Leonard Pearlin is a sociologist who extensively studied family caregivers over the past several decades, which resulted in the development of the caregiving stress process model and identified outcomes resulting from the stresses of caregiving.

The model portrays the caregiving trajectory through three main caregiving stages: role acquisition, role enactment, and role disengagement. Transitional events occur within each of the caregiving stages. During role acquisition, the transitional event is the onset of illness, which results in the start of care. In the role enactment stage, the care recipient may have in-home care, then experience the transitional event of a nursing home admit, which may result in long-term institutional care. The third caregiving phase of role disengagement begins with the transitional event of the death of the care recipient. This includes the bereavement and social readjustment caregiving phases within the role disengagement stage (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Intervention strategies during the role acquisition stage include education, prevention, and planning. During the next stage, role enactment, stress management, and resource enhancement are the intervention strategies. The final stage, role disengagement, involves closure and readjustment strategies.

Faith community nurses embrace education, prevention and planning roles throughout their work and can easily apply helpful caregiving interventions to support family caregivers. The FCN toolbox contains a variety of helpful interventions for reducing stress, for example, by integrating faith and health through using spiritual practices, individually or within a faith community, family caregivers can relieve the stress of caregiving. Navigating the referral process with a family caregiver to a variety of community-based resources is a significant role the FCN can play.

Finally, a FCN is well poised to support the family caregiver through their loved one's death and bereavement within the context of their established relationship in the faith community. Active listening, prayer, rituals and support groups are a few of the ways FCNs can intervene to assist with closure and readjustment for the caregiver.

Summary

Faith community nursing roles as defined in the ANA and HMA Scope and Standards 2017, have the potential to offer a significantly positive impact on the family caregiving journey now and in the future. Pearlin's model demonstrates the commonalities of the caregiving stages shared by caregivers along this journey and points to helpful intervention strategies for each one.

Chapter Two: Description of Search Strategies

To develop this critical review of the literature, search strategies included key words, selected search engines, and inclusion and exclusion criteria with broad applications to cover adequately the topic of faith community nurses supporting family caregivers caring for a loved one in the home setting.

Description of Search Strategies

Key words used included: family caregivers, quality of life, faith community nursing, faith community nurse, parish nurse or parish nursing, chronic illnesses, and older adults. Search engines used were Cochrane, CINAHL, Pub Med, Science Direct, and Scopus. Also utilized was a comprehensive bibliography on parish or faith community nursing articles (Faith Community Nursing Literature Reference List) available through The Church Health Center and this author's own professional library resources. The range of years searched spanned 2006-2017.

Additional searches included local and national professional organizations that support caregiving. Included are: Family Caregiver Alliance, Wilder Research, Minnesota Area Agency on Aging, Lyngblomsten, the Faith Community Nurse Network of the Greater Twin Cities, the International Parish Nurse Resource Center, now known as The Westberg Institute for Faith Community Nursing. Local nurse researchers Dr. Linda Shell and Dr. Joseph Gaugler; a prolific researcher in family caregiving at the University of Minnesota, School of Nursing, contributed to the literature search.

Criteria for Inclusion and Exclusion

Inclusion criteria included adults age 65 years or older who have two or more chronic diseases. The more diseases an older person deals with, the more complex the care for the caregiver. Much of the caregiving literature focused on caring for a family member with

dementia. Dementia is one of several commonly occurring chronic illnesses in the chosen demographic and is included in the research.

To focus the study on the specifics of the American environment and healthcare system, research from other countries was excluded. This family caregiving study is not limited to persons of certain races within the United States but while some of the studies from other countries raised good points, application to a different health care system may dilute the results of this study.

Because family caregiving crosses several literature domains, searches included articles in gerontology, psychology, and other social sciences as well as theology searching 2006-2017. Of note, two critical sources, Westberg (1990) and Pearlin (1995), were included.

Number and Types of Studies Selected for Review

Sixteen studies reflected the multi-dimensional factors of the family caregiver. Nursing, faith community nursing, psychology, mental health, physical impacts of caregiving, gerontology, and theology all provided insight into the role and unique challenges of the family caregiver. Additionally, faith community nurses approach caregivers and care recipients from a wholistic frame of reference. An economic/financial component is part of the family caregiving role as are policies that help or hurt family caregivers. Current policies and active legislation are included when considering the needs of the family caregiving unit.

Research related specifically to faith community nursing is limited but has grown in the past ten to fifteen years as more academicians have entered this specialty practice. Dr. Deborah Ziebarth is the most prolific researcher in the past decade and her dissertation focused on faith community nursing interventions related to transitional care. Ziebarth began as a faith community nurse, coordinated an award winning network of FCNs in the greater Milwaukee

area, and following her dissertation work has published two training manuals in transitional care for FCNs along with a variety of scholarly works in faith community nursing practice (Ziebarth, 2016).

Articles were reviewed based on the Johns Hopkins Nursing Evidence-Based Practice Model and Guidelines, Second Edition (Dearholt & Dang, 2014). Four levels of evidence and three levels of quality helped analyze these articles. Level I articles are defined as experimental studies with randomized control trials (RCTs), and systematic reviews of articles with or without meta-analysis. Only two of the articles reviewed met the criteria along with a quality rating of "A." This rating describes consistent articles with generalizable results and a sufficient sample size to support the study design. There is adequate control, definitive conclusions, and consistent recommendations of scientific evidence based on a comprehensive literature review.

Two of these articles received a Level II rating, which includes quasi-experimental studies, a systematic review of a combination of RCTs, and quasi-experimental studies with or without meta-analysis. Both of these articles also received a "B" rating for good quality, with reasonably consistent results and adequate sample sizes, some control and definitive conclusions and recommendations with a comprehensive literature review (Dearholt & Dang, 2014).

Level III studies were the most common, and represent non-experimental studies with a systematic review of a combination of RCTs, quasi-experimental, and non-experimental studies, or non-experimental studies only with or without meta-analysis. Five articles received a "C" quality rating based on little evidence with inconsistent results and insufficient sample size for the study design with inability to draw conclusions.

Summary

Searching a variety of discipline domains provided a broader approach to the many facets of the family caregiver experience. Articles based on the U.S. healthcare system provided the most relevant information for American caregivers, although other countries have contributed to the literature in this area. Additionally, national, state, and local caregiving organizations provided resources for evidence-based and current expertise related to family caregiving issues. Several articles addressed faith community nursing and family caregiving in the literature between 2006 and 2017.

Chapter Three: Literature Review and Analysis

What are the most compelling ways that faith community nurses support family caregivers? From the faith community setting to acute, transitional, and home settings, the faith community nurse offers a sustaining presence through the complexity of family caregiving. Wholistic consideration of the numerous aspects of family caregiving calls for a multidimensional approach accompanied by a trusting relationship shared by the faith community nurses and the family caregiver (See Figure 2 appendix).

Synthesis of Major Findings

Family caregiving is a complex endeavor that influences all dimensions of an individual family caregiver, both as a person and as a family member in relationship with the care recipient and within the larger family system. The literature examined the relational aspects of the family caregiving dynamic, primarily through qualitative research based on descriptive studies that are largely phenomenological in nature. Sample sizes in many of these studies were small and narrow in scope, compromising their ability to draw broadly applicable conclusions.

Faith community nursing and family caregiving.

Four studies specifically related to parish or faith community nursing: Dyess and Chase (2010), Grebeldinger and Buckley (2016), and Mock-Sheridan (2017) utilized three small samples based in one congregation with a faith community nurse on staff, whereas Rydholm et al. (2008) offered a larger sample of parish /faith community nurses encompassing numerous congregations from several regions of Minnesota. Quantitative studies focused on caregiver responses to specific aspects of the caregiving role. Randomized control trial (RCT) studies with

significant sample sizes contributed to the literature and provided evidence-based practice protocols for broader application to the caregiving knowledge base.

Family caregiving and the stress response.

In his classic work on caregiving and the stress response, Pearlin (1990) outlined several stress response concepts and their measures. Many recent articles in the literature on aspects of family caregiving and its resulting stressors referenced Pearlin's work. "Stressors are the problematic conditions and difficult circumstances experienced by caregivers (i.e. the demands and obstacles that exceed or push to the limit one's capacity to adapt. Outcomes refer to the consequences of the stressors" (Aneshensel, Pearlin, Mullin, Zarit & Whitlatch 1995). Below, their interventions strategies across the caregiving career, captures the stages of caregiving. Existing faith community nursing roles can positively influence and support the family caregiver through the caregiving trajectory.

