Advances in Nursing Science
Vol. 34, No. 4, pp. E23–E36

Delivering Specialized Palliative Care in the Community

A New Role for Nurse Practitioners

Lynn M. Deitrick, PhD, RN; Elke H. Rockwell, PhD, MSS; Nancy Gratz, MPA; Carolyn Davidson, PhD, RN, CRNP; Lou Lukas, MD; Donna Stevens, BS; Gretchen Fitzgerald, CRNP; Michele Naugle, CRNP; Jacaline Wolf, CRNP; Barbara Sikora, LPN

The rising population of older Americans with advanced illness challenges current care delivery models. We use the metaphor of advanced illness as a difficult journey and propose a specific role, that of the "OACIS NP [nurse practitioner]," who helps provide a place of refuge during this journey. "OACIS" is an acronym for Optimizing Advanced Complex Illness Support, a program to provide home-based palliative medical care. The 4 pillars of this collaborative model for advanced nursing care include care coordination, medical management, psychosocial support, and education. We make the case for this expanded role for nurse practitioners who specialize in palliative care. **Key words:** *advanced practice nurse*, *chronic illness*, *palliative care*

WITH the aging of the US population, the number of seriously ill patients with complex chronic conditions is expected to rise.[1,2] A substantial proportion of the seriously chronically ill live at home and receive care from primary care doctors in the community.[3] As these chronically ill patients progress along the illness trajectory, their need for concurrent palliative care increases.[4] The care needs of this population are not well met by the current health services delivery system[5] and this has led to the development of a variety of care models that strive to improve coordination, continuity, access, and quality of care.[6-8]

Early integration of palliative care for these patients has been shown to improve satisfaction with care and reduce the use of acute care services.[9] However, current care management programs for the seriously chronically ill "rarely incorporate standard palliative care assessment and interventions in their role and function."[3] As health care delivery systems are redesigned we need to consider including the provision of advanced illness medical support at home.[10]

House calls will likely become "an important part of how the health care system meets the needs of an aging population."[11] However, as demand for primary medical care increases, the number of physicians choosing primary care has been steadily declining.[12] This makes it all the more essential that

Author Affiliations: *Division of Community Health and Health Studies (Dr Deitrick), OACIS Services (Drs Rockwell and Lukas and Mss Stevens, Fitzgerald, Naugle, Wolf, and Sikora), Department of Family Medicine (Ms Gratz), and Evidence-Based Practice and Clinical Excellence (Dr Davidson), Lehigh Valley Health Network, Allentown, Pennsylvania.*

The authors thank Valley Preferred, a provider-owned, preferred provider organization aligned with Lehigh Valley Health Network, and The Dorothy Rider Pool Health Care Trust for their financial support for parts of this work. They also thank Kathleen Moser for her editing assistance.

The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

Correspondence: *Lynn M. Deitrick, PhD, RN, Division of Community Health and Health Studies, Lehigh Valley Health Network, 1628 W Chew St, PO Box 7017, Allentown, PA 18105 (Lynn.Deitrick@lvhn.org).*

DOI: 10.1097/ANS.0b013e318235834f

nonphysician providers, especially nurse practitioners (NPs), take on an expanded role to fill the growing gap and provide care for this patient population.[13-16] Advanced practice nurses are well suited to play a pivotal role in providing palliative care services to these patients.[17] We explore in this study the role of NP providers in a specialized palliative medicine house call service.

BACKGROUND

Setting

Lehigh Valley Health Network is an academic community hospital and the largest provider of health services in the Lehigh Valley, located in the eastern part of Pennsylvania and serving more than 800 000 people in the Allentown, Bethlehem, and Easton areas. This study focuses on Optimizing Advanced Complex Illness Support (OACIS) NPs, the response of Lehigh Valley Health Network to the care needs of patients with chronic serious illness in the community. Optimizing Advanced Complex Illness Support (OACIS) is a palliative medicine consulting service at Lehigh Valley Health Network with both an inpatient and outpatient component.

The metaphor

Metaphorically, the acronym OACIS symbolizes the term "oasis," a place of refuge on a difficult journey, as in the spring of water in a desert or, more abstractly, as a period of calm in the midst of a difficult situation.

The population

We use the term "advanced complex illness" (ACI) to identify the target patient population with serious, progressive complex illness. The majority of patients on service with OACIS are in the last few years of life, when the burden of chronic illness and health care utilization are highest.

OACIS nurse practitioner

The NP performs a key role in the OACIS care team by providing palliative care services to ACI patients in their homes. House calls by OACIS NPs are particularly beneficial to seriously ill patients who have difficulty leaving their homes for physician appointments. During the initial house call visit, the NP conducts a comprehensive patient assessment. Depending on the severity of the patient's condition and the patient's needs, this initial consultation lasts from 1 to 2 hours. Optimizing Advanced Complex Illness Support NP follow up visits generally occur every 3 weeks to 3 months, averaging 45 minutes with intervening phone calls as necessary. The NP provides ongoing monitoring of the disease process, helps patients manage symptoms, addresses emergent health issues, educates patients and family caregivers about the prognosis, medications and treatment options, engages in advanced care planning, refers patients to available community services, and facilitates family meetings.

