

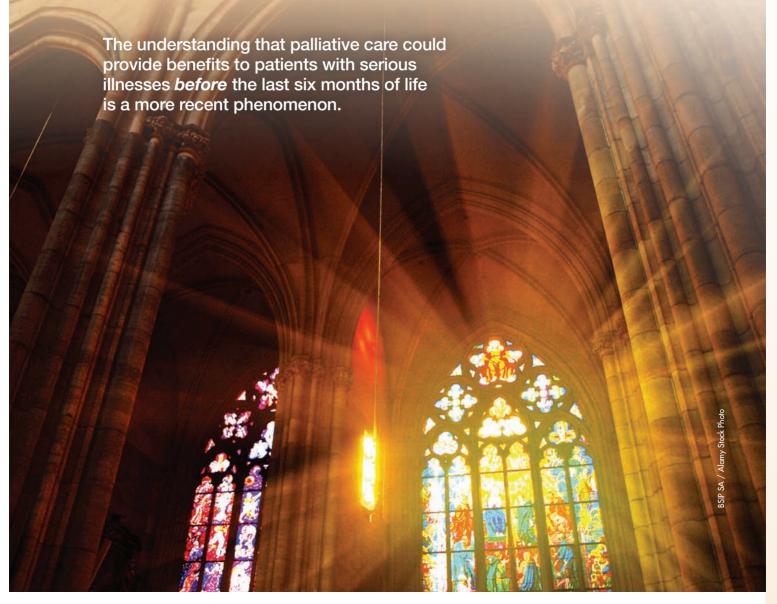
**ABSTRACT:** Although the specialty of palliative nursing and palliative care continues to grow in hospital and outpatient settings, a paucity of home-based palliative services remains. This article discusses a new paradigm of faith-based palliative care ministry using faith community nurses (FCNs). Under the leadership of a palliative care doula (a nurse expert in palliative care), nurses in the faith community can offer critical support to those with serious illness. Models such as this provide stimulating content for FCN practice and opportunity to broaden health ministry within faith communities.

**KEY WORDS:** faith community nursing, health ministry, hospice, palliative care, palliative care doula, serious illness

By Judy C. Lentz

AN INNOVATIVE ROLE FOR FAITH COMMUNITY NURSING

# PALLIATIVE CARE



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lthough palliative nursing is considered one of the newer nursing specialties, nurses have cared for the seriously ill and the dying since the beginning of nursing. The American Nurses Association (ANA) and Hospice & Palliative Nurses Association (HPNA) state that "palliative care is embedded in all nursing practice in the relief of suffering; all nurses practice Primary Palliative Nursing" (2014, p. 19). All nurses would benefit from additional learning about palliative care. In addition to increasing knowledge about palliative nursing, this article provides faith community nurses (FCNs) with

serious illnesses. The understanding that palliative care could provide many benefits to patients with serious and life-threatening illnesses *before* the last 6 months of life is a more recent phenomenon. This concept of extending palliative care to the initial diagnosis with serious and life-threatening illness is becoming the norm. Palliative care emerged from the hospice model and began the palliative nursing specialty area of practice.

Palliative care for adults and children is offered when individuals suffer from pain or other symptoms due to any serious illness; experience physical or emotional pain that is not under palliative care (NINR, 2011). Palliative care does not replace healthcare services but augments and coordinates care to help meet patient and family needs and goals.

Palliative nursing is defined as both an art (being *present*) and a science (evidence-based), for patients with acute or chronic potentially life-limiting illnesses, with outcomes focusing on quality of life, as well as alleviating suffering (ANA & HPNA, 2014; Lynch, Dahlin, Hultman, & Coakley, 2011). The NINR (2011) explains,

Palliative care is comprehensive treatment of the discomfort, symptoms and stress of serious illness. It does not replace your primary treatment; palliative care works together with the primary treatment you're receiving. The goal is to prevent and ease suffering and improve your quality of life. (p. 1)

Palliative care has been in existence for nearly a quarter of a century. Much progress has extended the availability and effectiveness of palliative care. Currently, more than 1,700 hospitals with 50 or more beds offer formal palliative care services, whereas smaller hospitals are realizing the benefits and doing their best to create some form of this service (Center to Advance Palliative Care [CAPC], n.d.). Training for palliative care has grown as formal organizations for palliative care emerged. When referral to formal or hospital-based palliative care is made by a provider, most insurance companies will cover the cost of palliative care (CAPC; NINR, 2011).