Family caregivers and quality of life.

Bull (2013) and Funjinami et al., (2012) addressed self-care deficits and quality of life in family caregivers. Winter, Moriarity, Atte, and Gitlin (2015) developed the REACH Tool, specific to family caregivers whose care recipients had a diagnosis of Alzheimer's disease. LeBlanc, Driscoll, and Pearlin (2004) and Yeh and Bull (2009) addressed spiritual well-being, mental health, and religiosity and its impacts on family caregivers. Spiritual well-being and religiosity often enhanced family caregiver's coping skills, while their mental health was strained by the challenges of caregiving.

Coleman (2015), Gaugler (2005, 2006, and 2015) and Pearlin (2004) examined quality of life measures while Gaugler (2005, 2006) and Hong (2005) addressed community-based resource

utilization in family caregiving. Farran (2016) specifically analyzed physical exercise and its effects on family caregivers as a means of coping with the physical and mental challenges of caregiving. Farran noted improved outcomes from participants adopting his suggested physical protocols. Gaugler (2005, 2006, and 2015) drew heavily from the social sciences and from the academic literature, but failed to address the spiritual or religious aspects of caregiving in his research and writing.

Family caregiving assessment tools.

Coleman (2015), Gaugler, (2015), and Pearlin, Mullan, Semple and Skaff (1990) developed tools to assess and demonstrate self-efficacy as a caregiver, the Minnesota Adaptation on the NYU Caregiver Intervention, and the stress response process and resulting outcome measures. All of these offer valuable, scientific data to promote insight and understanding into the family caregiving role.

Major Strengths and Weaknesses in the Faith Community Nursing Literature

Two articles specifically referenced faith community nursing and aspects of family caregiving. Dyess (2010) and Grebeldinger (2016) maintained small samples sizes with limited ability to generate meaningful conclusions across a broader demographic spectrum. Replication of these important studies with larger sample sizes may yield results that are more meaningful.

Rydholm et al. (2008) offered a larger sample size spanning several regions in Minnesota that included rural, suburban, and urban demographics. Data collected used a Data, Interpretation, Action, Response, and Yield Tool (DIARY), which demonstrated the remarkable success that FCNs have in building bridges between formal and informal networks of care, the faith communities, and health care systems. More recently, Sheridan-Mock (2017) launched a small, qualitative study in a Presbyterian church setting in a mid-western state to uncover the

value and meaning of faith community nursing from the perspectives of both clients (or parishioners) and nurses. Sheridan-Mock identified five themes of the FCN role valued by both FCNs and parishioners: services, nursing expertise, spirituality, familiarity, and community support.

FCN influence was broadened further as Ziebarth and Campbell (2016) described a transitional care model whereby FCNs help parishioners navigate the continuum of care between hospital, a short-term rehabilitation facility, and home. Specific FCN skills at critical junctures can make the difference between success at home and an unnecessary hospital readmission. While promoting the overall health of parishioners, FCNs can also mitigate significant cost savings for the health care system by helping avoid penalties leveled by Medicare for high readmission rates.

Summary

The studies reviewed captured the dynamic interplay of the challenging role of family caregivers, offering tangible results to inform faith community nurses and other health care professionals in their work with the family caregiving unit. A multitude of family caregiving assessments, tools, and resources are available to faith community nurses through local, state, and national caregiving organizations. Specific continuing educational modules on family caregiving resources are recommended as additional modules to augment existing Faith Community Nurse Preparation Courses.

Question: What are the most compelling ways FCNs support family caregivers?

Citation /Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability, & Validity		
Bull, M. (2014). Strategies for sustaining self, used by family caregivers for older adults with dementia, *Journal of Holistic Nursing, 32*(2) 127-135. http://jhn.sagepub.com doi: 10.1177/0898010113509724. *John's Hopkins Model Evidence Level & Quality Guide:* Evidence Level: III	Family caregivers (FC's) describe strategies that sustain them in their care giving roles while caring for an older family member diagnosed with dementia. Resilience and psychological distress in family caregivers is also described	Sample inclusion: Eighteen family caregivers identified from 5 adult day centers (ADC's) where their loved ones received services in a Midwestern city in the United States. One of the faith based adult day centers was faith-based. All of them had non-profit status.	A narrative, mixed methods design was used along with standardized scales for resilience and depression. The university and the ADC's obtained IRB approval. Caregivers were identified by ADC staff and gave written permission if they agreed to participate. Permission to audio record	Wagnild and Young's (1990) 25 item Resilience Scale and Symptom Distress questionnaire with 92 yes/no items. (Kellner, 1987). Reliability and validity are reported as extensive, particularly between those who are clinically depressed and not depressed (Bull, 2014). Data analysis: verbatim narrative transcripts verified by	Demographic data: 18 FC's aged 18-86 years. Avg. age=64 yrs., 39% caring for spouses; others were adult children. 67% of FC's were female. 60% White and 40% African American. 89% identified as Christians. FC's provided care for older adult for avg. of 10 years. 71% of older adults attended an ADC 5 days/wk. Four strategies emerged from narrative data for FCs to cope: Drawing on past life experiences, nourishing self, relying on	Implications for practice: nurses providing a care focus on the inter-relationship of physical, psychological, spiritual and social health in the assessment. Promote a shift from problem based to strengths based holistic nursing assessment. Nurse's knowledge of FC's self-sustaining strategies along with encouragement of FCs to care for themselves. Future research with larger samples is needed to conduct statistical analysis

Quality Level: C			interviews was obtained. Telephone interviews from 50-90 minutes were conducted.	investigator for accuracy. N-Vivo software employed.	spirituality and seeking information. 94% of FC's scored high on resilience. Psychological distress was within the normal range based on the tools.	correlating psychological distress and resilience. Rural FC's may not have access to similar resources. Longitudinal studies to test self-sustaining strategies FC's can be used, at the outset of their loved one's initial diagnosis.

Citation in APA/Level & Quality	Purpose of Study	Sample /Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments (include reliability& validity)		
Coleman, E., Ground, K., & Maul, A. (2015). The family caregiver activation in transitions (FCAT) Tool: A new measure of family caregiver self-efficacy. *The Joint Commission Journal on Quality and Patient Safety, 41*(11), 502-507. FC=Family Caregiver *Johns Hopkins Model Level Evidence & Quality Guide:*	Family Caregiver Activation in Transitions (FCAT) Tool was developed to foster more productive interactions between health care professionals and family caregivers. It was developed with direct input from family caregivers.	Phase One: Cognitive testing of convenience samples of family caregivers (July-August 2013) N=54. Phase Two: Pilot testing, (September 2013-October 2013). N=50. Phase Three: Two groups were randomly recruited from web-based national samples. N=187, N=247. FCAT qualitative study tool. (November 2013-March 2014). N=32 family	Psychometric testing of the FCAT Tool was guided by a partial credit of Rasch model using Conquest 2.0. (This model helps in working with polytomous data-restricted to one set of values.)	Validation completed in three phases. Reliability 0.84 (person separation).	Participants recommended revising the script to eliminate redundancy and simplify structure. Five themes of FCAT study: 1. FC contributions to care of their loved one are dynamic; 2. FCs have goals that may differ from patient goals. 3. FC feels unprepared for post-discharge medication management. 4. Need encouragement to assert and identity.	Future studies can build on the FCAT tool. Potential as an outcome measure vs. a process of care measure. Future studies may address family caregiver preparation and confidence as it relates to preventable readmission rates and medication errors.

Level: I Quality: A		caregivers. Sample demographics included age, sex, education, race, service area (metro vs. non-metro), and region of the U.S. and English-speaking. FC loved one, (patient) must have been hospitalized within the past 12 months for one or more diseases: COPD, atrial fibrillation, cancer (not skin), diabetes, heart or kidney disease, or stroke.			5. Assume responsibility for organizing post-discharge care plans. **Limitations:** Self-reported vs. performance-based tool. Sample groups from Area Agency on Aging and Alzheimer's Association may have limited generalizability. Phase three was web-based, limiting less technologically proficient family caregivers' responses.	