Palliative care or palliative medicine

On their Web sites, national organizations, such as the American Academy of Hospice and Palliative Medicine, the Center for the Advancement of Palliative Care, and the Hospice and Palliative Nursing Association show a predominant use of the term "palliative care," though there are some inconsistencies and at times the terms "palliative care" and "palliative medicine" are used interchangeably. The OACIS model is a physician/NP-based medical model and for this reason we have chosen to call it a "palliative medicine service." Using this terminology highlights the role of the NP in medical decision making and management and distinguishes it from nurse-based programs. The OACIS NP provides this medical care and management in conjunction with other palliative care services and in the full context of palliative and nursing philosophies that emphasize the whole person approach.

Preexisting data

Prior to the study of the OACIS NP role described here, several of the authors were

involved in the analysis of data derived from the initial evaluation of the OACIS outpatient service. Pertinent preexisting qualitative data included interviews with 30 staff members from 7 collaborating practices, as well as interviews with 25 family caregivers and written responses from 67 patients to 2 open-ended questions on a satisfaction survey.

As the researchers worked through the analysis of the preexisting data, they began to recognize the uniqueness of the OACIS NP role as a practice model for the provision of care to complex chronically ill patients in the community. These emerging insights prompted a more thorough analysis of the OACIS NP role, the subject of this article.

In this study, the role of the OACIS NP is examined from the perspective of the NPs themselves, other program staff, and of collaborating primary care practices, patients, and family caregivers. We also reflect on the implications of this service model for an expanded role for NP providers in such a comparatively new specialty area and the potential contributions such a service could make to improve health services delivery for patients with serious complex illness in the community. A more detailed description of the operational features of the service, economic impact, and related health resource utilization outcomes will be the subject of manuscripts currently under development.

METHODS

A Grounded Theory approach was used as the theoretical and analysis framework for this study. In Grounded Theory, the investigators do not approach the study with preconceived notions about what they will find. In this approach, data are examined and lead the researchers to their conclusions and resulting theory or model.[18-21] Because the purpose of the study was to understand and create a model of the OACIS NP role, the application of Grounded Theory as both the theoretical and methodological framework was appropriate.[18-21]

The leader of the OACIS NP study is a doctoral level nurse-anthropologist with expertise in qualitative research and evaluation in the health care setting. She provided research oversight for the study and trained the team members in interviewing, use of NVivo 7 software, and qualitative data analysis.[22] This study was reviewed and approved by our hospital's institutional review board.

Review of preexisting data

The first step was to review the preexisting OACIS evaluation data described earlier. Data from these sources were examined through a limited number of computer-based word searches for information that might provide preliminary insights into the NP role.

Information about the role of the NP extracted from this preexisting data was used to develop initial insights into the NP role and the components of that role. Information from these sources also provided information about topics that should be explored in new interviews with the OACIS NPs.

OACIS NP interviews

The next step in our study was to develop and conduct semistructured, depth interviews with all 6 of the OACIS staff including all 3 OACIS NPs, and the 3 OACIS program staff including the medical director, the program director and the clinical coordinator of the OACIS palliative medicine outpatient service. No one was excluded from the depth interviews.

Ten interview questions addressed topics including description of the NP role, specific functions of the NP during the home visits, changes in the role over time, thoughts about the impact of the NP on the lives of the patients and their families, relationship with different physicians and practices, and differences in the NP relationship with primary care versus specialty practice physicians, and

other topics. Interviews were conducted in person by members of the study team and recorded digitally, then transcribed, deidentified and placed in a limited access file on the project computer.

Data analysis

NVivo 7 software was used to help with the organization and analysis of the study data.[22] A Grounded Theory approach with open, axial coding was used for analysis of the 6 OACIS NP and staff interviews.[19,20] The analysis and model building process was conducted as follows: After the 6 OACIS staff interviews were completed and transcribed, the study team members individually read each interview transcript, identified themes, and assigned themes to transcript passages, using an open-coding approach. The study team then met to reach consensus on the themes assigned to specific interview passages and agreed upon a preliminary list of themes and representative passages for each theme.

A second, axial level of coding of the 6 OACIS interviews took place and resulted in linkages of ideas and themes and led to the development of the "pillars" of the NP role. A preliminary model of the NP role was developed, and specific NP tasks were identified and assigned to each section or pillar of the model.

After the 4 "pillars" and their constituent elements were derived from the detailed analysis of the 6 interviews with the OACIS NP's and other OACIS staff, the findings were then corroborated by comparing the interview results with results obtained from the analysis of qualitative data from the larger preexisting OACIS program evaluation described earlier.

Once these analyses and data corroboration were completed and our pillar model, role table, and figures were drafted, we did a final member-check of our results with the OACIS NPs and program staff to ensure the accuracy of our model and the NP tasks assigned to each pillar. The end product of the analysis was the development of the OACIS NP model described in the next section of this study.