However, although hospital-based palliative care services have expanded, a paucity of home-based services remain. With life spans lengthening, care needs in the home are significantly increasing. An estimated 45 million Americans live with one or more chronic conditions that continue to worsen (Institute of Medicine, 2015). These statistics emphasize that many individuals desperately need palliative care services.

# MINISTRY

an innovative model of a palliative care ministry through the faith community. Models such as this provide stimulating content for FCN practice and address additional opportunities to broaden health ministries within faith settings.

# EMERGENCE OF PALLIATIVE CARE

Hospice nursing emerged in the mid-20th century with the hospice movement, as the understanding of how to give care at the end of life grew. Due to U.S. Medicare regulations and the thinking about end of life, the hospice movement became associated with the last 6 months of life (ANA & HPNA, 2014, p. 16). Originally, the hospice model of care was based on care of cancer patients rather than all



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control; and/or need help in understanding their illness, future, and coordinating their healthcare (Hospice and Palliative Credentialing Center [HPCC], n.d.; National Institute of Nursing Research [NINR], 2011). The National Consensus Project for Quality Palliative Care (NCP) offers the widely accepted definition of palliative care:

Palliative Care means patientand family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing the physical, intellectual, emotional, social, and spiritual needs and [facilitating] patient autonomy, access to information, and choice. (NCP, as cited in ANA & HPNA, 2014, p. 1)

Individuals with serious and chronic illnesses such as heart, lung, and renal diseases; cancer; cystic fibrosis; diabetes; Alzheimer's disease; neurological disorders; and autoimmune deficiency disorder, are among the diseases that research has shown benefit from

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#### **PALLIATIVE CARE SERVICES**

When patients are admitted to hospitals that offer palliative care, triggers occur that automatically alert a team of palliative professionals, who go into motion. The team seeks quality of life, as defined by the patient, and works diligently to match the patient-stated care goals with the care provided. These fortunate patients usually have successful outcomes in terms of achieving quality of life and meeting their wishes. Family members and patients enthusiastically vocalize their appreciation.

But what about individuals earlier in the disease process of serious illness who need benefits? Many struggle with the concerns of their disease. Unless they have been formally admitted to an outpatient palliative care program, these individuals typically lack advocacy, support, and education. They may be overwhelmed, bewildered, and frustrated with the deterioration of their health, as well as have limited understanding of how to

navigate the complex healthcare system. In the early stages of a serious illness, care goals may not be discussed by the physician or other providers. Patients and families may not be told what might happen next or taught to understand the consequences of poor disease management, such as with an insulin-dependent diabetic.

When an individual or family asks about palliative care, many are told, "You are not ready for that yet," as if there is a specific time when palliative care should be offered. Conversely, researchers have found an improvement in quality of life and longer survival in patients who received early palliative care at diagnosis (Bakitas et al., 2009; Temel et al., 2010).

An underlying assumption of palliative care is to offer interdisciplinary team care from the moment of diagnosis and continue throughout the trajectory of the serious illness, despite the number of years that might transpire (ANA & HPNA, 2014, p. 2). When the person's disease progresses to where they are

seemingly eligible for hospice, they can be told palliative care is not an option if they continue aggressive therapy. Aggressive therapy can include medications not covered by insurance, so the family must pay premium dollars for these medications. As hospice pays for medications prescribed to treat the disease, hospices decline the person's eligibility when they opt for aggressive treatment that engenders high expenses (U.S. Centers for Medicare and Medicaid Services, n.d.). In some cases, it is determined that after trying these costly medications, they are ineffective because the disease has advanced, or the morphology has changed, preventing an efficacious benefit. In the Medicare payment system, adults are not permitted to seek aggressive therapy simultaneously with hospice care. Fortunately, this is different for the pediatric community in the Pediatric Concurrent Care program (Pediatric Palliative Care, 2012).

Another area of concern is a lack of communication and continuity of care between providers. If admitted to a nursing home, often the person's primary physician and specialists are no longer the care providers. Instead, the individual is under the care of the nursing home physician. Some internal regulations and payment systems are punitive to physicians, causing those physicians to make difficult decisions that may not be in the patient's favor (such as the 30-day mortality postoperative rate) (Hansen, Hjortdal, Andreasen, Mortensen, & Jakobsen, 2015).

This paper presents a model of providing support, advocacy, and education for community-based individuals who are not eligible for or ready to choose hospice. This model is designed for the faith community and provides an example of palliative care ministries, utilizing a *Palliative Care Doula* (PCD) who is a palliative care expert, and a palliative care ministry team made up of nurses.

