

ABSTRACT: *In 2015, there were 43.5 million informal, unpaid caregivers in the United States. Caregivers reported a moderate to high level of burden of care, including performing medical and nursing tasks they were not trained to do. A study of family caregiver experiences with parish/faith community nurses reveals four key ways parish nurses support caregivers and offers important implications for parish nurse preparation and practice.*

KEY WORDS: *caregiving, faith community nursing, nursing presence, parish nursing, spiritual care*

Healthcare needs are on the rise due to the aging U.S. population and an increase in the number of chronic illnesses. As hospitalizations become shorter, patients may be sent home with care needs that family members must provide. With this combined increase in the aging population and decrease in hospital length of stay, the number of family caregivers giving care to loved ones in their homes is expected to rise. Parish nurses can play a critical role in supporting patients and caregivers.

WHO ARE CAREGIVERS?

A 2015 study by the National Alliance for Caregiving (NAC, 2015) reports there are 43.5 million informal, unpaid caregivers in the United States. Over half (60%) are female and around 49 years old, although one in 10 (7%) are 75 years of age or older, and caregiving without any additional unpaid help. The majority (34.2 million) cares for an adult age 50 or older. Most (85%) care for a relative; 49% care for a parent or parent-in-law and have been providing care for four or more years. Half say they had a choice to provide care; the other half reports they had no choice.

You Are Not Alone:

PARISH NURSES BRIDGE CHALLENGES FOR FAMILY CAREGIVERS

By Teresa A. Gebelinger and Kathleen M. Buckley



How much care do caregivers provide? On average, 24.4 hours a week, whereas 23% of caregivers provide 41 hours a week or more of care. Those who care for their spouse give care 44.6 hours a week. Those providing 21 hours a week or more of caregiving have been doing so for 10 years or longer. Only one-third of all caregivers has any additional help, paid or unpaid. The recipient of care most often lives in his or her own home (48%), whereas 35% live in the caregiver's home (NAC, 2015).

Of huge significance is the fact that 42% of all caregivers perform care without any training or preparation; 63% of higher-hour caregivers say they perform medical or nursing tasks without training (NAC, 2015).

Unpaid caregiving comes at a high price. The burden and stress that family caregivers encounter lead to physical, economic, social, and psychological challenges. Only 32% of caregivers use any kind of paid help, such as aides or housekeepers (NAC, 2015). As the level of care increases, isolation for the caregiver may ensue.

The Level of Care Index, which combines number of hours of care, activities of daily living (ADLs) performed (i.e., bathing, dressing, feeding), and Instrumental ADLs (i.e., grocery shopping, transportation, managing finances), reveals that 40% of caregivers report a high burden of care, whereas an additional 18% report a moderate burden of care. Caregiving most often requires physical care that can negatively impact the health of the caregiver, especially older caregivers who have

preexisting health problems. Higher-hour caregivers (>21 hours a week) are more likely to be in fair-to-poor health, have difficulty performing routine ADLs, and feel emotional, physical, and financial stress (NAC, 2015). Family caregivers can experience additional challenges because the care recipient may be discharged earlier from hospitalization, was not eligible for skilled nursing due to insurance requirements, and/or may require the caregiver to learn new equipment and procedures

tions and challenging behaviors, physical care instructions, and descriptions on day-to-day caring issues (Given, Sherwood, & Given, 2008; NAC, 2015).

In addition to general information, caregivers need tailored interventions for providing care specific to their situation, such as managing toileting or where to find affordable assistance. Furthermore, they need discussions about their own cares and concerns. Caregivers need advocates who will listen, assist them in learning, support

63% OF HIGHER-HOUR CAREGIVERS PERFORM MEDICAL OR NURSING TASKS WITHOUT TRAINING.

that, in the past, were only done in the hospital setting (Family Caregiver Alliance [FCA], 2009).

From a business standpoint, 60% of caregivers have to cut back their work hours or take a leave of absence (NAC, 2015). Caregivers who are able to return to full-time employment after caregiving are more likely to earn lower wages, have a job with poor benefits, and receive reduced retirement assistance benefits. Yet in 2009, their services were valued at \$450 billion (FCA, 2012).