RESULTS

From the analysis of the interviews, 4 components, or pillars, emerged as constituent elements of the OACIS NP (NP) role (the Table). The pillars are (1) care management and coordination, (2) medical management, (3) psychosocial support of patient and family, and (4) education. These serve as an organizational framework for the diverse activities of the OACIS NP, contributing discrete yet often interdependent care functions that are employed in providing support to community-dwelling patients and their families.

The first pillar: Care management and coordination

Looking at the big picture

Care management and coordination are essential tools in achieving the best possible quality of life.[17] Determining what quality of life means in each individual case, requires the NP to "listen underneath" what the patient is saying, to "read between the lines" and take into consideration the manifold medical, psychosocial, and spiritual factors that comprise the overall patient situation. As one of the NP's observes, "The biggest thing is really stepping back and looking at the big picture. I really think that is one of the biggest things we do." This whole-person approach is the foundation on which to build realistic and patient-centered goals of care and treatment plans congruent with the patient's values and wishes.

To assemble the overall picture of the patient situation, including the goals of care, the NP establishes a trusting relationship with the patient and his or her family. During recurring, extensive house calls, the NP then can form an understanding of the patient's true concerns and priorities. One of the OACIS program staff describes this process as follows:

> At home they [the NP's] can get an accurate view of what the patient's med lists are, how the patient feels about what is happening, how they

Table. Four Pillars of the Nurse Practitioners Role

Pillar 1: Care Management and Coordination	Pillar 2: Medical Management	Pillar 3: Psychosocial Support	Pillar 4: Education
Linkages	Assess and treat	Listen to patient	Work with patient to develop goals of care
Communication	Patient comfort	Advocate for patient wishes	Explain illness, trajectory, and options
Connections—patient, family, physician	Prescribe medications	Presence	Determine patient priorities
Goals of care	Diagnostics, laboratory tests	Relationship with patient, family, physician	Teach self-management skills
House calls	Order medical equipment	Counsel	Educate family about disease process
Coordination of care	Bill for home visits	Patient story—sense making	
Flexibility		Spend extended time with patient	
Team approach—nurse practitioner, physician, specialists, patient		Trust	
Coordination of resources		Guidance	
Collaboration with physician(s)			
Look at "big picture"			
Patient-centered care			

interact with their family members, what kind of supports really are there versus perceived supports, what kind of need areas really exist—I don't think you can get that unless you are in the home.

The value of looking at the big picture by the OACIS NP is recognized by collaborating primary care providers as exemplified in the following statement:

I'm here in an office situation and seeing people periodically in an office for a fixed amount of time, not being able to see them in their home environment, interactions that they have with their family members, the support structure that they have at home, those types of things.

Synthesizing fragmented care

Advanced complex illness patients face multiple challenges. They often see several physicians and receive services from a number of agencies. Treatment regimens can be complex and overwhelming and treatment recommendations may be poorly understood and sometimes contradictory. At this stage in the illness trajectory, many people become part of the treatment scenario and their efforts are often poorly coordinated. As one OACIS program staff observes:

We have lots of entities. We have patients and their families; a variety of doctors. But there is very little relationship between them in most cases. . . .

Normally entropy takes over—everybody is off doing their own little thing.

This statement describes the fragmentation of care many ACI patients experience. In this situation, the OACIS NP acts as the lens that focuses the care process on the patient. The NP becomes the person who tells "the patient story so others understand how whatever is going on in the patient's life is affecting them completely." The OACIS NP is instrumental in gathering everyone involved in the patient's care together into a team with one shared purpose, patient-centered, quality care. Some patients are aware of this aspect of the role as evidenced by one patient who found the NP helpful by "having her [NP] pull all the 'pieces of the puzzle' together regarding my illness." An OACIS program staff respondent summarizes the care coordination role of the NP as follows:

It is reconciling a lot of the different treatments and medicines . . . whether they [patients] really want them, whether they [medicines] are really working and whether the physicians know about everything. It's the coordination of all the physicians and providers involved with the patient. It's helping the patient navigate the health care system easier, as well as supporting the family.

Translational role

Assembling the "big picture" and creating these linkages requires not only time, assessment skills, and perceptiveness to fully appreciate the patient's situation, but also the advanced nursing and medical knowledge and mindset to transmit the insights gained from the house calls to the physicians in such a way that they can become integrated into the treatment plan. One OACIS staff respondent describes this facet of the OACIS NP role as the "translational role" and emphasizes the need for the level of professional knowledge and preparation the NP possesses as a prerequisite for functioning competently and effectively in this role. She says:

I don't think you could send a lay person out or a less-educated person/person of a lower-level license to do this because you have to be able to talk to the doctors . . . . They [NP's] really need to engage in those conversations about, 'Why do you want to treat their hypertension in that way?' and have a credible conversation. Being able to translate the patient saying, 'I can't take all these pills,' to working with the doctor and saying, 'Which of these pills can we not take?' That's a pretty important role.