### THE PALLIATIVE CARE DOULA

The term *doula* is borrowed from the U.S. obstetrics field, dating back 50 years. The obstetrical doula supports the

What if palliative care was not hospice, hospital, or community-based, but **faith-based**?



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Faith community nurses sensing God's call to begin a palliative care ministry can obtain training for palliative care and develop the PCD role.

mother through the birth process, following the wishes of the mother (Associates in Obstetrics and Gynecology, 2017). In this case, the PCD serves, provides advocacy, support, and education to the person and family experiencing a serious illness (Horovitz, 2017; Lentz, 2014). The PCD offers opportunity to give voice to those who suffer and wonder what might lie ahead.

Who can benefit from a PCD? The care of those experiencing serious illnesses often is fragmented, provided by a specialist related to the person's primary diagnosis. Some patients may be in communities where palliative care is limited or unavailable, or decline palliative care services due to cost or because they think it is for end of life (like hospice). These individuals are medically managed and may have little information about what might come next. Furthermore, the healthcare system is confusing and frustrating. The patient who knows little about medical terminology and is experiencing disease-related problems is called upon to bridge communication gaps. The PCD seeks to overcome communication barriers by working directly with the individual to have the necessary conversations to pave a smooth road on this journey of serious illness.

In particular, the PCD helps the individual articulate his/her definition of quality of life, asks about current care goals, inquires about appointments, explains what is happening pathophysiologically, and offers explanations of healthcare information and treatment options. Frequently, the PCD suggests questions to ask providers, offers to accompany him/her to a physician visit, attends a family conference, and is present in crisis. The PCD works directly with the patient/family and conducts the necessary conversations to support, educate, and advocate for the wishes of the seriously ill person. These conversations can occur by phone,

electronically, or in person, according to the individual's preferences, occurring monthly, weekly, or daily, if necessary. This description of the services the PCD offers describes what I have practiced in the community setting.

## A NEW PARADIGM: PALLIATIVE CARE MINISTRY

What if palliative care was not hospice-, hospital-, or communitybased, but faith-based? Five years ago, God challenged me to offer a Palliative Care Ministry in my church. My clinical experience is in hospice and palliative care as an advanced practice, certified palliative care nurse. I thought, where could it be better to address the needs of the mind, body, and spirit of those experiencing serious illnesses, than in the faith community? The ministry was intended to assure holistic would care be received by parishioners experiencing serious and life-threatening illnesses, by augmenting pastoral spiritual ministry.

After exploring this concept with church leadership and acquiring the necessary approval to move forward, other interested nurses from the congregation were recruited. Education in palliative philosophy and care was the next step, followed by communicating the new ministry to church membership. The ministry was then offered to those on the prayer concerns list of the church with serious illness. Individuals interested in participating were assigned to a palliative care ministry partner. Regular contacts between the ministry partners and clients were established, and team members maintained services according to need. The expert PCD served as the ministry coordinator and overseer.

After 3 years, this ministry has grown, with 25 individuals receiving direct services. Several participants have succumbed to their disease since the ministry began, and new participants

have been identified and served. Because this ministry is offered through the faith community and is free of charge, many are comfortable seeking out the palliative care ministry.

Palliative care ministry in the faith community is unique but replicable. By offering information regarding the physical aspects of a person's serious illness, the ministry team of nurses led by a PCD provides assurance, leading to peace of mind and associated biopsychosocial and spiritual comfort. In many ways, palliative care ministry is similar to the advocacy role FCNs often play for parishioners needing healthcare support and services. A difference is the focus on enhancing quality of life in serious illness.

This model has now been replicated in a second church, where I reside seasonally. The ministry process was replicated over the past year, and again, has proven beneficial. Because the ministry is a service of support, advocacy, and education, these contacts can be made by phone, by electronic means, and by periodic visits. The PCD coordinator not only leads the team but offers continuing education on palliative care, while coordinating and serving parishioners who desire these specialty ministry services. With prayer and God's guidance, both ministries have been well received and continue to grow.

#### **ASPECTS OF PALLIATIVE MINISTRY**

Numerous important issues have been identified, based on our experience helping parishioners. These issues have been addressed with successful outcomes for appreciative parishioners and their family members. From our work in palliative care ministry, we realize the need to offer the following points of care:

- Goals-of-care discussions with patients and/or family;
- Understanding of disease progression;

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- Support and assistance in communicating needs, such as when formal palliative care services are refused;
- Eligibility or ineligibility of hospice due to preference for aggressive therapy;
- Communication gaps in healthcare;
- Bridging gaps of care;
- Regulatory and insurance barriers for health, palliative, and hospice care;
- Understanding complex medical management.

