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REVIEW ARTICLES

Providing care and sharing expertise: Reflections of nurse-specialists in palliative home care

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ABSTRACT

Objective: This study explored the experiences, perspectives, and reflections of five nurse-specialists in palliative home care, whose dual role includes caring for patients in their daily practice as well as sharing their knowledge, skills, expertise, and experiences with other home care nurses in the community.

Methods: A qualitative research design, incorporating face-to-face semistructured interviews, was used. Interviews were based on open-ended questions such as: "What is your experience in providing palliative home care to patients and their families? How do you feel about sharing your expertise and experiences with home care nurses?" Data were content analyzed using the constant comparative method.

Results: Three major themes and a number of subthemes emerged: (1) acknowledging one's own limitations and humanness: (a) calling for backup, (b) learning as we go along, (c) coping with emotional demands, and (d) interacting with family members; (2) building a collaborative partnership: (a) working collaboratively, (b) sharing information, (c) guiding home care nurses, and (d) being nonjudgmental; and (3) teamwork and implementing palliative home care teams.

Significance of results: Nurse-specialists play a key role in palliative home care as both carers and as resources of expert knowledge for other home care nurses caring for palliative patients. As the population ages, the health care system will be faced with increasing requests for high-quality palliative home care. The results of this study demonstrate that, from the perspective of the nurse-specialists of NOVA-Montréal (a nonprofit social and health service organization), nurse-specialists can work collaboratively with home care nurses to improve patients' quality of care and their quality of life. Moreover, patients and their families would benefit from the more widespread establishment of palliative care teams within community health organizations.

KEYWORDS: Palliative care, Home care nurse, Nurse-specialist, Collaborative partnership

INTRODUCTION

With a shift in the Canadian health care system away from institutional care toward home and community care, in conjunction with increased population age and incidence and prevalence of chronic health conditions, the number of patients requesting palliative home care will continue to grow (Jannings & Armitage, 2001; Sharkey et al., 2003). Statistics mask that the majority of terminally ill persons spend most of their last year of life at home being cared for by their families (Meier et al., 2004). Around 90% of patients facing death choose to die at home (Tzuh et al., 2003), but only about 20% achieve this (Ellershaw & Ward, 2003). Home care nurses play a primary role in both organizing and delivering

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continuous, personalized, and holistic care for patients and their families facing life-threatening illness (Storey et al., 2002; Yuen et al., 2003). Appropriate care for these patients requires great competence, experience, expertise, and skills from their home care nurses (Groot et al., 2005). However, these nurses often lack the confidence necessary to provide the support and extensive interventions palliative patients and their families need (Simpson, 2003). Possible explanations may be the low number of palliative patients that home care nurses care for per year (Groot et al., 2005), their increasing caseloads (Simpson, 2003), and insufficient palliative care training in the provision of physical, psychosocial, and spiritual care to dying patients (Bestall et al., 2004).

The development of nurse-specialists, described by Benner (1984) as proficient experts in specific areas of nursing practice, has contributed to the development of nurse-specialists in palliative care. In the 1980s, the Macmillan Nurses in the United Kingdom were pivotal in the development of specialized palliative care services in different settings (Seymour et al., 2002; Skilbeck et al., 2002). Their goals were to pass on good practice guidelines for the control of symptoms such as pain and to facilitate a person's choice to die at home (Corner, 2003). Nurse-specialists in palliative care have two important roles: (1) caring for palliative patients referred to them directly, generally for symptom management and emotional care (Bestall et al., 2004); and (2) providing support for and sharing their expertise and knowledge with other health care providers to help them better care for their dying patients (Aitken, 2006; Husband & Kennedy, 2006).

In Montréal, Québec, nurse-specialists in the delivery of palliative home care are known as NOVA nurses. NOVA-Montréal, established in 1898 and formerly part of the Victoria Order of Nurses Canada, is a community-based health and social service organization, specialized in providing high-quality health care services that meet the physical, psychosocial, and spiritual needs of both the patient and the family. Despite the fact that they have pivotal roles as both care providers for patients and as an expert resource for other nurses caring for palliative patients, research on the experiences of nurse-specialists is lacking. Therefore, this study articulates the insights and reflections of the five nurse-specialists in palliative home care working at NOVA-Montréal who care for patients in their daily practice as well as share their knowledge, skills, and expertise with home care nurses. Gaining an understanding of nurse-specialists' perspective on the services they provide is fundamental for evaluating the effectiveness of this service and for considering whether it may be an appropriate option for other jurisdictions addressing the needs of people dying at home. As the word *expert* is often used differently in different contexts (Maylor, 2005), the nurse-specialists in this study are characterized as "clinical experts" or "experienced practitioners" in the field of palliative care. In this article, "home care nurses" are understood to be nurses working in community health care organizations other than NOVA-Montréal.