Citation in APA/Level & Quality	Purpose of Study	Sample/Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments (include reliability& validity)		
Dyess, S. & Chase, S. (2010). Caring for adults living with a chronic illness through communities of faith, *International Journal of Human Caring 14*(4) 38-44. **Level:** III **Quality:** C (A 7,000 member faith community used N=8 when the FCN had been in her position for 10 years?)	To build on a 2004 Study by Carson & Koenig, et al., which demonstrated that participation in faith communities positively contributes to health for those living with chronic illness. Presents a portion of the findings that contribute to under-standing caring community practices.	7,000 member Catholic faith community where a FCN was employed for 10 years, located in the SE region of the U.S. Purposive sample if 8 adults aged 69-91 years, four men and four women, members of the faith community with two to nine chronic illnesses, 2-19 daily meds & active involvement in the faith community. English speaking able to read and write English.	Phenomenological, qualitative study. Van Manen's (1990) method, guided by hermeneutic research that immerses the researcher in the data using writing, rewriting and balancing individual experiences with the whole perspective. Interviews were audiotaped and transcribed. 150 pages of transcribed interviews, field notes revealed several themes.	Question used: "What is the meaning of living with a chronic illness while being actively affiliated with a community of faith with an active faith community nursing program**?"**	Themes emerging from data analysis: 1. Living in Abundance (the goodness of the mystery of God and faith community members & the greater comm.) 2. Caring relationship in the context of the community of faith-highly valued by participants. 3. Thriving from Caring while living with chronic illness in the community.	Participants living in community not focused solely on their disease. Enhancing multiple linkages in caring community models can affect health care costs/reform. These caring models may also expand access to care. **Limitations:** Small sample size, one congregation, Caucasian, recommend expanding to larger population. Further research including development of whole person models of care.

Citation in	Purpose of	Sample/Setting	Design	Results	Authors'

APA/Level & Quality	Study		Methodology	Instruments (include reliability& validity)		Recommendations
Farran, C., Etkin, C., Eisenstein, A., Paun, O., Rajan, K., Castro Sweet, C., Evans, D. (2016). Effect of moderate to vigorous physical activity intervention on improving dementia family caregiver physical function: A randomized controlled trial. *Journal of Alzheimer's Disease & Parkinsonism* *6*(4)1-10. Doi: 10.4172/2161-0460.1000253.	Physical activity has been identified as one of the best approaches for improving physical and mental health; however, few known family caregiver physical interventions have been conducted. 1) To examine the context of dementia family caregiving as baseline and 12-months, concerning caregiver and care recipient socio-demographic characteristics, and caregiver	A community-based sample of strained family caregivers of persons with ADRD (Alzheimer's Disease Related Disorders) on an ongoing basis and assigned them to either the EPAI treatment or the CSBI control group. 211 caregivers met eligibility criteria: 1. At least 30 years of age, 2. English speaking, 3.Caring for a person with dementia and residing at home. 4. Providing >10 hours a week of unpaid	Caregivers were randomly assigned to one of two groups: EPAI or CSBI. MVPA assessed with a self-report measure; physical function was assessed with two measures: Intention to treat analysis used descriptive, categorical, and generalized estimating equations with a correlational matrix and log to examine interactions in change in MVPA over time. Caregiver	Comprehensive in-person assessment at baseline, six and 12 months, with three- and nine-month assessments by telephone. Research associates (RAs) trained and monitored by project manager. RAs were unaware of treatment assignments. Randomized members of both groups completed a simple random-sequence table generated by a statistician. Community Health Activities Model Program	Given the prevalence of ADRD, the need for family care, and the toll that caregiving takes on family members' mental and physical health this study addressed a majority public health problem-increasing physical activity of sedentary caregivers. A major contribution of the study was a combination	Recommendations for future studies to improve family caregiver physical activity research should emphasize understanding inactivity and the synergy between physical activity and other health behaviors. Researchers suggest that even small increases in activity on inactive individuals may be beneficial to public health. Objective measures along with self-report measures assist in characterizing activity patterns, and increase understanding of how physical activity and physical function

Johns Hopkins Model Level & Evidence & Quality Guide **Level: 1** **Quality: A**	stressors, resources, and background health to determine if there were differences between the EPAI and CSBI at baseline and 12 months. 2) Test the hypothesis that the EPAI, compared to the SCPBI, will attain higher MVPA adherence (>150 min/week), and attain greater physical function using two Senior Fitness tests, I. e. 2 min Step Test and 30 s Chair Stand.	caregiving. 5. Not participating in MVPA> 60 min./wk. in the past 6 months. 6. Free of medical or functional conditions that would limit MVPA 7. Report of strain with at least one item from the caregiver health effects study measure criteria. 8. No prior participation in a physical activity intervention.	strain, stressors, and Resources measured personal instrumental ADL's; whether caregivers had others to provide care; and mental/physical strain in providing the care. Mini Mental State Examination (MMSE) Crohnbach's alpha with TRAC sample=0.82, (range 0-30). Chicago Health and Aging Project (CHAP) epidemiological study measures assessed caregiver burden.	for Seniors (CHAMPS); a 41-item self-report tool was used. Physical function measured by two objective assessments: The Senior Fitness Test 2 min. step test (well validated and has positive correlations with other similar measures). (r=0.73-0.74) (Range 0-100) and the 30 s Chair Stand Test. (Positive correlations with other similar measures (r=0.71-0.78 for men and women, respectively).	of self-report physical activity and objective physical function.	are interrelated.

Citation /Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability, & Validity		
Funjinami, R., Otis-Green, S., Klein, L., Sidhu, R., & Ferrell, B. (2012). Quality of life of family caregivers and challenges faced in caring for patients with lung cancer. *Clinical Journal of Oncology Nursing, (16)* 6, DOI: 10.1188/12. CJON.E210-E220. *Johns Hopkins Model*	Family caregivers (FCGs) of patients with lung cancer experience multi-faceted challenges in their care-giving roles. This study examines two case studies drawn from a National Cancer Institute funded program project. 1. Describe current empirical evidence regarding the Quality of Life (QOL) of FCGs of patients with lung cancer. 2. To use two case FCG studies to describe these	Two composite caregiver case studies from an NCI-funded program, whose purpose was to test the efficacy of an inter-disciplinary palliative care intervention delivered by Advanced Practice RN's (APRN's), for patients and families living with a non-small cell lung cancer. FCGs n=163 of patients receiving usual care for one year from	Research nurses asked each FCG to complete a survey and self-reports at baseline at 7, 12, 18 and 24 weeks following accrual. Needs from each case study were identified in three arenas: psychosocial support, patient advocacy and self-care. Interdisciplinary team members provided interventions, which were then coordinated	Using validated tools, FCGs were assessed for QOL, distress level, functional level, level of preparedness for care giving, and caregiver burden. Questionnaires and interviews were used to collect data. Selection for inclusion required major challenges in two or more QOL domains, (physical, psychological, social, and spiritual). Tools were referred to, but not discussed in depth.	Complex challenges face patients and family caregivers alike, when non-small cell lung cancer is diagnosed. The QOL of the patient and the family caregiver are co-dependent. Oncology nurses who assess and identify needs can collaborate with inter-disciplinary team members to offer resources and interventions tailored to support both the patient and the caregiver through the cancer journey.	An extensive appendix with national resources in advance care planning; bereavement; education; housing, home health and hospice care; individual and family counseling; legal and financial assistance; self-care; support groups; sexual health; smoking cessation and transportation is included in this article. Implications for nursing practice: Quality of life in cancer diagnoses affects the interchange between the caregiver/care receiver dyad. Oncology nurses, as well as nurses in other specialty practices, can benefit from coordinating an

Evidence Level & Quality: Level: III Quality: C	QOL issues. Identify interventions and resources to mitigate deficits.	the medical oncology adult ambulatory care clinic at an NIC designated compre-hensive cancer center.	by the oncology nurse. Two spousal caregiver case studies with two or more QOL challenges were presented.			interdisciplinary team effort to offer support and resources to the family impacted by cancer as a unit. Models of care, checklists, and resources make this a practical contribution to the literature.