What if you are not a palliative care nurse but serving as an FCN? Faith community nurses sensing God's call to begin a palliative care ministry can obtain training for palliative care and develop the PCD role. The HPNA and HPCC offer extensive education and certification in palliative care (see Further Resources). Basic certification is available for registered nurses, for advanced practice palliative care, for nursing assistants, and in pediatric and neonatal loss (HPCC, 2016). Online education and national conferences can help any nurse with training in palliative care. Table 1 offers suggestions for how to discern if a palliative

care ministry is right for your faith community and something God may be calling you to do.

## CASE STUDIES IN PALLIATIVE MINISTRY

To further understand palliative care ministry, four case studies with successful outcomes due to services of two palliative care ministers and a PCD as coordinator, are offered.

Significant Diabetes Mellitus. M. F.\* is a 50-year-old woman with diabetes. She is insulin dependent and takes metformin twice a day. However, she has a poor understanding of the negative outcomes and long-term consequences of diabetes and poor compliance. When the palliative care ministry team was first alerted by prayer requests for her challenges with disease management adherence, she had stopped taking her insulin, due to the ever-increasing costs, and stopped checking her blood sugars. As a result, her hemoglobin A1C was 15. Her physician was caring, sympathetic, and tolerant of her challenges with disease management.

After educating M. F. on about the palliative care ministry, She decided to

receive assistance. As a ministry recipient and participant in her care, M. F. has received firm guidance, accountability, and education regarding the long-term effects of nonadherence to the diabetic treatment regimen. Her education includes a weekly luncheon provided by her primary palliative care ministry team member. She makes recipes from a diabetic slow cooker cookbook to discourage the use of fast foods and frozen dinners for this working wife and mother. The team member provides objective data when educating M.F. about the importance of frequent, regular, consistent glucometer readings. The weekly lunches provide viable mealtime options, educational sessions for data review, as well as prayer time for spiritual support and encouragement. Above all, this continuing ministry provides support, advocacy, and the education needed by M.F. to lessen the long-term negative effects of hyperglycemia.

The successful outcome of palliative care: M. F. reports that her A1C was reduced from 15 to 7.6. She states she is less fearful of her diabetes now and feels hopeful for the future.

#### TABLE 1: CONSIDERING A PALLIATIVE CARE MINISTRY

Pray for God's leading Assess the faith community and needs for palliative care ministry Discuss with existing Health Ministry to see where a palliative care ministry would fit Approach the pastor/church leaders about the vision and needs you discovered Develop a vision for the ministry in your faith community Seek training if you are not already experienced in palliative care Recruit other nurses for the team Develop protocols for assessment of potential clients, and how and what services will be provided Announce the palliative care ministry to the congregation



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Oncologic emergency. A. L.\* was age 81 and active, having retired 1 week before he began experiencing severe shoulder pain. An orthopedic specialist suggested cortisone injections. Twentyfour hours after the second injection, A. L.'s right arm became flaccid. A surgeon ordered a Magnetic Resonance Image scan and discovered a tumor pressing on the cervical spinal cord; A. L. was referred to a neurosurgeon. He was seen on a Thursday and scheduled for surgery the following Tuesday. On Friday, A fell and was unable to get up. He called the church asking if someone could come to his home, and palliative care ministry was urgently consulted.

The PCD immediately went to the home where A. L. was found on the floor. Emergency services were called. It was discovered that A. L. had a spinal cord compression, an oncologic emergency. After getting him to the emergency room and admitted with the confirmed diagnosis, emergency radiation therapy was expected to be started. However, the neurosurgeon wanted to do the planned surgical intervention instead.

The day before surgery, A. L.'s right leg became paralyzed. Postoperatively, although the pain was somewhat relieved, A. L. developed more problems and was diagnosed with widely metastatic small cell lung cancer. The cancer had spread to his liver and spine, and was widespread in his thoracic cage. In addition to his right-sided paralysis, he developed additional complications: syndrome of inappropriate antidiuretic hormone; steroid-induced hyperglycemia; a stage 3 coccygeal ulcer; and was no longer anticoagulated for his atrial fibrillation.

