The Role of the Palliative Care Registered Nurse in the Nursing Facility Setting

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ABSTRACT

There is a growing recognition of significant, unmet palliative care needs in nursing facilities, yet limitations in the workforce limit access to palliative care services. Attention to palliation is particularly important when there are efforts to reduce hospitalizations to help ensure there are no unintended harms associated with treating residents in place. A specialized palliative care Registered Nurse (PCRN) role was developed as part of the OPTIMISTIC program, a federally funded project to reduce potentially avoidable hospitalizations. Working in collaboration with existing clinical staff and medical providers, the PCRN focuses on managing symptoms, advance care planning, achieving goal concordant care, and promoting quality of life. The PCRN serves as a resource for families through education and support. The PCRN also provides education and mentorship to staff to increase their comfort, knowledge, and skills with end-of life care. The goal of this article is to provide an overview of the PCRN role and its implementation in nursing facilities, and describe core functions that are transferrable to other contexts.

KEY WORDS

Consultant, nurse's role, nursing facility, palliative care, nursing homes

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This is the author's manuscript of the article published in final edited form as:

Hickman, S. E., Parks, M., Unroe, K. T., Ott, M., & Ersek, M. (2020). The Role of the Palliative Care Registered Nurse in the Nursing Facility Setting. Journal of Hospice and Palliative Nursing: JHPN: The Official Journal of the Hospice and Palliative Nurses Association, 22(2), 152–158. https://doi.org/10.1097/NJH.0000000000000634

INTRODUCTION

There is a growing recognition of significant, unmet palliative care needs in nursing facilities.[1-7] However, nursing home staff lack training in primary palliative care and nursing home residents do not have consistent access to palliative care specialists.[8-13] Attention to palliation is a particularly important part of efforts to reduce potentially avoidable hospitalizations of long-stay nursing facility residents, with potential to decrease transfers related to in adequate symptom management and promote efforts to provide goal-concordant treatment in place. When increased management of acute and chronic conditions provided in place, it is essential to ensure there are no unintended harms related to unmet palliative care needs such as symptom management.

OPTIMISTIC (Optimizing Patient Transfers, Impacting Medical quality, and Improving Symptoms: Transforming Institutional Care) Project is a multi-component, federally-funded demonstration project designed to reduce potentially avoidable hospitalizations of long-stay nursing facility residents through enhanced geriatric care for acute and chronic conditions, improved transitions for residents who do transfer, and palliative care.[14-17] It was one of seven national demonstration project sites, each with its own unique clinical model, originally funded through the Centers for Medicare and Medicaid Services (CMS) Innovation Center and the CMS Medicare-Medicaid Coordination Office. [17] The OPTIMSTIC intervention was delivered by specially trained project nurses (RNs) and nurse practitioners (NPs) embedded in 19 partner nursing facilities in central Indiana. In an external evaluation of Phase I (2012-2016), OPTIMISTIC was found to significantly reduce both potentially avoidable hospitalizations and all-cause hospitalizations with no negative effects on quality[18] or mortality.[19] The role of the clinical staff in OPTIMISTIC has continued in a Phase II of the demonstration project (2016-

2020), which has added novel Medicare billing codes to the clinical model to increase motivation and ability to care for acutely ill residents in place by allowing facilities to bill an additional amount when caring for residents with specific clinical issues (e.g., urinary tract infections).[15,17] There are a total of 40 facilities in Phase II of the project; the full clinical model, including PCRN support, is available in 17 facilities in central Indiana.