"Translational" in this quotation refers to the NP's ability to discern the embedded meaning in a patient's story and to transmit it in such a manner that it allows the physician to choose a course of action in accordance with patient need and preferences.

Fostering relationships

As the OACIS NP spends time creating relationships with patients and families, she also builds relationships with the practices of referring physicians. This, too, is a process that takes time and commitment. It grows in viability and productivity through collaboratively caring for this population and results in shared learning. The interviews revealed that depending on any given physician's degree of familiarity with the OACIS service, the particular practice style and/or the attitude toward palliative care of primary care providers or specialists, there are many variations in the interaction patterns between the OACIS NP and referring physicians. The range of variation is apparent in the following statement by one of our OACIS staff members:

In some practices, we have been a respected, trusted colleague. In other practices, everything has to be checked through the physician, still, just by virtue of their practice style. It's dependent upon what type of relationship the practices want with us. We are open to whatever that is. Any way you go it really is a benefit to the patient and the practice.

The greatest level of teamwork and synergy is achieved in highly collaborative and reciprocal relationships where the OACIS NP becomes an extension of the practice, a virtual member of the primary care or specialist physician's office team. A physician, commenting on the challenges primary care

practices face in providing optimal care for the ACI patient, identified "lack [of] time and resources" as the key factors and went on to say that comanaging patients with the OACIS NP has allowed the practice to "more clearly understand the concept of team and how we can function in a team concept beyond our practice." One of the NP's illustrates truly collaborative interaction with the example of a busy primary care practice that cares for many elderly patients:

> She is a physician who meets with one of my coworkers and myself every six weeks. She pulls us in at 7 AM and we go over a list of six to ten patients that I am caring for. It is very insightful and educational. It helps to build a relationship. That is the ideal situation. She is the type of physician if you call the office, the office staff knows that we are OACIS nurses and she comes out of a patient's room to talk to us. That is the respect we get. That's the best scenario.

The most important feature in the relationship described earlier is the degree of reciprocity, the recognition that each has a unique perspective to contribute which, when thoughtfully joined together, will result in improved and effective patient care. Some providers have even commented that the collaboration with the OACIS NP has an effect on the nature and quality of their office visits with complexly ill patients. As one of them said, "It actually makes for . . . a better exchange in the office visit 'cause you don't feel completely overpowered by all the concerns and questions, and some of these are being dealt with on a more timely basis." The quotation illustrates the value of the OACIS NP in the overall management of the patient's care.

Collaboration and team building

Finally, the care management and coordination activities of the OACIS NPs involve the prompt linkage of patients and families with community resources, such as the local Area Agency on Aging, private duty nursing, mental health services, food banks, or transportation services provided by members of a local time bank.[18] This work is done in collaboration with the office-based clinical coordinator of the program and reflects the view expressed by one of the OACIS staff members that "the only way to take care of a complex patient successfully is by a team approach." The OACIS NPs are not just members of the team; but rather, they are the facilitators who create the conditions that allow for synergies. During the interviews, the metaphor "glue" was used repeatedly to describe this aspect of the OACIS NP role. One of the OACIS staff members remarked: "From the outpatient perspective, it [the role of the NP] really is the glue holding the structure up that is supporting the patient." The distinguishing feature of this team is an NP with a strong nurse-based coordinating function, who brings to bear substantial medical knowledge and well-developed palliative care skills and makes them accessible to seriously ill patients and their families in their homes, while working in close alignment and cooperation with the referring primary or specialist physicians.

The second pillar: Medical management

Palliative expertise

Medical management is the second pillar of our OACIS NP model. Medical management begins with the NP conducting a comprehensive assessment of the patient, including palliative needs, during the first house call and continues with recurring visits to the home to monitor the patient's health status and symptom burden. During this same visit the NP provides encouragement and supports conversations about goals of care with the patient and their family. These follow-up visits provide the ability to keep symptoms under control while also allowing for timely intervention by the NP in the event of emerging health issues and exacerbations, possibly avoiding hospitalization. Moreover, involved physicians are alerted to any significant changes in the patient's health status that may require further medical assessment and intervention.

Transition to hospice

A fundamental goal of the OACIS NP is to provide care consistent with patient wishes. As the patient's illness progresses, the OACIS

NP guides the patient and family through difficult health care decisions and communicates patient preferences to all involved providers. The OACIS NP provides education about hospice and, when appropriate, helps to ensure a smooth transition to hospice care. Once transfer to hospice is complete, the OACIS NP no longer is involved in the care of the patient.

Medical decision making

Recognizing the medical management support provided by the OACIS NP's, a member of one of the collaborating primary care practices commented, "She [NP] has a pretty good rapport with some of our sicker patients. She sees them pretty often. And so when they start getting just a little bit off, we're aware." Although the OACIS NP will work in collaboration with the patient's physicians whenever possible and to the maximum level as authorized by the state NP licensing board, as an advanced practice clinician, she has the authority to initiate treatments, prescribe medications, order diagnostic tests and durable medical equipment, and bill for services.