METHODS

Participants

All five female nurse-specialists working for NOVA-Montréal participated in this study. To demonstrate that the data presented in this article come from all five participants we reference quotes using the identifiers S1, S2, S3, S4, and S5. Although we use the organization's real name in this study, to maintain the anonymity of the nurses, sociodemographic data are presented as group data. Sociodemographic data were collected prior to the in-person interview. Participants ranged in age from 38 to 60 years and older, and all were highly experienced, having between 18 and 44 years of nursing practice. Four nurses have worked for 8 or more years as a nurse-specialist in palliative care within NOVA-Montréal and one nurse for about 20 months. Two participants have a Bachelor of Sciences in Nursing, one has a Registered Nurse diploma from a teaching hospital, and three hold a College Diploma in Nursing. All nurses attended palliative care workshops or conferences, two nurses followed a course in palliative care, and one a specialized training program.

Design

A qualitative explorative research design was used to collect the data, as it allowed the nurses to share their experiences freely. Data collection took place in January 2007. Ethical approval was obtained from the NOVA-Montréal Board and the University Review Committee. All the semistructured interviews were about 40 min in length and were conducted by the same interviewer at a location of the nurse's choice in either French or English. The data collected in French were translated into English by the authors to appear in this publication. The interview guide consisted of a series of broad open-ended questions, for example, "What is your experience in providing palliative home care to patients and their families? How do you feel about calling one of your nurse-specialist colleagues for advice? How do you feel about sharing your expertise and experiences with home care nurses? Why do you think home care nurses may be reluctant to call a

nurse-specialist? Have you encountered situations where a person who needed specialized palliative nursing care failed to receive it?"

Analysis

All textual data have been content analyzed using the constant comparative method to identify main themes in each interview (Strauss & Corbin, 1990). Themes that repeat themselves have been clustered into categories that represent key content. An audit trail was established to keep track of decisions made during analysis, and, to enhance data credibility, informal member checking with participants was performed.

RESULTS

Three major thematic categories emerged from the nurses' experiences: (1) acknowledging one's own limitations and humanness, (2) building a collaborative partnership, and (3) teamwork and implementing palliative home care teams. These categories were not mutually exclusive and overlapped frequently. The first reflects nurse-specialists' perceptions toward their role as care providers for palliative patients within their own team. The second and third reflect their experience of working with home care nurses.

Acknowledging One's Own Limitations and Humanness

Given the multidimensional needs of palliative patients and their families, it is not surprising that nurse-specialists are often confronted with "complex" cases. Although the complexity of the case may be one reason for referring a patient to a nurse-specialist, the nurses in this study acknowledged that being a nurse-specialist did not mean they had all the answers. Furthermore, being experienced with palliative care did not mean that they were less affected emotionally by the suffering and death of their patients. Four subthemes emerged with regards to their work as carers within NOVA-Montréal: (1) calling for backup, (2) learning as we go along, (3) coping with the emotional demands, and (4) interacting with family members.

Calling for Backup

Despite their extensive experience as palliative care nurses, all commented on the importance of having their colleagues within NOVA, especially certain senior nurses, to back up their decisions regarding patient care management. They were all very appreciative of this type of support. A member of the NOVA team said: "Often I have to call my colleagues—very often. For example, if patients have tried so many different kinds of laxatives and still they were constipated. So before suggesting [a different laxative] to a patient I always would have a backup and make sure I'm giving the right advice [to the patient]. I would call to be sure, to double-check" (S4). Another stated: "And if I spoke to a colleague like [name of nurse], with the experience she has, I would have said to her 'This and this is happening'; then she would tell me 'look, try this to see what it could do, and if it doesn't work call me back!' Well then I become a lot less stressed. . . . For us that is a lot, it allows you to do your job, to make it through: for us, it's our support" (S3).