Citation in APA/Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability& Validity		
Gaugler, J., Kane, R. L., Kane R.A., & Newcomer, R. (2005). Early community-based service utilization and its effects on institutionalization in dementia caregiving, *The Gerontologist 45*(2) 177-185. *Johns Hopkins Evidence-Based Level & Quality:* Level: II Quality: A	To determine whether utilizing community-based services early in the dementia caregiving career delays time to nursing home placement.	Data utilized from a three-year prospective study that recruited 4,761 dementia caregivers from eight catchment areas in the U.S. Areas included Rochester, NY; Urbana, IL; Memphis, TN, Portland, OR; Cincinnati, OH; Parkersburg, WV; Minneapolis, MN; and Miami, FL. Inclusion criteria: All	Longitudinal data from the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE). The hypothesis tested whether dementia caregivers who used more community-based long-term care services earlier in their caregiving careers were more likely to delay nursing home placement of the care recipients.	A Cox proportional hazards model. Primary objective stressors of caregiver burden were measured by the seven-item Zarit Burden Scale (reliability 0.87). Secondary caregiving hours measured per interview. Global well-being measured by the Geriatric Depression Scale (reliability=0.98) . Bivariate analysis was also used. Caregivers ADL and IAD dependencies were also	By the conclusion of the study period, 2,185 care recipients (45.9%) had been institutionalized. Among those care recipients institutionalized, the average length of time in the study was 473.44 days (SD=238.44; range=31.00-1094.00). 21.3% of the individuals (n=1,104) did not use in-home help prior to institutionalization. 62.7% of all caregivers or care recipients (n=2,986) did not utilize adult day services during MADDE. An analysis of	The findings suggested the practical importance and cost-effectiveness of early community-based service use, and they emphasized the role of timing when one is conceptualizing the proliferation of stress in the dementia caregiving career.

		older adults had a physician-certified diagnosis of an irreversible dementia; were enrolled in Medicare Parts A & B; had service needs and resided at home in one of the eight aforementioned MADDE catchment (geographical) areas.	In-person interviews by trained nurses and social workers were conducted every six months for a three-year period.	measured at 0.84 and 0.75, respectively. R=.62; p <.001	interaction terms in the Cox regression model found that those individuals who utilized in-home help services earlier in their dementia caregiving careers were more likely to delay institutionalization. **Limitations:** Care-givers and care recipients were not randomly sampled even though the sample size was large for a dementia study. The results also emphasized important conceptual and methodological issues related to the longitudinal analysis of dementia caregiving outcomes.	

Citation in	**Purpose of**	**Sample/Setting**	**Design**	**Results**	**Authors'**

APA/Level & Quality	Study		Methodology	Instruments, Reliability& Validity		Recommendations
Gaugler, J., & Teaster, P. (2006). The family caregiving career: Implications for community-based long-term care practice and policy, *Journal of Aging and Social Policy, 18*(3/4)*, 141-154.* Doi: 10:1300/J031v18n03_10 *Johns Hopkins Model Evidence Level & Quality* Level: III Quality: A	To link emerging longitudinal research on informal long-term care with policy and practice recommendations to alleviate negative caregiving outcomes. To summarize the psychosocial and health effects of caregiving over time.	Key trends, studies, and findings in longitudinal studies of family caregivers.	Longitudinal study with meta-analysis on at-home caregiving and how this helps to address policy and practice concerns in the delivery of long-term care.	Classic studies, such as Pearlin, Vitaliano, Zhang, & Scanlan.2003. The Digital Symbol test from the Wechsler Adult Intelligence Scale, 3 self-report questionnaires, the Screen for Caregiver Burden, Hamilton Depression Scale Rating and the Sleep Disorder Questionnaire were used.	Education, support groups, and respite are the recommended modalities.	More study needed on the trajectories and transitions in family caregiving. More research is needed between links between policy initiatives and program design, resulting in improvements in community-based long-term care.

Citation in APA/Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability, & Validity		
Grebeldinger, T. & Buckley, K. (2016). You are not alone: Parish nurses bridge challenges for family caregivers, *Journal of Christian Nursing, 33*(1) 50-56. doi: 10.1097/CNJ.0000000000000242. *Johns Hopkins Model Evidence Level & Quality:* **Level**: III Qualitative, non-experimental study. **Quality**: C (very small sample size).	Reveals four key ways parish nurses support caregivers and offers important implications for parish nurse preparation and practice. Examines family caregiver burdens and stressors, sources of social support, perceptions of support provided by parish nurses.	Fifteen family care-givers were recruited through parish nurse coordinators of two parish nurse networks in a large metropolitan area on the East Coast.	Individual semi-structures interviews between January and May 2008. Interviews were audio taped and lasted less than two hours.	Interview guide with open-ended questions. Tool created by researchers with questions to discover caregiver burden and stressors, support and coping strategies, and the role and support provided by the parish nurse. Data analyzed using thematic content analysis. PhD RN reviewed transcripts.	The gift of presence, the bearer of blessings, the messenger of spiritual care, and a bridger of the challenges of navigating through the health care system.	As bridges between the faith community and healthcare system, parish nurses can be pivotal in reducing costs of care from delays in seeking healthcare and encouraging early intervention. Limitations: Sample size too small and limited generalization to other caregivers. Being familiar with a parish nurse may have influenced participant responses. Pearlin Stress Process Model for assessment. Include caregiver assessment and goal setting in PN prep. courses.

Citation /Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability, & Validity		
Hong, L., Chadiha, L., & Morrow-Howell, N., (2005). Association between unmet needs for community services and care giving strain, *Families in Society: The Journal of Contemporary Social Services (86)*1. ProQuest Psychology Journals, Jan-Mar 2005, p. 55-62. *Johns Hopkins Model Level & Quality:*	Description of informal caregivers' unmet needs for community services associated with care giving strain.	Caregivers caring for an older adult who received community services numbered 463Sample was extracted from the Family Caregiving in the U.S. survey. (National Alliance for Family Caregiving and American Association of Retired Persons, 1997).	Participants were randomly selected from a random-digit-dial sample of U.S. Telephone households and a supplemental sample of ethnic minority caregivers. A telephone survey of 1,509 caregivers of whom 975 met the following criteria: At least 18 years of age, English-speaking, providing care to a family member aged 60 or older living on his or her own, a relative's or friend's home and used at least	Dependent variable: Caregiving strain, rated on a 5-pt. scale. Authors discussed a single-item measure vs. a multi-item strain measure. Both have been supported by previous research. Independent variables: an unmet service need from a list of eight community-based services. FCGs were asked if they used one of the above in the past 12 months. Control variable: stressors and	68.7% of caregivers were female, average age of 43.2 years. 47.1% White, 19.1% African American, 17.2% Hispanic, and 16. 6% Asian American Caregivers. 4.3% were spouses, 49.5% adult children, and 46.2% were relatives or friends. The average age of care receivers was 80.2 years old. 38.4 % of care receivers lived alone. Over two-thirds of the caregivers worked full time and provided an average of 18 hrs./wk. of care. 59.5% of	One-third of caregivers reported that services included in the eight categories did not meet their needs. Limitations included: while the single-item strain measure is valid, the multi-level strain measure may have had increased validity. Low number of spousal caregivers. National probability sampling was a strength of this study. Service providers need to assess tools and procedures used to determine client needs, provide tailored services, and understand that caregiver needs vary over time. Further

Level: II *Quality: B*			one community service in the past 12 months. Four hundred sixty three caregivers emerged whose family members still had unmet needs.	coping methods as measured by the Level of Care Index (LOCI). Factor analysis yielded a two-factor solution. Univariate analysis described caregiver and care receiver characteristics.	caregivers reported emotional strain and 42.6 % reported physical strain. Adult day care 43.2 %, respite care 37.6%, and meal services 27.8% were the most frequently reported services with unmet needs.	studies of longitudinal or experimental design would help to establish a causal link between unmet needs and caregiving outcomes.