When asked what differentiates the NP from an RN, one of the OACIS program staff respondents explained:

> . . . it is mostly the cognitive piece of looking at the problem differently. It is looking at the problem and having to solve it, rather than looking at the problem and giving it to somebody else and expecting something back.

Although the OACIS NPs often share their observations and clinical decision-making processes with involved physicians and solicit their opinions, they do so to promote synergies that augment care at the primary care provider level, not because they need the physicians to be the decision makers. The OACIS NP brings to bear substantial medical knowledge and specialist training in palliative care in her consulting role with primary care and specialist physicians. In addition, she has full command of the particular skill set and knowledge base that come with a nursing background.

Symptom management

The potential benefits that can arise from the combination of the OACIS nurse practitioner's skill set and practice setting in the home may be illustrated in the case of patient symptom management. The NP's ability to spend time listening to the patients, as well as including family members perspectives about the patient's condition can lead to a better understanding of the significance of a particular symptom the patient might be experiencing. Together with this deeper understanding of the patient's concerns and response patterns, the NP has the expertise to review treatment plans, including medication lists, and can make recommendations to the physician regarding changes to the regimen that may result in better adherence to a treatment protocol and improved patient outcomes.

Physician-office–based health care workers are often frustrated by the time constraints that impact their patient encounters. As one primary care provider said, "You wish you could spend an hour and a half or 2 hours with people and their families, going through every facet of everything, and you can't." To help with this frustration that is also shared by patients, the OACIS NP sometimes serves as the patient's health communication coach. For example, to help patients get maximum benefit from a physician office visit, the NP may focus part of her home visit time on coaching the patient in asking the right questions of the physician. A comment by one of our NPs illustrates this point:

> Working with the specialist, who of course is the real expert in an area, sometimes it's me giving the patient the right tools or right questions to ask their specialist, so they are able to understand what is going to be best for them.

This role of coach spans several of the pillars of our NP model, including care coordination, medical management, and education.

Population specialist

Finally, the OACIS NPs possess not only generalist medical knowledge, but also, as Hospice and Palliative Nurses Association

certified professionals, specialist knowledge in palliative medicine, which is made available in the ambulatory primary care setting. In addition, they have extensive knowledge and understanding of the ACI patient. As one of the OACIS staff members put it, they are "population specialists" and, as such, an important resource for the primary care practice team for whom this type of patient constitutes only a small fraction of the entire patient panel, yet requires a comparatively large amount of time and effort.

The third pillar: Psychosocial support

Building trust

Every one of the OACIS NPs emphasized the importance of the psychosocial support they provide to their patients and families. Meeting the patients "on their turf" and not being distracted by competing responsibilities and tight timeliness creates the environment in which a trusting relationship can develop that will allow the patient and/or family caregiver to open up and tell about what life is really like in this difficult illness situation. The support involves listening and truly hearing what the patient is communicating. As one of the OACIS program staff respondents describes it, they "validate the realness of what they [patients/families] are going through. So often, families aren't heard. They [patients] really appreciate somebody listening to their circumstances and seeing it in a different light than usual. Taking the time to listen." This view is shared by one of the family caregivers who said:

> She [NP] is very calming and very thorough and is not in a rush, like she will sit there and talk to you and give you some time to collect your thoughts. . . . She's very patient and listens, and as we sit and talk, then the questions might come up.

From this basis of trust and understanding, the OACIS NP becomes the advocate and guide for her patient and their family. When one NP was asked about her role, she explained that it is to "assist and help patients and families transition to end of life care or hospice care as gently as possible; to honor patients' wishes and be a patient advocate." An important component of this advocacy role is the ability to be flexible and to possess the self-awareness to be able to clearly distinguish between the wishes of a patient and one's own personal preferences, or, in the words of the NP, "to sometimes leave your beliefs at the door." Although the OACIS NP educates and guides, it is the patient who ultimately chooses the path to be followed.

Providing guidance and support and assisting patients and families in finding ways to make sense of the experience they are going through requires a significant amount of time and energy from the OACIS NP. One NP estimates that she spends about 80% of the time on emotional/psychological issues related to how the illness affects the patient and family. Achieving a sense of calmness and reduced anxiety in the patient/family provides her [NP] with a sense of accomplishment.

Improving quality of life through patient empowerment

The OACIS NP offers counseling on how best to manage the effects of the illness and how to lessen its impact on daily life to the extent possible so the patient can regain some sense of control that has been eroded by the illness. These small victories do not change the basic course of the disease process, but they contribute meaningfully to a patient's sense of well-being. One of the NPs explains this as follows:

> They are going to harp on things they want control over. Their eating, bowels, sleep. These things just irritate them. They are small, but if they can get control of them, that makes them so happy because they can't control COPD. They can't control their congestive heart failure (CHF); it controls them.

By paying attention to these seemingly "small" issues that are often ignored in the broader focus on fighting cancer or getting CHF under control, the OACIS NP can significantly impact the patient's quality of life and reduce discomfort and distress. If anxiety and

depression are at a level that warrants mental health counseling, the NP will connect the patient or caregiver with appropriate resources in the community.