Each component of the intervention is overseen by a core consisting of clinical experts from Indiana University and collaborating institutions. The Palliative Care Core focuses on oversight of the palliative care interventions with a focus on advance care planning (ACP) and symptom management. To support delivery of the Palliative Care Core interventions, project RNs and NPs receive training in advance care planning using the Respecting Choices Advanced Steps facilitation model [20] to integrate the Indiana Physician Orders for Scope of Treatment (POST) form[21], which is based on the National POLST Paradigm.[22] The POST permits documentation of residents' preferences as orders about cardiopulmonary resuscitation, medical interventions, antibiotics, and artificial nutrition. In addition to this intensive ACP training, all project RNs and NPs complete the geriatric version of the End-of-Life Nursing Education Consortium training.[23-25] During Phase I, a palliative care physician provided consultation and support for project RNs and NPs for up to 4 hours per week around difficult cases. At the outset of Phase II, the leadership team decided to invest more in the palliative care component of the intervention. As part of this project adaptation, the program shifted from physician consultation with project staff, which was limited in its scope, to a nurse-driven, hands-on clinical role that could be more responsive to resident and OPTIMISTIC staff needs across the participating facilities. This led to the development of the OPTIMISTIC Palliative Care registered nurse (PCRN) role. To date, this role has been implemented with one nurse (and co-author, MP).

The goal of this article is to describe the PCRN role including interventions designed to enhance the palliative care of nursing facility residents enrolled in the OPTIMISTIC project. The PCRN interventions represent potential approaches to enhancing palliative care for residents in long-term care and other geriatric settings.

The OPTIMISTIC Palliative Care Registered Nurse (PCRN) ROLE

Training and Background

The OPTIMISTIC PCRN role was adapted from the specialized OPTIMISTIC RN role and targeted a nurse with a background in both hospice and geriatrics. She underwent additional training as a Respecting Choices® Advanced Steps Instructor, and completed project-specific, evidence-based dementia training. Additionally, she obtained certification as a Certified Hospice and Palliative Nurse [26] during her first year in her role as PCRN. While all OPTIMISTIC RNs have received some training in palliative care, the intent was to provide more specialized support across the facilities in the project through the creation of this role.

The PCRN is a member of the OPTIMISTIC Palliative Care Core, working in collaboration and under the supervision of the project medical director, who is a geriatrician. Her major responsibility is to support all of the OPTIMISTIC project nurses and OPTIMISTIC facilities, in contrast to other project nurses who are dedicated to specific facilities. When the PCRN role was first launched, facility and corporate leaders were given a written overview of the role, and the PCRN met with facility administrators to explain the services and scope of the PCRN role.

Components of OPTIMISTIC and the PCRN Role

Advance care planning (ACP) discussions. As a Respecting Choices Instructor, the PCRN provides additional one-on-one training in Respecting Choices Facilitation, role modeling, final facilitator certification reviews, and annual facilitator re-certification assessments for OPTIMISTIC RNs and NPs. She also conducts ACP discussions when OPTIMISTIC staff are unavailable and consults on particularly challenging cases. Case 1 is illustrative of this role.

Case 1

Mr. B is a 76-year old male with advanced Alzheimer's disease admitted to the nursing facility when his wife was no longer able to care for him in the home. The resident's wife wanted her husband admitted as "full code." Nursing facility staff described her as "unrealistic" and unwilling to discuss the resident's physical and cognitive decline. The OPTIMISTIC RN embedded in the nursing facility requested a consult from the PCRN when the resident experienced weight loss and a decrease in functional status. After seeing the resident, the PCRN phoned the wife to discuss the resident's dysphagia and collaborate on possible interventions. The PCRN also asked questions about the resident's former interests and activities and learned of the resident's love for dogs. Pictures of dogs were brought in to decorate the walls in his room, and the activities director arranged therapy dog visits. In time, a trusting rapport was established between the PCRN and the resident's wife. The wife began asking questions about her husband's condition and the PCRN used these opportunities to educate on the progression of Alzheimer's, likely complications such as dysphagia, pneumonia and other infections, and the importance of ACP. Following a facilitated ACP discussion with the PCRN, the wife signed a POST form with treatment preferences: DNR and Limited Interventions. The resident remained stable, and the PCRN continued to provide weekly visits & support. A few months later, the resident had a fall resulting in injury and was hospitalized. When the resident returned to the nursing facility, the PCRN met with the wife to revisit the goals of care. In reflecting on her husband's stressful experience in the hospital (unfamiliar caregivers, delirium), the wife expressed the goals of care as a focus on comfort and to avoid hospitalization. A new POST form was completed to reflect a focus on comfort care and the PCRN coordinated with nursing facility staff to ensure comfort needs were met. At the time of this writing, the resident remains in the nursing facility. Although he continues to decline, he has not been hospitalized. Instead, his medical conditions and symptoms are managed at the facility. His care plan was revised and now includes regular pet therapy visits which he enjoys very much.