Citation in APA/Level & Quality	Purpose of Study	Sample/Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments (include reliability& validity)		
Murphy, J., Nalbone, D, Wetchler, J., & Edwards, A. (2015). Caring for aging parents: The influence of family coping, spirituality /religiosity, and hope on the marital satisfaction of family caregivers, *The American Journal of Family Therapy, 43:* 238-250. doi: 10.1080./01926187.2015.1034636 *Johns Hopkins Model Level & Quality:* Level: II	To assess the effects of family coping, spirituality/religiosity, and hope on the marital satisfaction of adult children who care for their aging parents.	191 family caregivers recruited through online caregiving support groups, listservs, and Facebook groups. Participants identified themselves as married individuals who provided care for their aging parents or whose spouse provided this care; 48.1% males and 51.9% females with average age 38 years, with a range of 22-63 years; 61% Indian, Caucasian, 31%; 46% identified	Self-report questionnaire was administered online. Convenience sampling and snowballing methods were used. Seven demographic questions regarding caregiving were used, along with 11 standard demographic questions.	A set of five measurements were used based on overall reliability and validity. Couple Satisfaction Index with reliability from .80 to .95., with strong convergent and construct validity. Family Crisis Overload Personal Evaluation Scale with reliabilities from .63 to .83 and good internal validity. The Brief Multi-dimensional	Of the caregivers, 44% cared for their own aging parents, 32% said both they and their spouse cared for their aging parents, and 56% acknowledged that one of their care-recipients had memory issues. Caregiving tasks: Cooking, 71%; cleaning, 61%; managing finances, 60%; driving, 55%; and laundry, 52%. A key strength of this study was that it fills a gap in the caregiving	More qualitative and quantitative studies should be conducted to determine the family's role in the coping process of caregiving; most studies focused on the caregivers as individuals rather than as a couple. Clinicians should view family caregiving from a family systems perspective and a framework of family resilience.

Quality: B		as Hindu, and 32% as Protestant Christians.		Measure of Religiousness/ Spirituality with reliability. Alpha levels of .91 for daily spiritual experiences, .82 for organizational religiousness, and .72 for private religious practices. The Hope Scale had internal reliability from .74 to .84 for overall hope, .71 to .76 for agency, and .63 to .80 for pathways. Pearlin's caregiver stress burden scale revealed an alpha level of .80.	literature by examining specific variables that seem to protect the relationship satisfaction of family caregivers. This study found that family use of effective coping strategies and spirituality/ religiosity had a significantly positive effect on the marital satisfaction of adult children who provide care for their aging parents.	

Citation in APA/Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability& Validity		
Pearlin, L, Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures, *The Gerontologist, 30*(5) 583-594. *Johns Hopkins Model Level and Quality.* Level: III Quality: A	Join efforts to increase sophistication of caregiver research and to bring sound measurement closer to the many aspects of caregiving and its impact.	555 participants from the San Francisco Bay and Los Angeles areas through local Alzheimer's Associations n= 326 spousal caregivers and n=229 children caregivers. Multiwave study with interviews of participants over a two-year period.	Conceptual scheme for the study of caregiver stress and development of measures that assess the multiple components of the scheme. Open-ended, exploratory interviews. Interview transcripts revealed conceptual themes resulting in structured questions that were pretested and revised.	Factor analyses from data gathered. Scales developed from questions with correlations between primary and secondary stressors noted. Mini-mental Test. Alpha reliability noted for each identified caregiving stressor.	Primary and secondary stressors identified: Cognitive status problematic behavior, overload, relational deprivation, family conflict, Job-caregiving conflict, economic strains, role captivity, caregiving competence, personal gain, management of situation, management of meaning, management of distress and expressive support.	Elements of emotional distress surface first giving rise to mental and physical health challenges, which may result in reluctant yielding of caregiving duties. Caregiver stress is a mix of circumstances, experiences, responses and resources that vary among caregivers and vary in their impact on health and behavior. Stress model should be built upon in future studies to result in an increased appreciation for informal caregiving, what it entails and what it costs.

Citation in APA/Level & Quality	Purpose of Study	Sample/Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability& Validity		
Rydholm, L., Moone, R., Thornquist, L., Alexander, W., Gustafson, V., & Speece, B. (2008). Care of community-dwelling older adults by faith community nurses. *Journal of Gerontological Nursing, 34*(4) 18-29. *Johns Hopkins Model Level Evidence & Quality Guide:* Level: III Quality: A	In response to the recognized need to support informal caregivers of older adults in the community, the Metropolitan Area Agency on Aging (MAAA) in Minnesota, launched a two-year exploratory project entitled Supporting Seniors Across Systems (SSAS).	Two hundred FCNs in metropolitan, central, and northeastern counties in MN. Metro FCNs N=101 N=713 DIARY notes received, Additional notes n=348 (denotes notes received when older adults were served more than once by FCN). Total notes collected: 1,061 from 75 FCNs working with 713 older adults.	Mixed Methods study with both qualitative and quantitative strategies used.	DIARY charting process (Rydholm, 1997). D=Data I=Interpretation A=Action R=Response to FCNs intervention. Y=Yield (benefit of interaction). Note: Rydholm developed outcome-based charting (DIARY method) for a MN Region 9 Area Agency on Aging grant in 1997.	This study provided strong confirmation that the interventions of FCNs significantly affect the health and well-being of older adults and caregivers and showed that these interventions likely result in health and long-term care cost savings for individuals, health plans/insurers, and publicly funded health and longer-term care programs.	The findings of this study demonstrate the remarkable success of faith community nurse in bridging care between the informal, faith-based care system and the formal, acute healthcare system.

					Nature of older adult concerns: Psychosocial and spiritual-40%; signs and symptoms warranting care-25%; functional safety concerns-14%; illness self-care deficits-9%; depression linked to isolation-8%; detrimental lifestyle habits-4%.	

Citation in APA/Level & Quality	Purpose of Study	Sample/Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability& Validity		
Sheridan Mock, G., (2017). Value and meaning of faith community nursing: Client and nurse perspectives, *Journal of Christian Nursing, 34*(3). 182-189. Doi: 10.1097/CNJ.0000000000000393. *Johns Hopkins Model Level & Quality:* Level: III Quality: C	To explore the value and meaning of FCN ministry as described by clients and nurses.	One FCN program, discusses the value, meaning and importance of FCN in that congregation. 10 participants: Seven client and three FCNs in a Presbyterian congregation in an affluent neighborhood of a large Midwestern city. FCN program existed for 2 years prior to study and supports 100-200 clients/month. Participants were white, non-Hispanic individuals ages 28-85. Two	Qualitative investigation using open-ended questions collected through semi-standardized interviews. Observatory field notes were also collected.	Content analysis of interview analysis and field noted. Coding and analysis using NVIvo 10 was used. Recurring points were organized into 5 themes.	Five themes: Services, Nursing Expertise, Spirituality, Familiarity and Community Support. Themes suggest the utility of the FCN model and describe the value of the trusted nurse-client relationship. Client understands the FCN role was directly related to the frequency of interaction with the FCN. Identifies rich value of the FCN role.	While this study supports the development of FCN programs in faith communities, more research is needed to explore both services provided by the FCN and the financial support necessary to develop FCN programs.

		males and five females were included.				

Citation /Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability, & Validity		
Winter, L., Moriarity, H, Atte, F., Gitlin, L. (2015). Depressed affect and dimensions of religiosity in family caregivers of individuals with dementia. *Journal of Religion & Health (2015) 54:* 1490-1502. Springer Science+Business Media, New York 2015. DOI: 10.1007/s10943-015-0033-6. *Johns Hopkins Model*	Research based on caregiver well-being and religiosity is expanded by identifying several aspects of religiosity by correlating mood and other distinctives to identify trends of association. Additionally, the study seeks to test contradictory findings related to religiosity and mood by adding two	REACH I project data (Resources for Enhancing Alzheimer's Caregiver Health), a multi-site study of ADRD family caregivers; 1,227 family caregivers from 6 US cites. Mean caregiver age=62 years. 81.5% female, 56.2 % White, 48% Spouses and 4.3 years as a caregiver.	Cross-sectional study data from REACH I family caregiver participants 1997-2000, (Herbert, 2007). Interview in caregiver's home. Religiosity/Spirituality questions: 1. How often do you attend religious services? 2. How often do you pray or meditate? 3. To what extent have religious services been a source of help/comfort to you in caregiving?	Depressive Symptoms measured by Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). Three types of social support assessed: Social integration (Lubben Social Network Scale (LSNS, Lubben 1988), 17 item Inventory of Socially Supportive Behaviors (ISSB). (Berrara, 1981), measured received support; negative interactions were assessed with a 4-item scale, (Krause, 1995). The Revised Memory & Behavior Problems Checklist (RMBPC; Teri et al. 1992) assessed CG distress and CR memory & problem behaviors. A Financial Difficulty Scale 1-4 rated difficulty paying for basic needs. CG/CR relationship was coded as spouse/non-	Covariates used t-tests or Pearson product-moment correlations. Spearman's Rho identified associations between five religiosity items. Five multiple regression models were used to evaluate each of the five religiosity items' thought to contribute to depressive outcomes in the CG. No individual contribution is identified solely as a source of help and comfort to the CG. Associations with mood	Caregivers vary in their level of coping strategies, support and religiosity. Religious coping in caregivers is recommended for future research. Although large, the sample was limited to caregivers of dementia patients. A noted strength was the use of the REACH I Study data. Not all domains of relevant religiosity were reflected in the study. Implications: Research on caregiver well-being would be enhanced by researching prayer-related items in particular.