The fourth pillar: Education

Health guide

As mentioned earlier, the 4 pillars comprising the OACIS NP role are interrelated and frequently operate simultaneously. This is especially true in the case of the education component. Whether the NP coordinates a patient's care, is involved in medical management, or provides psychosocial support or education of the patient and family is often an integral part of these processes. However, patient and family education is important enough within the scope of the role of the OACIS NP to merit a separate pillar in our model.

At the most generalized level, the educational role of the OACIS NP may best be captured by the metaphor of the "guide" which most of the OACIS team members used at some point during the interview. As one of the NPs observed, "I see us as a guide, trying to help them [patients/families] get through the health care system." Patients often need immediate and practical assistance with navigating the complexities of the health care system as they grapple with a myriad of issues such as: Who should they see first? Where do they need to go? What will they need to do? Will insurance cover it? The OACIS NPs, in collaboration with the clinical coordinator for the program, address these questions by providing information and connecting patients and families to needed resources.

In addition, ACI often raises difficult questions that require informed and sensitive anticipatory guidance and substantial medical knowledge. The NP provides needed information and thoughtful education that touches more deeply on personal values, difficult trade-offs and choices in deciding on treatment options and goals of care, often unspoken fears about pain and other types of suffering, as well as concerns about independence and the safety and well-being of patient and family members that may begin with helping the patient and family recognize where they are along the illness journey. When the NPs first encounter their patients, many of them do not understand where they are along the illness trajectory. One of the NP respondents explained this by saying:

> That is probably the biggest challenge—to help them understand what is available, where they are . . . .

The NP assists with understanding treatment options and their likely consequences, as well as medications and their benefits and possible side effects.

Patients and family caregivers acknowledge the need for and appreciate the health education the NPs provide. One of the patients identified "information related to my illness" as helpful, while another one said, "I appreciate they [NP] talk with you and explain things very well." This information and education about the illness, its likely trajectory and its impact on quality of life empowers patients to engage in goals of care conversations, rather than leave them overwhelmed by a host of poorly understood options. One NP observed, "I think a lot of times they [patients] are given this full buffet of options but no one goes through them individually. What does that really mean? I think that is our responsibility—to an extent." The quotation reflects a multidimensional understanding of education that is not limited to providing information, but encompasses helping the patient to situate this information in his or her individual life context and assimilate it into a personal sense-making process.

DISCUSSION

Figure 1 depicts the OACIS program and the OACIS NP within the broader context of the health care system. This systems model shows an interrelated structure with dotted-line connectivity among key agents, all of which are targeted to improve patient and family care within the home. Figure 2 depicts the interconnectedness of the 4 pillars of the

Figure 1. The OACIS nurse practitioner in the community health care system. OACIS indicates the optimizing advanced, complex illness support.

NP role to each other. It should be noted that the boundaries between each pillar are fluid with some functional overlap between them.

The OACIS NP role

Palliative care with its considerable emphasis on interdisciplinary efforts has been suggested by some as an emerging practice area for NPs because of the broad scope of their practice capabilities. As Shea et al[23] point out,

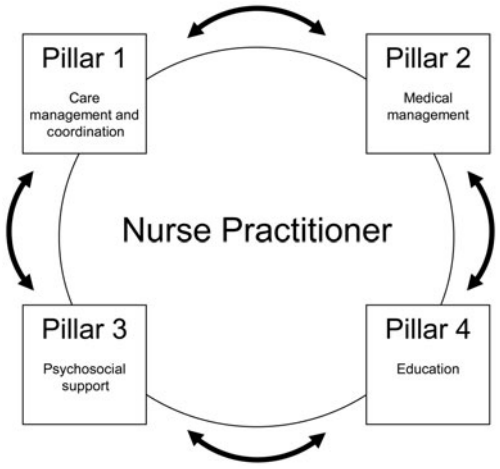

Figure 2. The OACIS nurse practitioner model. OACIS indicates optimizing advanced, complex illness support.

advanced practice nurses (APNs) are uniquely positioned to contribute to the development of quality palliative care for all patients who experience serious chronic illness or terminal illness.[23] Given the evidence that many community-dwelling older adults with serious chronic illness who are not hospice eligible experience inadequately treated pain and nonpain symptoms,[24] skilled palliative care professionals are not only needed in hospital and clinic settings, but also and especially in the community and in patients' homes.