Comfort Care Reviews. Another key responsibility of the PCRN is to ensure appropriate symptom assessment and management for residents who have identified comfort as the primary goal of care. OPTIMISTIC RNs notify the PCRN when a resident has a new POST "comfort

measures" order. The PCRN then performs a chart review and evaluates the care plan to ensure that comfort can be achieved. This includes a review of pharmacologic and non-pharmacologic therapies for pain and other common symptoms. She also performs a medication audit to identify medications that may no longer be appropriate and to ensure that the resident has medications ordered to manage symptoms. The PCRN discusses her recommendations with the nursing facility provider, who then discusses these options with the resident/family. The physician leaders in OPTIMISTIC are available to discuss with the PCRN as needed. Case 2 provides an example of this process.

Case 2

Ms. Y was an 83-year-old female with a medical history that included a gastrointestinal bleed, anemia, diabetes, and Lewy Body Dementia. The resident had a necrotic coccygeal wound with a poor healing prognosis related to poor nutritional status. The resident was also receiving outpatient blood transfusions and erythropoietin for anemia. As the result of a routine ACP discussion between the OPTIMISTIC nurse and the resident's niece (her legally appointed surrogate), a POST form was prepared with orders including DNR/ Comfort Measures/No Artificial Nutrition, triggering involvement by the PCRN. The PCRN conducted a chart review and discovered that wound treatments were extremely painful for the resident, but there was no pain medication ordered to administer prior to treatments. The PCRN consulted with the resident's provider, and pain medication was ordered and administered prior to wound care. The PCRN met with the niece to further define comfort goals. The niece did not want her aunt to receive painful needle sticks for lab draws and blood transfusions. Ms. Y's nutritional status was discussed and the PCRN was able to provide education about her nutritional issues as well as to explore the possibility of a more liberal diet focused on pleasure foods rather than a strict

diabetic diet. Ms. Y's quality of life became the focus of care and the resident was able to eat and drink favorite foods that had previously been restricted. Glucose checks and her statin, vitamins, erythropoietin, and folic acid were discontinued. Oral opioids were ordered to manage chronic and intermittent pain. The resident was bedbound but was able to listen to her favorite music and television shows in her room. As a result of these changes, Ms. Y was able to enjoy her final weeks without returning to the hospital and without pain during wound care. She died peacefully in the nursing facility.

Comfort Care Transfer Reviews. In support of the overall goals of the initiative to reduce potentially avoidable hospitalizations, OPTIMISTIC RNs conduct a root cause analysis on all resident transfers to the hospital.[27] To supplement these efforts, the PCRN performs a secondary review of all transfers of residents with POST comfort measures orders to look for patterns and additional opportunities to intervene to honor resident goals.[28] If. For example, if a transfer was related to unmet symptom need such as uncontrolled pain, the PCRN would review the record to determine what interventions were provided in the facility to try to avoid the transfer and if so, why these were ineffective. The PCRN evaluates whether there were communication issues, such as whether the provider was aware of a documented preference for comfort care and what role the family had, if any, in the decision to transfer the resident. The PCRN then uses this information to ensure that changes are made to the care plan to reduce the likelihood that the resident is hospitalized in the future.