CAREGIVER NEEDS

Thirty-eight percent of caregivers relay high emotional stress, whereas 19% report high physical stress; 18% report high to very high financial strain. All of these needs, especially physical stress, are closely related to the complexity of the situation, such as number of hours of caregiving, caregiver age, and needs of the care recipient. Only 32% of family caregivers report having a conversation with a healthcare provider about what they need to do to care for their loved one. Even fewer (16%) report being asked about *their* needs. Yet 84% say they want more information. Sadly, only 14% report receiving preparation to perform medical or nursing tasks. Caregivers want information about the diagnosis of the care recipient, what to expect from the diagnosis, managing recipient emo-

them in their current struggles, and help them prepare for the road ahead.

A variety of services not generally available in the traditional healthcare system have been evaluated to help family caregivers. Interventions have ranged from community-based educational initiatives to online support groups (Klemm, Hayes, Diefenbeck, & Milcarek, 2014; Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012; McGinnis & Zoske, 2008). However, it remains unclear what services caregivers appreciate the most.

PARISH NURSING

The ministry of nurses through the faith community holds significant potential for supporting informal caregivers. Parish nurses offer an array of roles that impact the health of individuals and communities, including health educator, referral agent, health advocate, trainer of volunteers, organizer of support groups, personal health counselor, and integrator of spirituality and health (Carson & Koenig, 2011; Dandridge, 2014; Pappas-Rogich & King, 2014). Solari-Twadell and Hackbarth (2010) identified 30 core-nursing parish nurse interventions based on the Nursing Intervention Classifications (NIC) system, most of which were in the Behavioral Domain and include communication activities, such as active listening, presence, and touch.



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The authors declare no conflict of interest.

Accepted by peer-review 7/20/2015.

DOI:10.1097/CNJ.0000000000000242

Common spiritual interventions that have been reported include being present, listening, praying, leading devotionals, and facilitating participation in religious services or activities (Shores, 2014).

Although some roles and interventions of parish nurses in the care of individuals and families have been identified, there is limited information on how parish nurses might best provide support to family caregivers in home settings. Faith community/parish nurses have been reported as a source of support for family caregivers and their loved ones (Brudenell, 2003; Rydholm et al., 2008). However, given the multiple challenges family caregivers face, identifying specific interventions family caregivers find most helpful from parish nurses has the potential to assist nurses, congregations, and healthcare organizations in developing and sustaining faith-based

community programs to support family caregivers. Although the American Nurses Association and Health Ministries Association's (2012) *Faith Community Nursing: Scope of Standards of Practice* refers to the specialty as faith community nursing, in this article the term *parish nursing* will be used, as recommended by some (Patterson & Slutz, 2011) and used in many faith communities.

FAMILY CAREGIVER EXPERIENCES

An exploratory qualitative descriptive study was designed to offer insight into the roles parish nurses employ in meeting the needs of family caregivers. The purpose of the study was to examine family caregiver: (a) burdens and stressors, (b) sources of social support, and (c) perceptions of support provided by parish nurses. Family caregiver was broadly defined as a parent, spouse, other relative, partner, or close friend, who has a personal relationship with, and provides unpaid assistance for, an older adult with a chronic illness or disabling condition (FCA, 2015).

Inclusion criteria required that the family caregivers had experienced a minimum of two encounters with a parish nurse, were at least 21 years old, and spoke English as their primary language. Following approval from the authors' university Committee for the Protection of Human Subjects, written informed consent was obtained from each participant. Family caregivers were recruited through parish nurse coordinators of two parish nurse networks in a large metropolitan area on the East Coast. Descriptions of family caregivers' experiences were collected via individual semi-structured interviews from January to May of 2008. The researchers developed the interview guide, which contained open-ended questions to discover caregiver perceptions. Interview topics included caregiver burden and stressors, support and coping strategies, and the role and support provided by the parish nurse. All interviews were audio-taped and lasted less than 2 hours.

Data were analyzed using thematic content analysis (Creswell, 2009). A second doctorally-prepared nurse

reviewed the transcripts. Findings were discussed until agreement on the themes was mutual. There were no significant discrepancies in the identified themes and the conclusions reached from the data.