The OACIS NP role entails an expansion of the range of professional activities into the comparatively new field of palliative care and into a new practice setting. APN's have been a presence in hospital-based palliative care programs for some time.[25] There are also increasing numbers of clinic-based palliative care programs, especially in conjunction with ambulatory cancer treatment facilities.[26] The OACIS program, however, creates an opportunity for NPs to provide nonhospice, home-based palliative care services for a population with varying diagnoses and various comorbidities, making these services available earlier on the illness trajectory and improving the issue of access. Locating OACIS service delivery at the level of the NP introduces new opportunities for professional activity, collaboration, and responsibility. Not only does the NP advocate for, educate about, and refer to end of life services, the NP plays a key role in providing these services, thereby showing "how the dying process can be transformed."[27]

The OACIS NP practice model also provides innovative opportunities for collaboration between NPs and primary and specialty care physicians. The OACIS NP allows augmentation of existing medical services in the ambulatory setting and constitutes an external resource that outpatient practices can draw on to help in taking care of a patient population typically representing a small fraction of their entire patient panel, but with intense and varied service needs. The role of the OACIS NP exemplifies one way in which the social capital of a practice[28] can be enhanced for the benefit of patients and practices.

The nurse practitioner has the necessary training, skills, and prescriptive authority to assess, treat, and effectively coordinate and comanage the care of this high-need, complexly ill population. For the generalist, as well as the specialist physician, the NP is a valuable resource and functions as an expert practitioner in the delivery of palliative care. The NP's unique perspective on the patient situation based on home visits, the key role in the care team and the level of professional expertise lend a considerable degree of credibility to the NP's observations and suggestions. This may help to overcome some of the problems that have been encountered with implementing the recommendations of palliative care specialists in the primary care setting.[29]

Given the complexity and scope of the OACIS nurse practitioner's work (the Table and Figure 2), we suggest that this role requires the education and experience of a NP and cannot be optimally fulfilled by a baccalaureate level home health nurse, social worker, or non–nurse advanced practice clinician. Her assessment skills, prescriptive authority, and ability to assemble the entire complex patient situation into a coherent narrative that is communicated to the collaborating physicians to inform treatment planning makes this role fundamentally different from the supporting role of a health coach or patient navigator, as well as the scope of practice and role of a home health nurse. According to O'Grady,[30] "There are no clinicians better prepared than NPs and other advanced practice registered nurses (APRNs) to promote evidence-based practice, lead quality and cost reporting and improvement efforts, and integrate new technologies, all wrapped into highly individualized patient-centered treatment."

From a resource utilization and health systems perspective, we would also argue that NPs are well suited for this role. In light of the anticipated growing demand for quality end of life care and the predicted shortage of primary care physicians,[31] the OACIS NP role provides one example of how this service gap might be addressed. The full utilization of NPs in the provision of specialized palliative care services increases access and quality at a lower cost than a comparable physician service. Our OACIS NP model suggests an innovative approach to celebrating "differences in practice" and exploring "opportunities for collaboration" in the process of building full partnerships between primary care physicians and advanced practice nurses[32] with the goal of improved patient care. The OACIS model provides one example of how the Institute of Medicine's 2010 call for a greater role of nurses in the reform of the health services delivery system could be realized.[33,34]

Furthermore, we suggest this new role of OACIS NPs delivering specialized palliative care in the community through ongoing medical care, care coordination, psychosocial support and education may be useful as an integral component for primary care practice transformation to a patient-centered medical home or accountable care organization. Nurse practitioners and APRNs "could be the lynchpin to help ACOs and medical homes succeed."[30] According to the Agency for Healthcare Research and Quality recommendations regarding The Roles of Patient-Centered Medical Homes and Accountable Care Organizations in Coordinating Patient Care, "care coordination improves the quality, appropriateness, timeliness, and efficiency of clinical decisions and care, thereby improving the quality and efficiency of health care overall."[35] We contend OACIS NPs implement a valuable type of advanced level patient-centered medical home care management, working in collaboration with primary care physicians, and specialists to coordinate in-home patient care for complex patients.

LIMITATIONS

This article focuses on the exploration of the role and function of the OACIS NP. It does not address the operational features of the program and associated financial considerations, nor does it discuss the impact of this program on health resource utilization. Both

topics are discussed in detail in 2 manuscripts currently under development. It should also be noted that we could not observe NPs on the job due to patient privacy and confidentiality concerns.

The OACIS nurse practitioner's practice scope described here reflects Pennsylvania state specific conditions. While it is known that state boards of nursing vary widely in their NP practice acts, NPs are an elemental source in providing primary care in a cost-constrained health care system.

CONCLUSION

This article makes the case for a new and expanded role for NPs who specialize in palliative care. The role of the OACIS NP as illustrated in our model provides an example of utilizing resources more effectively to achieve quality outcomes in a time of health care reform. The OACIS NP model fills a need for targeted home-based specialized palliative care for patients with ACI.

This type of service, provided by skilled NPs, has the potential to transform the way patients with palliative care needs are cared for in the community. Nurse practitioners are well positioned to fulfill this need. We also suggest using the term "OACIS nurse practitioner" to delineate this role, because the term is not only an acronym but also a metaphor for providing comfort along the journey toward the end of life.