Extended Transition Support. Another component of the role of the PCRN is to coordinate integration of palliative care services for long stay residents with repeated admissions, i.e. - those who have been readmitted to the hospital within 30 days of a hospital transfer. This is done through Extended Transition Support (ETS). The PCRN identifies residents eligible for

ETS through reports generated in the project database. Once identified, the medical record is reviewed to help determine whether unmet symptom management needs contributed to the multiple transfer events. If symptoms are contributors, the PCRN will (a) identify physical or emotional unmet needs; (b) collaborate with the project NP and RN to see if the resident might benefit from a palliative consult; (c) provide education to families and facility staff; (d) assist with ACP and goals of care discussions as needed.

Direct Palliative Care Consultation. Another PCRN activity is to provide palliative care consultation services for residents who are referred by facility providers and staff and OPTIMISTIC staff. Generally, the referral is for a specific purpose, such as symptom management, resident or family education and support, or advance care planning. Depending on the purpose of the consult, she reviews the medical history and gathers pertinent demographic and social information including existing ACP discussion and/or documentation. She also performs a complete physical, psychosocial and spiritual assessment in accordance with National Consensus Project Guidelines.[29] When needs are identified, the PCRN works with the facility's interdisciplinary team to address these needs using a holistic approach. Residents who are referred for PCRN palliative care consultation may receive one or more visits, depending on the complexity of the situation and need for follow-up and reevaluation. Palliative care consultation visits are discontinued when the resident's and family's needs are met, the resident dies, or if the resident enrolls in hospice. (Note: Per CMS guidelines for Phase II, hospice admission results in discharge from OPTIMISTIC). The following case exemplifies a typical palliative care consultation.

Case 3

Mrs. H was an 87-year-old resident with end-stage Alzheimer's disease. She was experiencing weight loss, a decline in functioning, and increased agitation. The nursing facility staff found it

increasingly difficult to provide care to Mrs. H due to her frequent screaming and challenging behaviors. A POST form was in place indicating: do not resuscitate (DNR), comfort care, antibiotics consistent with treatment goals, and no artificial nutrition. Two adult sons were involved in the care of the resident and they were supportive of keeping their mother comfortable. The OPTIMISTIC RN requested a palliative care consult to assess for symptom management needs and to help staff manage the resident's challenging behaviors. The PCRN observed the resident and soon discovered the resident did not do well in overly stimulating, noisy environments such as the activity and dining rooms. The resident would scream, fidget, thrash around, and did not respond to staff's attempts to redirect or assist with activities of daily living (ADLs). The PCRN sat with the resident in her own room with no distractions, speaking calmly and trying different approaches to caring for persons with dementia-related behaviors. The resident initially allowed assistance with ADLs, and shortly thereafter she was cooperative with physical assessments. The PCRN also identified that the resident had neuropathic pain and osteoarthritis, and she met with the provider to discuss treatment options. Scheduled and as needed pain meds were ordered to manage pain. The PCRN provided nursing facility staff education on techniques to manage challenging behaviors and symptoms using nondrug strategies. Pain was well managed, behaviors improved, and the resident became more interactive for several weeks before contracting a serious respiratory infection. The family elected to not enroll in hospice but to continue with palliative care support. The provider and the PCRN reviewed OPTIMISTIC's "Comfort Care Order Guidelines" and the provider wrote additional orders to manage symptoms (See Figure 1). These guidelines were developed after a review of the literature and with extensive feedback from the OPTIMISTIC palliative care core. At this time, morphine for labored breathing and lorazepam for anxiety were initiated. Staff checked on the resident frequently to reposition her for comfort and provide oral care and personal hygiene. A chaplain provided spiritual support. The resident died a couple of days later and the family was present during her final hours.

Family Support. The PCRN also provides support to residents' families to augment the care already provided by nursing facility staff. When working with residents who are imminently dying, the PCRN meets with family members to explain end-of-life signs and symptoms and strategies for managing them. Families who want to participate in the care of the resident are encouraged to do so with staff training and support as needed. When working with residents who have dementia, the PCRN contacts the surrogate decision-maker after assessing the resident to relay any pertinent findings, significant changes in condition, and pharmacological or non-pharmacological interventions that will be implemented. The PCRN also contacts families she has worked with to share a heartwarming or funny story about the resident, and sometimes to let the family know that the resident is stable, comfortable, and having a good day. Several family

members have commented that these calls are appreciated and extra palliative care support is reassuring in the midst of a difficult situation.