Study participants consisted of 15 family caregivers who were predominantly female, African American, middle-aged, college educated, and Protestant (Table 1). As a result of the recruitment strategy, five of the caregivers had participated in a basic parish nurse training program, and some were familiar with the researcher prior to the study. Most of the family caregivers provided care for their parent (60%), whereas others cared for a sibling (20%), spouse (13%), or friend (6.7%). Care was provided in the caregivers' homes (53.3%) and care recipients' homes (46.7%). Almost half (47%) of the family caregivers spent less than five hours per day in caregiving activities. The family caregivers rated their health as either good or excellent, with the most commonly occurring health conditions being high blood pressure, arthritis, and diabetes, respectively.

CAREGIVER BURDENS

The family caregivers described several stressors that contributed to the amount of burden they experienced including: (a) having difficulty during times of transition of the loved one between healthcare settings and home, (b) making lifestyle adjustments, (c) communicating with healthcare providers, and (d) difficulty finding community resources. For several family caregivers, the decline in health status of their loved one brought considerable changes and required a major rebalancing of their lives. Acute hospitalizations of their family member led to role transitions for some, but in other cases, the gradual decline of the health of the care recipient brought unique challenges. Some family caregivers stated they needed to leave their place of employment to provide care. Others lamented major restrictions on their social life, and several reported financial constraints due to caregiving.

Another significant challenge was difficulty in communicating with

Table 1.
DEMOGRAPHICS OF THE
FAMILY CAREGIVERS

	Total:
Gender	
Female	13
Male	2
Age	
Range	38–70
Mean ± SD*	57.4 ± 7.6
Ethnicity/Race	
Black	8
White	6
Asian	1
Education	
High School	3
College Graduate	7
Graduate Degree	5
Family Income (annual)	
<\$50,000	4
\$50–\$79,000	5
>\$80,000	6
Religious Affiliation	
Protestant	14
Roman Catholic	1

*SD: Standard Deviation



healthcare providers. Additional knowledge regarding their loved one's status, or how to best meet healthcare needs, was needed by the family caregivers. Caregivers reported they were not always able to access the necessary information for making decisions. They were not always aware of the resources available to them, and they needed extra assistance in garnering community resources.

The caregivers reported physical, psychological, and emotional impacts from caregiving. Physical complaints such as fatigue, tension, and depression were common. For example, a 59-year-old female caregiver described a series of losses she experienced:

My sister noticed that I was very depressed. I could feel something within me that was kind of empty because I lost my job, my friends, my coworkers, the interactions with them. I lost my hobby... I lost my home... So, I lost everything.

Family caregivers reported emotional turmoil over guilty feelings they experienced related to the increased duties of caregiving and the competing priorities between their own immediate family and their loved one for whom they provided care.

CAREGIVERS NEED TAILORED INTERVENTIONS FOR PROVIDING CARE SPECIFIC TO THEIR SITUATION.

SUPPORT PROVIDED BY PARISH NURSES

Through the interviews, four themes were identified that describe the support provided by parish nurses to the family caregivers.

The gift of presence. Being present as a nursing intervention is being with another person in both a physical and psychological sense during times of need (Bulechek, Butcher, Dochterman, & Wagner, 2012). Parish nurses offer presence through being present and being available. The parish nurses were present through visits to the family caregivers' homes, by telephone, during times of hospitalization for their family member, and in the faith community setting. Caregivers discussed the presence of the parish nurse in positive ways. For some, the parish nurses helped reduce caregiver stress levels or simply provided comfort and reassurance. For others, the presence of a parish nurse offered information. For example, a 70-year-old caregiver, who was caring for her husband, was asked to give examples of encounters with the parish nurse. She related, "It was all very supportive,

very much appreciated by my family member. In fact, he looked forward to the parish nurse coming."

The parish nurse offered the gift of presence through being available. Availability was not only described through face-to-face contact, but also by use of the telephone. A 38-year-old caregiver remarked, "She gave us recommendations on what we should do and how we should do it ... If we had a question, she always had the answers. It was just like—call her." Another caregiver related receiving emotional support through phone calls from the parish nurse:

Then to get a call out of the clear blue and it is right at the time when you think you are by yourself. All of us feel isolated at times, and then a call will come—and then you realize you are not alone. And then you start thinking about all of the blessings and all of the other folks that are there for you, as well. So, you are not alone.

Availability through interactions also occurred in faith community settings through health screenings, office hours,

or direct contact at church events. One caregiver described the presence of the parish nurse as “having the different programs, like the health fair, and the blood pressure screenings, sharing different resources.”