The PCD suggested and urged the family to request a palliative care consult. The hospital care team responded, "That isn't needed." The PCD encouraged the family to be adamant in their request for the consult and a family conference, which was granted. Over the next week, the PCD assisted the family in obtaining a hospice consult and contacted the hospice intake nurse to provide a detailed report

of the patient's condition. A. L. died 2 weeks later in inpatient hospice care, a quadriplegic but having achieved his goals of care: to spend as much time with his family as possible, to watch the Stanley Cup Finals, and to die with dignity. A. L. passed 4 weeks from the day of his diagnosis and just weeks after his retirement.

The successful outcome of palliative care: a formal palliative care consult, family conference, and hospice consult eased the burden of symptoms experienced by the patient and family over this short but difficult end-of-life situation, while achieving the patient's stated care goals.

Lou Gehrig's Disease. J. R.\* was diagnosed 3 years ago with bulbar amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease). J. R. understood his disease is incurable and wanted to achieve quality of life, as defined by him, for as long as possible. This included managing the anxiety he experienced when he became short of breath. J. R. had lost his ability to swallow and was aphasic. He used a keyboard to communicate. He began experiencing occasional periods of shortness of breath that occurred without warning. His son, a gastroenterologist, recommended that J. R. ask his neurologist for low-dose oxycodone to take when he would become dyspneic, knowing this would reduce pain, relax J. R., and help calm his fears. J. R. asked his neurologist, who according to J. R.'s wife, responded, "I do not order opioids!" J. R. told his son about his neurologist's reaction, and his son suggested he talk to his internal medicine physician. The internist understood J. R.'s need and ordered the medication.

On the next visit to the neurologist, J. R.'s wife told the neurologist how helpful the oxycodone was and asked if he would order another prescription. According to the family, the neurologist's reaction was negative and accusatory. J. R. and his wife were embarrassed and angered. They felt their relationship with the neurologist was fractured, and they feared for the future of J. R.'s care. J. R.'s wife requested the help of the PCD.

## Further Resources

- Center to Advance Palliative Care—https://www.capc.org
- End-of-Life Nursing Education Consortium—http://www. aacnnursing.org/ELNEC
- Get Palliative Care (directory) https://getpalliativecare.org
- Hospice & Palliative Nursing Association—http://hpna.advanc ingexpertcare.org
- Hospice & Palliative Credentialing Center—http://advancingexpert care.org
- National Hospice and Palliative Care Organization—https://www. nhpco.org
- Scope and Standards of Practice: Palliative Care Nursing—An Essential Resource for Hospice and Palliative Nurses (2014).
   ANA & HPNA
- Palliative Care Nursing, 4th Edition: Quality Care to the End of Life (2014). Marianne Matzo and Deborah Witt Sherman, Springer Publishing
- Conversations in Palliative Care: Questions and Answers with the Experts, 4th Edition (2017). Kathy Plakovic, Barton Bobb, and Patrick Coyne, editors, HPNA
- Journal of Hospice & Palliative Care Nursing, Wolters Kluwer Lippincott Williams & Wilkins
- Clinical Pocket Guide to Advanced Practice Palliative Nursing, 1st Edition (2017). Constance Dahlin, Patrick Coyne, and Betty Ferrell (Editors), Oxford University Press

The PCD immediately connected J. R. to the palliative care services of the tertiary facility where his neurologist was located. J. R. asked the PCD to attend the palliative care appointment. The PCD explained to the palliative care physician about the tense relationship with the neurologist. This physician was happy to intercede on J. R.'s behalf, bridge the communication gap, and assured J. R. that she would be the person prescribing his opioids in the future. J. R. and his wife were immediately reassured. This case study illustrates complex patient issues that were poorly communicated prior to

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receiving formal palliative care and intervention by the PCD.

The successful outcome of palliative care: Consultation was facilitated with the hospital system's Palliative Care Services; concerns about future need for pain control and shortness of breath was communicated and resolved; the concerns about the broken relationship with the neurologist and patient/family were relieved.

Aortic valve replacement. R. R.\*, a 68-year-old female, was hospitalized for open-heart surgery to replace her aortic valve. R. R. had a lengthy history of problems involving her lungs (asthma) and heart (congestive heart failure). She also had Sjögren syndrome, a past breast cancer, and several orthopedic restorative surgeries. She had great concern for the upcoming cardiac surgery, but was advised that her situation was dire, and without surgery she would not live more than 6 months to 1 year. Her greatest fear was that she would not be able to be taken off the ventilator required for the procedure. Her physician echoed her concerns. However, she consented to the surgery.