Evidence Level & Quality: Level: II Quality: B	variables: prayer as a source of help/ comfort and services as a source of help/ comfort.	Informed consent and IRB approval granted. Caregiver= CG Care Recipient= CR	4. How important is your faith/spirit to you? 5. To what extent have prayer and meditation been a help/comfort to you as a caregiver?	spouse. MMSE assessed disease severity. (0-30). Activities of daily living (ADL, Katz, 1963 scored 7 items. Size & diversity of sample lent credibility to external validity of study.	resulted in overlap between importance of religion, frequency of religious attendance and services. Increased prayer frequency was associated with a greater depressive effect. All other variables were fixed.	

Citation /Level & Quality	Purpose of Study	Sample/ Setting	Design		Results	Authors' Recommendations
			Methodology	Instruments, Reliability, & Validity		
Yeh, Pi-Ming & Bull, M., (2009). Influences of spiritual well-being and coping on mental health of family caregivers for elders, *Research in Gerontological Nursing, (2)*3. DOI: 10.3928/19404921-20090421-08. *Johns Hopkins Model*	To describe the spiritual well-being of family caregivers of elders with congestive health failure (CHF) and to examine the relationships among family caregivers' spiritual well-being, coping, and	Data collected from a convenience sample of 50 caregivers, recruited from medical/surg. units from two hospitals one with 700 beds, the other, 365 beds. The smaller hospital had a religious affiliation. Criteria: Over 18 years old, able to read/write English, primary caregiver to elder who needs assistance with at least one ADL. Theoretical framework of stress, coping, and adaptation. Modified from Lazarus and Folk man (1984): "Causal antecedents;	Descriptive, correlational design. Questionnaires given to caregiver at pt. discharge. IRB approval and consents obtained. Specific research questions: 1. Is the spiritual well-being of family caregivers providing assistance to elders with heart failure? 2. What is the relationship between spiritual well-being and the mental health of family caregivers of elders with	The JAREL Spiritual Well-Being Scale (SWBS) (Hunglemann, Kenkel-Rossi, Klassen, & Stollenwerk, 1996) measured 21 items: Faith/Belief-6 items Life/Self-Responsibility- 7 items; and Life Satisfaction/Self-Actualization-8 items. Results were scored on a 6-point Likert Scale. The Carer's Assessments of Managing Index (CAMI) has 38 items (Nolan, Keady, & Grant, 1995). Problem solving and Coping-16 items, Alternative Perception of Events, 10 items, and Dealing with Stress	Mean age of FCG was 60.3. Seventy percent of women, 74% married and 74% lived with spouse. Ninety percent identified as Christian. CHF patient mean age was 76.47. 70 % were women, 52% married, and 38% widowed. 80% needed help to walk, 66% required help in/out of bed. 56% needed help toileting, and 70% needed help to dress/undress. 34% needed help to eat. Spiritual WB: FCG scores 67-125. 92% agreed with the statement Prayer	Obtain more demographic information initially. Future studies might increase the sample size drawn from several large hospitals and a more ethnically diverse sampling. Research examining family caregivers who coped using problem solving and reappraisal of events may have fewer negative mental health symptoms. Enlist a chaplain (or parish nurse) on an interdisciplinary team to improve spiritual well-being.

Evidence Level & Quality: Level: III Quality: C	mental health.	patient's activities of daily living dependence; mediating processes of spiritual well-being and coping strategies resulting in long term effects on mental health" (p.174).	heart failure? 3. What is the relationship between coping strategies and the mental health of family caregivers of elders with heart failure?	Symptoms-12 items. Results were scored on a Likert 4 pt. scale. Symptom Questionnaire (SQ) on caregiver's mental health was measured by the 92-item SQ and included: Anxiety, Depression, Somatic, and Hostility. Instruments were selected for their reliability and validity. Data analysis used SPSS version 15.0. Descriptive statistics were used to examine data. Pearson's product-moment correlation was used to test research questions.	is an important part of my life, and 96% stated "I have spiritual well-being." Coping strategies: CAMI scores 89-135 indicating high levels of coping strategies. Mental Health: some scored in the moderate ranges for depression and somatic symptoms. Finding support, the theoretical framework, and family caregivers' positive spiritual well-being was associated with better mental health as was positive coping and less depression.	

Citation in	**Purpose of**	**Sample/Setting**	**Design**	**Results**	**Authors'**

APA/Level & Quality	Study		Methodology	Instruments, Reliability& Validity		Recommendation
Ziebarth, D., & Campbell, K., (2016). A transitional care model using faith community nurses, *Journal of Christian Nursing, 33*(2), 112-118. Doi: 10.1097/CNJ.0000000000000255. *Johns Hopkins Model Level Evidence& Quality Guide:* Level: III Quality: B	To define specific FCN care that occurs pre- and post-hospital discharge that supports the patient in transitioning from one level of care to another, and to move toward wholistic health and avoid unnecessary readmission.	Literature review revealed that FCNs identified 16 nursing interventions, five of which are unique to FCN practice. A total of 799 of 3,400 IPPS hospitals reported well enough in 2015 to avoid penalties in 2016.	Literature review and model development.	Model developed based on literature review findings to address decreasing hospital readmission rates.	Five FCN interventions: spiritual care, including integration of faith and health; resources and referrals were multi-disciplinary and interdisciplinary; coordinate, implement, and sustain ongoing activities; utilize/apply survey results; train and utilize volunteers from faith community.	As hospitals increasingly use FCNs for transitional care to reduce patient readmissions, the FCN Transitional Care Model serves as a professional guidebook for FCNs to provide consistent, high-quality care.

Chapter Four: Discussion, Implications, and Conclusions

Introduction

The question addressed in this literature review is, what are the most compelling ways that faith community nurses (FCNs) support family caregivers? This literature review gives rise to multiple aspects of the family caregiving role and how the FCN can support family caregivers in the midst of their many challenges. Implications for emerging roles of the FCN through the transitional care process and an examination of the need for FCN education in family caregiving are also considered. Finally, proposed changes to pre-licensure nursing curricula include the addition of family caregiving dynamics across nursing specialty practice arenas.

Synthesis of the Literature

As the literature demonstrated, family caregiving is a complex process engaging both caregiver and care recipient as whole persons within the contexts of their larger family systems, congregations, and communities. Unwelcome demands on a caregiver's life included physical, emotional, mental, spiritual, economic, political, occupation, and social dimensions. While the FCN will not utilize all possible dimensions of the FCN Model (see Figure 2, Anderson, 2017) in every caregiving situation, it behooves the FCN to be aware of potential areas for referral, particularly in the financial, occupational, and political domains.

Nursing, as a discipline, requires preparation to be able to respond to these complex demands as care recipients with chronic illnesses live longer, thereby stretching the resources of family caregivers. The challenges will increase for people in all nursing specialty practice areas who care for families as these family caregiving units travel the healthcare continuum. "Eighty-five percent of the care given to older adults comes from

family members. The number of adults able to provide that care is expected to drop dramatically in the next 20 or 30 years" (Gaugler, 2017, p. 1).