Staff Education. The PCRN also educates staff in participating nursing facilities, an activity that both provides new information and skills and helps build relationships. Previous trainings included ACP, end-of-life care, hospice versus palliative care, and the benefits of palliative care throughout the continuum of chronic illnesses. The PCRN also supports quality initiatives to enhance palliative care delivery. For example, one nursing facility designed a specific unit to care for residents at the end of life, and the PCRN provided training to both licensed nurses and certified nursing assistants on topics related to care of the dying. In addition to group in-services, the PCRN offers one-on-one education and mentorship to staff who show a particular interest in palliative or end-of-life care. For example, staff nurses have asked the PCRN for help in identifying non-verbal signs of pain, administering opioids safely, and recognizing when a resident is actively dying. Some staff have expressed that they want to "do more" for residents and their families at the end of life, but have minimal experience or confidence in this area. The PCRN is able to take time and mentor staff members who desire to increase their knowledge and skill levels.

In addition to teaching and mentoring facility staff, the PCRN educates OPTIMISTIC RNs and NPs using a "train the trainer" approach focused on sharing palliative care best practices. The OPTIMISTIC RNs and NPs are then able to teach and demonstrate these practices to nursing facility staff. The PCRN develops and maintains palliative educational resources for the clinical staff, and these materials are shared with nursing facility staff, residents, and families as appropriate. She also writes a "monthly focus" newsletter highlighting specific palliative care topics, such as defibrillator deactivation, transfusions at the end of life,

nutritional needs at end of life withdrawal of dialysis, as well as grief and bereavement. The PCRN also responds to and provides educational materials and training on specific requests from OPTIMISTIC staff. As a certified Respecting Choices Advanced Steps Instructor, the PCRN also supports newly certified OPTIMISTIC staff and leads annual RC recertification trainings for all OPTIMISTIC NPs and RNs.

Finally, the OPTIMISTIC project has been involved in promoting National Healthcare Decisions Day (NHDD) [30] under the leadership of the PCRN. NHDD highlights the importance of appointing a healthcare representative, making advance healthcare decisions, and providing education and tools for making these decisions. For this initiative, the PCRN and her team put together an NHDD Toolkit of resources for each OPTIMISTIC RN. Each RN displays these resources in the nursing facility lobby during the week of NHDD and is available to answer questions and provide assistance to residents and families. Feedback from this initiative has proven its value and interest grows each year.

Discussion

The OPTIMISTIC PCRN role was developed in the context of a federally funded demonstration project. The goals of the role are to enhance resident care through direct care and increased capacity to care for residents in place within partner facilities. Consults are received via embedded RNs in each facility, as well as generated through triggers including new orders for "comfort measures," transfers to the hospital in the context of orders for "comfort measures," and any long stay resident with repeated hospital transfers. In this project, the PCRN was able to cover multiple facilities due to having embedded RNs with primary palliative care training. Although some of ways in which this role was operationalized is context dependent, all of the

interventions described have the potential to be adapted and implemented in other settings where care is provided to seriously ill patients.

Based on our experience, we recommend that a job description for the role include: 1) at least 5 years' clinical experience in a nursing facility setting; 2) Training in hospice/palliative care; 3) certification in a standardized approach to ACP such as Respecting Choices,[20] Serious Illness Conversation Guide,[31,32] Veterans' Health Administration Goals of Care Communication Training[33]; 4) demonstrated teaching and mentoring skills[23,26] and 5) strong communication skills to navigate complex interpersonal dynamics. Additionally, the PCRN requires support from organizational leadership. This support should ideally include protected time for PCRN activities, policy and procedure development, and the availability of a clinician with expertise to support symptom management and medication changes.

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