Bearer of blessings. The second theme derived from interviews was the parish nurse being a bearer of blessings. The bearer of blessings is one who serves as a spiritual representative of God’s unconditional love and is attentive to others’ life and faith experiences (Wells O’Brien, 2011). The interactions or discussions with the parish nurse were described in beneficial terms. A 60-year-old caregiver stated, “I first became acquainted with her in 2003, when mother had her heart attack. She was such a blessing because she would come out to the house...” Another caregiver, who also was a parish nurse, stated,

Well, I’ll tell you, if everybody has a parish nurse like mine then they are truly blessed! I think whoever invented this thing was just brilliant. Because as a nurse in the congregation—and I work with the health ministries department—I see how valuable it is, whether somebody is in the hospital, or at home, or whether it’s a caregiver. I have seen [the parish nurse] do something for the caregiver just to make them feel like they are not forgotten.

THE PARISH NURSE IS “A REALLY GOOD BRIDGE BETWEEN THE MEDICAL CARE THE DOCTOR GIVES AND THE CARE THE FAMILY GIVES.”

Messenger of spiritual care. A third theme discussed by the participants was the parish nurse as a messenger of spiritual care, as one who offers spiritual guidance and interventions through the role of integrator of spirituality and health. In this role, the parish nurse was able to link the health of clients with their faith beliefs. By offering spiritual interventions, the parish nurses were not only able to bring their presence to the family caregivers but also act as representa-

tives of the church. This provided a sense of community and encouragement for the caregivers. A 54-year-old male caregiver shared thoughts on how parish nurses are representatives of the faith community:

They check where you are emotionally, physically, spiritually, the whole works... It bodes well for your church because they represent your pastoral staff to the congregation of a caring person. So that makes them [the faith community] look good too.

Another 38-year-old caregiver described the parish nurse in this way:

She is very spiritual. She has a connection with the Lord, and you can see it. It blossoms, and she cares about people. She truly loves people, and she cares for their health, and she wants them to be well. I think that’s the most, the best thing ... The best example that she has been to us is that she loves the Lord. If you want somebody to pray for you, you just call her.

Prayer was commonly identified as a supportive measure. A caregiver shared, “That is one thing about our parish nurse. It is an extremely rare occasion that she will leave us without saying a prayer. That means a lot to us.”

Bridging challenges. Bridging challenges is identifying and building linkages to overcome gaps in information and resources. The family caregivers described difficult situations, such as lacking essential information regarding healthcare for their loved ones, difficulty finding resources, and being unprepared for unanticipated changes. In these cases, the parish nurse was able to intervene and provide guidance and resources that were of tremendous help to the caregivers. Being familiar with

the healthcare system, the parish nurse was able to assist the family caregivers in navigating through resources and prepare them for possible future needs.

One caregiver described the parish nurse as:

...a really good bridge between the medical care the doctor gives and the care the family gives.” Another shared thoughts about the parish nurse offering anticipatory guidance: “I think everybody, every congregation, every community ought to have one [parish nurse] because they will bring up awareness to you of caregiving, health, or medical issues that you may not even be aware of, or how to anticipate certain things because that in itself cushions the blow of unexpected change.

DISCUSSION

Family caregivers’ level of burden emerged as they described their experiences caring for a loved one. The caregivers discussed parish nurses as a resource in dealing with the challenges of caregiving through four essential themes.

When the family caregivers described the social support provided by the parish nurses, the gift of presence was reported frequently. O’Brien (2003) proposes that the greatest gift a parish nurse may give is *being present*. She describes this as the opportunity of the parish nurse to be fully present (body, heart, and soul) during a person’s physical illness or suffering. Wallace, Tuck, Boland, and Witucki (2002) described the parish nurse as *being available* as part of presence. The theme of presence has been associated with active listening as one of the most common strategies used by parish nurses when providing care (Solari-Twadell & Hackbarth, 2010). Congruently, in the Christian faith, Jesus ensures his presence throughout our lives, saying, “And surely I am with you always, to the very end of the age” (Matthew 28:20, NIV).