Research related to the aspects of healthy caregiving included Bull's (2014) caregiving strategies for sustaining the self, while caring for a family member with dementia. Coleman, Ground, & Maul (2015) developed a Family Caregiver Activation Tool (FCAT) aimed at fostering increasingly productive interactions between caregivers and health professionals. Dyess and Chase (2010) underscored the importance of senior adult's participation in a faith community as a means of positively coping with chronic illnesses. Farran et al. (2016) demonstrated how physical activity among caregivers improved both the physical and mental health of caregivers by using a variety of tools and measures.

Funjinami, et al. (2012) measured quality of life in family caregivers of patients with lung cancer specifically. Gaugler, Kane, Kane, and Newcomer (2005) measured early caregiver utilization of community-based services used by those who cared for loved ones with dementia. Gaugler and Teaster (2006) examined the long-term care policy and practice related to relieving negative caregiving outcomes.

Grebeldinger and Buckley (2016) examined the parish nurse role specifically related to supporting family caregivers. Four key interventions included the gift of presence, the bearer of blessings, the messenger of spiritual care, and the ability to navigate through the healthcare system. Rydholm et al. (2008) identified FCN interventions that significantly influenced the well-being of older adults and their caregivers resulting in health and long-term care cost savings for individuals, health plans, and insurers. Sheridan-Mock (2017) discovered five themes expressing the value of the FCN role in a selected congregation. These included services, nursing expertise, spirituality, familiarity, and community support.

Ziebarth and Campbell (2016) defined FCN care interventions that support the patient as they move along the transitions from acute to community-based settings. Five interventions included spiritual care, resources and referrals that were interdisciplinary and multidisciplinary, coordination, implementation of activities, and training volunteers from the faith community.

Hong, Chadiha, and Morrow-Howell (2005) examined the relationship between unmet needs for community services and caregiver strain. Murphy, Nalbone, Wetchler, and Edwards (2015) examined family coping, spirituality, and religiosity related to the marital satisfaction of couples caring for their aging parents. This study found that family use of effective coping strategies, particularly spiritual strategies had a significantly positive impact on the marital satisfaction of family caregivers. Winter, Moriarity, Atte, and Gittlin (2015) examined caregiver well-being and religiosity using the Resources for Enhancing Alzheimer's Caregiver Health (REACH) I Tool. Yeh, Ming, and Bull (2009) studied the spiritual well-being of family caregivers of elders with congestive heart failure, another commonly occurring chronic illness, using the JAREL Spiritual Well-Being Scale.

Pearlin, Mullan, Semple, and Skaff (1990) identified the Caregiving Stress Process. This process describes both primary and secondary stressors that result in caregiver overload.

Implications for Nursing Education

Nursing education serves as a starting point in placing the emphasis of nursing care on the needs of caregiving families, from hospital to community-based healthcare delivery sites to home and everything in between. For example, BSN-level programs need curricula that intentionally address family caregivers' learning needs, such as caregiver cognitive

assessments, ability to learn hands-on care skills, and navigating the healthcare system. Courses focusing on the care of infants and children, those with needs for advanced medical care, patients with mental health needs, cross-cultural care, and community based nursing care are enhanced by curricula that assess the strengths of the caregiving family unit.

Faith Community Nursing Practice Implications

Faith community nursing (FCN) is uniquely poised to address family caregiving issues for several reasons. First, FCNs support the caregiving families within the context of their community of faith. Second, FCNs develop deep, trusting relationships with caregivers and their families over the long trajectory of their journeys. Lastly, through these trustworthy relationships, FCNs can bridge community resources and support to honor and assist caregiving families, and thereby promote positive health-related outcomes. When FCN interventions help to support the overall health of the family caregiver, the family unit is strengthened, which can result in improved quality of care for the care recipient and a greater length of time for caregiving to occur successfully in the home.

Faith community nurses offer a consistent presence through which the caregiver can access the FCN for guidance, questions, and spiritual and emotional support throughout their caregiving journey.

Much of American healthcare today is episodic in nature and devoid of trusting, long-term relationships between healthcare providers and patients. FCNs stand in contrast to this dynamic, reaching people where they gather in times of crisis and celebration, health and illness, life and death. As such, FCNs can extend care to families deeply within the communities where they live and worship, both extending and enhancing the ministry of nursing.

Another method, which meets the needs of caregiving families, is through inter-collaborative practice roles within the healthcare team. Hospital nurses can begin the process of including the FCN as part of the healthcare team by asking patients at the point of admission if a patient connects with a faith community and/or has an FCN. Additionally, including the FCN as part of discharge planning has the potential to decrease readmission potential.

Healthcare systems are fond of talking about improving handoffs between sites with the goal of providing seamless care for patients throughout their journey. Including FCNs in the handoff process can contribute to that goal. Increasingly, healthcare systems are recognizing the value of the FCN role during transitions of care. As the number of FCNs grows nationwide, healthcare systems are forging partnerships with FCNs and faith-based organizations. For example, in Minnesota, the HealthEast Care System considered piloting such a position in the St. John's Hospital emergency department. (Anderson, 2012). Lyngblomsten, a faith-based senior living organization in St. Paul, MN, recently hired a FCN in its Transitional Care Unit (TCU). In recent years, healthcare systems in Florida and Georgia have hired FCN staff at their hospitals to help parishioners navigate their hospital stays (Westberg Symposium, 2014).

Expansion of the role and influence of FCNs woven throughout the healthcare experience will require data that demonstrates meaningful, cost-saving outcomes. For many years, FCNs have debated use of a variety of documentation methods to display collective outcomes, but as of this writing, no nationally accepted standard for FCN documentation meets exists. Additionally, the Faith Community Nurse Network of the Greater Twin Cities

(FCNNTC) leadership supports reimbursement for FCN work, but until recognized documentation reveals undeniably positive patient outcomes, reimbursement will not follow.

Faith Community Nursing Education Implications

Beyond pre-licensure nursing education implications, proposing an additional module specifically related to family caregiving strengthens FCN preparation for the emerging role of the faith community nurse. Ziebarth and Campbell (2016) provided a template for FCNs helping caregiving families mitigate the complicated maze of healthcare setting transitions. As supporting family caregivers becomes an increasingly compelling role for the FCN, more in-depth curriculum content is necessary in future revisions of the Foundations of Faith Community Nursing Preparation Course (International Parish Nurse Resource Center, 2014).

For FCNs who have completed the initial Foundations of Faith Community Nursing preparation course, continuing education venues may focus on augmenting family caregiving content. For example, many FCNs have access to local, regional, and state networks, healthcare systems, and online opportunities to procure this content. Ultimately, another option is to include content in the FCN portfolio certification process.

The economic dynamic at play in faith community nursing is the part-time nature of the role. While hospital systems in the 1990s began following the Westberg (1990) model of offering a receding grant type of financial partnership with local healthcare systems to help pay for new FCN positions, the pay rate for FCNs remains low on the scale of registered nurse pay rates. This inequity is largely due to churches being financially unable to fund the nurse's salary in a way that is commensurate with his or her education and

experience. As a result, many FCNs hold additional part-time positions to balance the discrepancy, thereby limiting their availability to their faith community.

Recommendations for Nursing Research

As noted above, Grebeldinger (2016), Dyess, (2010), Rydholm (2008), and Sheridan-Mock (2017) contributed salient findings to the research on faith community nursing and its impact on family caregiving of older adults. Larger sample sizes and broader demographic reaches could have improved the findings by making outcomes applicable to faith communities both large and small across the United States. The Rydholm (2008) article focused on one state, but included urban, suburban, and rural samples. Grebeldinger (2016), Dyess (2010), and Sheridan-Mock (2017) used sample sizes limited to one congregation and a small sample size within those congregations making broader applications difficult to make. Unless and until faith community nursing becomes more widely understood and embraced by the current healthcare system as a nursing specialty practice, the impact of FCNs will be limited. Beyond their role in supporting family caregivers, FCNs can promote, nurture, and sustain healthy communities of faith across the congregation members' lifespan, and throughout the nation. To that end, further outcomes-based research is necessary to provide compelling data that links FCN interventions with positive patient health outcomes. If the discipline of faith community nursing can demonstrate this data to potential funding sources, the FCN role will experience additional growth and sustained support.