REFERENCES

1. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 2nd ed. Pittsburgh, PA: BMJ Publishing Group; 2009:1-80.
2. Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Arch Intern Med*. 2002;162:2269-2276.
3. Meier DE, Thar W, Jordan A, Goldhirsch SL, Siu A, Morrison RS. Integrating case management and palliative care. *J Pall Med*. 2004;7(1):119-134.
4. Lynn J, Adamson DM. Living well at the end of life: adapting health care to serious chronic illness in old age. In: *RAND White Paper*. Santa Monica, CA: RAND. 2003:1-19.
5. Bodenheimer T. Coordinating care—a perilous journey through the health care system. *N Engl J Med*. 2002;358(10):1064-1071.
6. Brown KE, Levine JM, Fielin DA, O'Connor P, Sledge WH. Primary intensive care: pilot study of a primary care based intervention for high utilizing patients. *Dis Manag*. 2005;8(3):169-177.
7. Boult C, Wieland GD. Comprehensive primary care for older patients with multiple chronic conditions. *JAMA*. 2010;403(7):1936-1943.
8. Naylor MD, Brooten CA, Campell RL, Maislin G, McCauley KM, Schwartz JS. Transitional care for older adults hospitalized with heart failure: a randomized controlled trial. *J Am Geriatr Soc*. 2004;52:675-684.
9. Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life care. *J Pall Med*. 2003;6(5):715-724.
10. Buhler-Wilkerson K. Care of the Chronically ill at home: an unresolved dilemma in health policy for the United States. *Milb Q*. 2007;85(4):611-639.
11. Landers SH, Gunn PW, Stange KC. An emerging model of primary care for older adults: the house call-home care practice. *Care Manag J*. 2009;10(3):110-114.
12. Steinbrook R. Easing the shortage in adult primary care—Is it all about money? *The New Eng J Med*. 2009;360(26):2696-2699.
13. HPNA position paper—value of advanced practice nurse in palliative care. *J Hospice Palliative Nurs*. 2007;9(2):72-73.
14. Quaglietti S, Blum L, Ellis V. The role of the adult nurse practitioner in palliative care. *J Hospice Pall Nurs*. 2004;6(4):209-214.
15. Davidson PM, DeGeest S, Hill MN. Nurses addressing the challenges of chronic illness: from primary to palliative care. *Collegian*. 2010;17(2):43-45.
16. Kuehn BM. IOM: boost nurses' role in health care. *JAMA*. 2010;304(21):2345-2346.
17. Kuebler KK. The palliative care advanced practice nurse. *J Pall Med*. 2003;6(5):707-714.
18. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2nd ed. Thousand Oaks, CA: Sage; 2007.
19. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res*. 2007;17(10):1372-1380.
20. Strauss A, Corbin J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*.

2nd ed. Newbury Park, CA: Sage Publications; 1998.
21. Glaser B, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Press; 1967.
22. QSR International NVivo 7 [computer software]. Doncaster, Australia: QSR International; 2001.
23. Shea J, Grossman S, Wallace M, Lange J. Assessment of advanced practice palliative care nursing competencies in nurse practitioner students: implications for the integration of ELNEC curricular modules. *J Nurs Educ*. 2010;49(4):183-189.
24. Goldstein NE, Morrison RS. The intersection between geriatrics and palliative care: a call for a new research agenda. *J Am Geriatr Soc*. 2005;53(9):1593-1598.
25. Meier DE, Beresford L. Advanced practice nurses in palliative care: a pivotal role and perspective. *J Pall Med*. 2006;9(3):624-627.
26. Dalal S, Palla S, Hui D, et al. Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *The Oncologist*. 2011;16:105-111.
27. Ferrell B. On dying in America. Lecture presented at the Second Annual School of Nursing Lecture. Fairfield, CT: Fairfield University; 2006, as cited in Shea, Grossman, Wallace et al. (2010).
28. DiCicco-Bloom B, Frederickson K, O'Malley D, et al. Developing a model of social capital: Relationships in primary care. *Adv Nurs Sci*. 2007;30(3):E13-E24.
29. Rabow MW, Petersen J, Schanche K, Dibble SL, McPhee SJ. The comprehensive care team: a description of a controlled trial of care at the beginning of the end of life. *J Palliative Med*. 2003;6(3):489-499.
30. O'Grady ET. APRNs boldly form medical homes. *Nurse Pract World News*. 2011;16(5/6):8-9.
31. Colwill JM, Cultice JM, Kruse RL. Will generalist physician supply meet demands of an increasing and aging population? *Health Aff*. 2008;27(3):w232-w241.
32. Sussman J. It's time to collaborate—not compete—with NPs. *J Fam Pract*. 2010;59(12):672.
33. Kuehn BM. IOM: boost nurses' role in health care. *JAMA*. 2010;304(21):2345-2346.
34. Institute of Medicine of the National Academies. The Future of Nursing: Leading Change and Advancing Health. Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing, at the Institute of Medicine. Washington, DC: The National Academy Press; 2010.
35. Meyers D, Peikes D, Genevro J, et al. *The Roles of Patient-Centered Medical Homes and Accountable Care Organizations in Coordinating Patient Care*. AHRQ Publication No. 11-M005-EF. Rockville, MD: Agency for Healthcare Research and Quality; 2010.