As a bearer of blessings, parish nurses were described by family caregivers as offering positive affirmation, unconditional acceptance, and emotional support in handling the challenges of caregiving. For many, this support persisted through weeks and months of caregiving. Van Dover and Pfeiffer (2007, 2012)

studied patients' perceptions of the spiritual care provided by parish nurses and reported that "bringing God near" was a foundational echo that reverberated in patients' descriptions. Nurses in all roles provide spiritual care to their clients; however, this is an essential role of parish nurses and innate to their practice in a faith community (Shores, 2014).

Family caregivers described parish nurses as messengers of spiritual care. For many, prayer was an essential intervention the parish nurses provided. Parish nurses also reinforced connections of the caregivers with their faith community by bringing messages of church news and comfort. The role of the parish nurse as an integrator of spirituality and health has been reported by others in assisting family caregivers in understanding how faith and health are related (Carson & Koenig, 2011; Dandridge, 2014).

Parish nurses were portrayed as supporting caregivers in bridging the challenges of navigating through the healthcare system. Brudenell (2003) proposed that parish nurses link family caregivers to community resources as a strategy to overcome the fragmented healthcare system and meet the needs of the congregation. Other experts described the role as a coordinator who helps patients bridge between two competing worldviews of the medical model and the centrality of spirituality in one's well-being (Dyess, Chase, & Newlin, 2010; Schweitzer, Norberg, & Larson, 2002). The concept of bridging challenges appears to be similar to the concept of sustaining health as proposed by Dyess and Chase (2012) in their theoretical model of faith community nursing. 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 (Baig, Mangione, Sorrell-Thompson, & Miranda, 2010; Yeaworth & Sailors, 2014). As parish nurses screen individuals at home visits, church services, and in phone calls, they can identify problems early.

There are several limitations to this study. The small sample size and number

of parish nurses as participants and known to the researcher limits generalizability to other caregivers. Being familiar with the role of a parish nurse and the researcher may have influenced participants' responses. However, the information shared did not appear to be different from that obtained from other caregivers. The results do provide examples of the interactions and discussions that caregivers have with parish nurses.

PARISH NURSE PREPARATION AND PRACTICE


The need to support family caregivers is growing (NAC, 2015). In this study, family caregivers found great value in the unique support provided by parish nurses, who offered not only healthcare expertise but spiritual support. Support was found in the nurses being present and listening to concerns, education to prepare family caregivers for their roles, counseling to help them anticipate future options, spiritual interventions, and consultation in garnering support from community resources.

To enhance caregiver support, parish nurses must be aware of current and potential family caregiver needs. This information could be included as part of foundational parish nursing preparation curriculum and in continuing education programming. The Pearlin Stress Process Model offers an excellent framework parish nurses can use to assess caregivers. The model identifies primary stressors (i.e., care of their loved one), secondary stressors (i.e., job changes, isolation), stress mediators (i.e., friends, family), coping mechanisms (i.e., faith, exercise), available resources (i.e., faith community), and the outcomes of the caregiving experience (Pearlin & Bierman, 2013; Pearlin, Mullan, Semple, & Skaff, 1990). Parish nurse education could introduce caregiver self-assessment, goal setting, and the need for reevaluation and revision on subsequent visits. The nursing process could be used for addressing caregiver needs. Wholistic assessment, diagnosis, planning for support and resources, implementing plans, and ongoing evaluation of caregiver level of functioning and wellness could be taught through case studies.

Web Resources

- Family Caregiver Alliance—<https://caregiver.org>
- National Alliance for Caregiving—www.caregiving.org
- Caregiver Assessment—www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_english.pdf

Parish nurses would benefit from continuing education programs that are evidence-based and focus on the special needs and challenges of family caregivers. Content for continuing education programs might include updates on the availability of community resources, strategies to improve case management, and opportunities to role play and improve advocacy skills for family caregivers as they move through the healthcare system.

Many family caregivers are overwhelmed with multiple challenges. Parish nurses are an excellent resource to help alleviate some of the burdens caregivers encounter. Education about the needs of family caregivers would invite parish nurses to provide individualized nursing interventions to help families overcome challenges. Parish nurses can anticipate potential difficulties, engage caregivers in finding assistance, and aid in adjusting to the caregiving role by providing emotional, informational, and spiritual support. 

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Registration Deadline: March 31, 2018

Disclosure Statement: The authors and planners have disclosed that they have no financial relationships related to this article.

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