Specific protocols need development for assessing learning needs among family caregivers specifically related to physical skills, coordination of care, and other needs. These are recommended protocols for use by FCNs and those in any nursing role as part of the

process of discharging a patient to the next level of care. "Many family caregivers report they don't have the necessary skills and knowledge to provide sustained care for a person with a chronic illness, so they lack confidence and feel unprepared" (Given, Sherwood, & Given, 2016, p. 28). The transitional care role proposed by Ziebarth (2014) for FCNs can help to bridge this gap through the presence and advocacy of the FCN at the time of patient hospital discharge and in post-acute care settings.

Gaps in the Literature

The financial and political ramifications of family caregiving represent broader societal issues related to this unexpected role. While the FCN may not intervene directly, these areas represent salient points for consideration when planning supportive care for the caregiving family. For example, employed caregivers may need time off in the form of either a flexible schedule or a family medical leave. Faith communities may have care ministries that work in tandem with a FCN to provide for practical needs such as respite, transportation, and other services.

Productivity and job security may be at risk when a spouse, adult child, or other family member assumes a caregiving role. Both of these factors can place additional stress on the family caregiver, compounding the burden. According to the Center for Disease Control and Prevention (2016), "Caregivers and their families often experience economic hardships through lost wages and additional medical expenses. In 2009, more than one in four (27%) adults reported a moderate to high degree of financial hardship as a result of caregiving" (p. 1).

Another financial consideration includes the cost of care as the care recipient's needs escalate. In-home care and long-term care, when necessary, can quickly drain a

family's financial resources. While long-term care insurance is gaining in popularity, many families do not have these policies and rely on personal savings to finance caregiving costs.

Several national organizations that support policy development for caregiving families include the National Caregiving Alliance (NCA), the Family Caregiving Alliance (FCA), and the American Association of Retired Persons (AARP). "Rebalancing long-term care away from institutions and toward home and community-based services is a policy goal shared by older adults and their family caregivers" (Levin, Halper, Peist, & Gould, 2010, p. 118).

According to Gaugler (2017), "85 percent of the care given to older adults including those with different stages of dementia—comes from family members, not a nursing home or other healthcare provider. The number of adults able to provide that care is expected to drop dramatically, in the next 20 or 30 years" (p. 1).

Integrating Theoretical Framework

In light of the implications described above that impact the lives of family caregivers throughout their journeys, what are the most compelling ways that faith community nurses (FCNs) can support family caregivers? Pearlin's (1990) intervention strategies across the caregiving career, as indicated in Figure 1, provided a framework to define the needs of family caregivers at each proposed stage of their journey. FCNs can offer impactful interventions at each stage within the context of caregivers in their faith communities.

Pearlin described the first transitional event as the onset of illness, which leads to the start of the care-career phase for the caregiver. These concurrent stages result in "role acquisition" (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995, p. 307) for the caregiver. During this time, Pearlin recommended intervention strategies that include

education, prevention, and planning. Through the trusting and often longstanding relationships that caregivers have with their FCNs, this sacred trust can result in better outcomes for both the caregiver and care recipient. Defined faith community nurse roles, such as health educator and personal health counselor, allow the FCN to provide caregiver education, navigation through the healthcare system, and advanced directives guidance.

During Pearlin's second stage, in-home care occurs and a nursing home admit represents a transitional event, which may result in long-term institutional care. This stage for the caregiver is defined "role enactment" for the caregiver (Pearlin, 1995). Intervention strategies include stress management and resource enhancement.

Integration and Application

The FCN can coordinate a host of resources from within the faith community and the larger community to help the caregivers manage stress and function in that role themselves. FCN roles, such as integrator of faith and health, advocate, and referral source, will result in a listening presence for the caregiver, coordination of faith community resources (such as volunteers who care for practical needs like providing food, transportation, home maintenance, respite), and resources outside of the community not provided within the faith community's resources.

Respite care in the community offers a break for family caregivers. For example, Lyngblomsten, a Lutheran-based senior care organization in St. Paul, MN, trains and coordinates volunteers to provide group respite care referred to as The Gathering (Lyngblomsten, 2016). This care offers brain-stimulating activities for adults with memory loss two days per month while their caregivers receive a break from caregiving duties and find support in their caregiving roles.

FCNs offer a pastoral presence to the caregiver through confidential listening, acceptance, and understanding. This helps the caregiver to feel heard and understood which can relieve stress and promote hope and healing. The FCN can affirm and encourage the caregivers to find meaning in their evolving caregiving roles.

The third phase of the caregiving journey begins with the transitional event of the death of the care recipient. The caregiving career phases at this point include bereavement and social readjustment, defined by Pearlin (1995) as "role disengagement" (p. 307). Here, the FCN can help with the intervention tasks of closure and readjustment for the caregiver. Through the FCN role of integrator of faith and health, the FCN and caregiver may explore the meaning of the caregiving role and this might include coordination of a bereavement support group for faith community members or in the community at large, visits with the caregiver for listening and support, or referral to another health care professional as appropriate.

If the caregiver remains connected to the faith community throughout the caregiving trajectory and following the death of the care recipient, the continued support provided by the FCN and the faith community can provide deeply meaningful support through the grief process. In time, the caregiver may resume the role of a wounded healer who can in turn comfort others in their caregiving challenges.

The FCN role serves the family caregiver in the context of a faith community by offering a trusted, long-term relationship through which interventions of health education, referral, resource utilization, advocacy, presence, integration of faith and health, bereavement care, and navigation of the ever-changing healthcare system can support the family caregiver. Because FCNs view those in their care from a whole person perspective,

they can advocate for caregivers in the less understood dimensions of family caregiving, such as the economic impact that caregiving creates during the caregiving journey.

Through their advocacy role, FCNs can point to legislation that supports family caregivers, such as the CARE ACT, passed in Minnesota, (AARP, 2016) which allows patients to designate their family caregiver to act on their behalf and receive pertinent information on their healthcare needs.

The specialty practice of faith community nursing offers faith-based, person-centered care to a caregiving family from the nursing and spiritual care expertise offered by a faith community nurse within the context of a faith community and the larger community (see Figure 2). FCNs are experts at connecting people to resources and finding creative, cost-effective ways to meet their needs. Their impact is deeper and stronger as they leverage their trusted relationship with caregiving families to promote positive health and well-being in all domains of the caregiving journey.

Figure 1. Intentional Care of the Spirit

(Anderson, 2017) Legend: FC=Family Caregiver.

Conclusion

Family caregiving is gaining increased recognition as an emerging phenomenon across multiple disciplines. Most of the research in this literature review centers on one specific aspect of this complex role.

Historically, families cared for aging loved ones in the home setting without question, but doing so is no longer easy or even possible in some cases due to increased globalization resulting in families not living geographically in close proximity as they once did. In recent years, smaller families have become the norm, which results in fewer caregivers that are available when needed. Additionally, as elderly couples age, caregiving spouses may experience less capacity to fulfill the caregiving role as they may wish to do. Economic factors for working adult family caregivers may include potential for job loss related to their caregiving role, as well as a drain on personal finances, particularly when their loved one needs care for an extended length of time.

Dementias such as Alzheimer's disease represent a commonly occurring chronic illness of those over 65 years of age, often requiring a lengthy caregiving journey that taxes a caregiver's resources in all dimensions as indicated in Figure 2. Community based respite programs, such as Lyngblomsten's The Gathering, have waiting lists for older adults with memory loss still living at home with a family caregiver. Support groups and community education for caregivers is available, however the needs will soon exceed the resources available as Alzheimer's disease and related dementia's are expected to increase exponentially in the coming years.

Nursing leaders and leaders in comparable disciplines must collaborate to harness their resources and increase their accessibility to family caregivers through collaborative efforts. One example is the Metropolitan Caregiver Service Collaborative (MCSC) that convenes caregiving providers through regular networking meetings and a website to leverage current resources for family caregivers. Members include faith community nurses, who can share these resources with family caregivers.

Family caregivers often experience limited mental, emotional, and physical energy to marshal the resources that may benefit them and their loved one. An FCN can help caregivers sift through the available information and find pertinent resources specific to their needs, by acting as an advocate and liaison to these resources.

Armed with an FCN/caregiver relationship based on trust, built over time within the context of the faith community, FCNs can guide family caregivers through dark waters to safer shores that result in optimal health, well-being, and quality of life for both caregivers and care recipients for the duration of the caregiving journey.

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