Although her surgery seemed to go well, R. R.'s condition changed suddenly in the first 24 hours. For the first 12 hours, she progressed. Soon thereafter, she was no longer responding to simple commands and no longer tracking with her eyes. R. R.'s surrogate decision—maker, her niece, was unfamiliar with medical terminology and conditions. The niece contacted R. R.'s church, and palliative care ministry was consulted.

The PCD talked to R. R.'s niece frequently, answering questions, clarifying terminology, and offering support and advocacy. Each day brought more evidence of multiorgan system failure. R. R. needed an external pacemaker, dialysis, and increasing cardiac medications. She experienced rising bilirubin and became unresponsive neurologically. The PCD urged R. R.'s niece to request a palliative care consult. The cardiothoracic surgeon did not "see any need for palliative care" and continued to encourage R. R.'s niece to have patience.

After 15 days where R. R.'s life was sustained on mechanical and chemical support mechanisms, the cardiothoracic

surgeon suggested a family conference. R. R. niece asked the PCD to attend. It was evident at the end of the conversation, led by the cardiothoracic surgeon, that the family did not understand the extent of the multiorgan system failure and how dependent R. R. was on the medications and mechanical devices to sustain life. The surgeon encouraged the family to approve a brain scan to determine if R. R. might have experienced brain hemorrhaging. If the scan was positive,

In the Medicare payment system, adults are not permitted to seek aggressive therapy simultaneously with hospice care.

the surgeon recommended that support systems be discontinued. The PCD asked the surgeon to explain to the family what to expect if this outcome would occur. Once the surgeon described the discontinuation of dialysis, the cardiac support medications, external pacemaker, and the ventilator, the family responded, "Our Aunt isn't really alive, is she? It is the medications and machines that are keeping her alive, correct?" The surgeon agreed.

Reflecting on this information, R. R.'s family asked the surgeon to allow natural death should R. R.'s heart or breathing stop (Do Not Resuscitate). R. R. went into cardiac arrest while being transported to the radiology department for the scan. The family was appreciative of the help of the PCD in assisting them to understand complex medical management and the severity of R. R.'s situation, making their decision to allow death less difficult.

The successful outcome of palliative care: Complex medical management was clarified to ease difficult decision-making by the patient and surrogate/family.

## TESTIMONIALS FROM CARE RECIPIENTS

Testimonials by participants confirm the value of palliative care. M.F. wrote:

I never thought it would be possible to control my diabetes. I loved goodies too much! However, after working with the Palliative Care Ministry Team, I can say that I feel like control is attainable! I not only have a great friend, but a true advocate that helps me understand my diagnosis and how best to live with it. I visit the doctor with confidence now and ask knowledgeable questions. Before, I just wanted to get every visit over and move on to the next cookie. I know God sent the team my way as a wake-up call to manage my health so that I can help others.

R. R.'s family member stated, What the Palliative Care Ministry provided to us was invaluable! We appreciate your willingness to be available any time, day or night. It was so helpful to have someone to talk to that was knowledgeable and impartial when hard decisions had to be made regarding our aunt's care. When dealing with a loved one's end-of-life care, it was comforting to know that we had you (the PCD) and the team to guide us in asking the hospital staff tough questions that my sister and I weren't ready to face.

The four case studies presented here may seem unusual in their complexity, and yet, the cases illustrate the difficulties experienced by patients prior to their connection to the PCD or palliative care ministry team. These stories are common. Patients and family members struggle to understand what is being communicated. They do not understand how to navigate the complex medical system, how to overcome the barriers they experience, or how to interpret medical information and denial of requests for palliative care. In the presence of serious illness, patients and family members can make the right decisions, based on patient-stated goals of care, when they are fully informed.

Palliative care team members have found in some cases that the patient/family has been sheltered from the full details of their situation. Maybe the providers are trying to offer hope in filtering the information. Maybe the physician is struggling with the

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knowledge that this patient's health is failing. What are the answers? How can these patients' voices be heard? Palliative care ministry by FCNs with training in palliative philosophy and care can be a great starting point.

#### **CONCLUSION**

Replicating palliative care ministry in faith-based communities nationwide would have far-reaching impact. Such care would amplify the voices of those with serious and chronic illnesses who are bewildered and overlooked in today's complex healthcare setting. Allowing congregants to experience quality of life and honoring their goals of care is possible in the faith-based community. Our team members are enriched by providing this service and grateful to be an advocate to this vulnerable group. One parishioner stated, "Wouldn't it be wonderful if every church had a palliative care ministry?" I challenge Christian nurses to consider if God might be calling you

to begin a palliative care ministry in your faith community.

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