NOVA nurses' confidence in each others' expertise and experience can be seen by the fact that they will often page the "second nurse on call" during the night or on the weekends before contacting the patient's family or palliative care physician. "I will page the nurse [second nurse on call], 'ah, [name of nurse] I'm really stuck here, I have a medication and I don't know how to dose it—what do you think? It's this and this.' She will answer me. If she doesn't know she will answer 'I don't know [name of nurse].'" "We are alone out in the field . . . but you know I am never all alone; after that I have a doctor I can call if I'm stuck" (S3). Their trust in each other's capabilities is enacted in their sharing of on-call responsibilities: "When I'm on call, I'm on call for all the NOVA nurses and their caseload, not just my own patients, so I'm being called from patients of other nurses who might call at 10 or 11 o'clock at night" (S1).

Learning as We Go Along

If nurses are to be professionally accountable for the care they provide they have a duty to keep up to date with the knowledge base of their profession. NOVA nurses keep themselves informed by attending conferences and workshops on palliative and end-of-life care. However, their skilled knowledge is mainly gained via their day-to-day experiences and personal interactions with patients, families, their team, and other health care providers. One nurse said with regards to her training that for her it was "mostly learning on the job. I applied for the job here and just, kind of, learned as I went" (S1). "We learn how to deal with one person's problem because of what happened to several other people," said another nurse (S2). The view that palliative nursing is a field characterized by ceaseless learning is emphasized in the following nurses' reflections: "I have a number of years of experience and there are always things to learn. So there's a certain body of knowledge that's acquired and there's new things that we learn as we

go along" (S2). Another said: "My work consists of exchanges. I exchange with the health care team, I exchange with my patients too, and I exchange with the families too! You know, it is fun! I'm always learning" (S3). What is noteworthy is how these nurses experience the continuous learning process as a positive aspect of working in palliative home care.

Coping with the Emotional Demands

Dying is a natural part of life and is particularly meaningful to humans. As humans, nurses cannot entirely separate their professional and personal identities when practicing palliative care. In other words, the nurse as a professional cannot be separated from the nurse as a person (Davies & Orbele, 1990). Nurses in this study found the provision of palliative care demanding at times and often very emotional; however, none of them perceived the emotional issues as a source of stress. One nurse expresses it as follows: "Oh, I cry, I cry with patients! I'm not bawling but I'm shedding tears that run and I take them in my arms and then they start to cry. I permit myself to cry with others. After that I get into my car, I take some time, I take a deep breath, so that I can move on to the others" (S5). The nurses demonstrated an ability to experience emotional situations without becoming overwhelmed. Their ability to do so was fostered by their positive attitude toward their work in addition to the skills they had in maintaining emotional distance in some situations. "I really like what I do," says one nurse (S2). "I find it certainly demanding at times and very emotional, but for some reason or other I guess perhaps that what years sometimes do for us: we see all those sides of life, all the difficult things we ourselves have to go through and other people as well, and I can somehow fit in there and manage that without being overwhelmed, you know?" (S2). "And being able to set limits too; there are certain patients sometimes who have problems and you have to set limits. So that helps me enormously" (S3).

Interacting with Family Members

Interacting with the family was identified by the nurse-specialists as being one of the most important factors in providing palliative care for their patients. One nurse summarized it as follows: "But most of the time, they [families] are a huge help because as much as we [nurses] are the eyes for the doctor, they're the eyes for us. They're there 24 hours a day—the caregiver is usually a huge help" (S4). Family members can also assist nurses directly in the care of the patient as described by the following nurse: "It's wonderful when the family can be taught how to give the injections. We prepare them, and then the people are very closely followed, of course, in those last days" (S2). However, nurses found it emotionally difficult to deal with the family's reaction to the diagnosis of their loved one's terminal illness. Often families did not want the nurse to talk to their loved one about the prognosis or mention the word "cancer" or "palliative." One nurse said: "It's difficult because I'm about to do something with or for a patient and I can't really explain why. It's like lying" (S4). It was also difficult for them to deal with family members' conflicting points of views, for instance, in the case where some children believe their parent should be left to die peacefully and the other ones believe in giving hydration or intervention at any cost.

Building a Collaborative Partnership

The next two thematic categories concern nurse-specialists in their role as an expert resource for home care nurses caring for palliative patients. We understand "collaborative partnerships" in accordance with Gottlieb and Feeley (2006, p. 8) as the pursuit of person-centered goals via a dynamic process that requires the active participation and agreement of all partners. In the present study, the concept of collaborative partnership has, at its core, a reciprocal relationship between the home care nurse and the nurse-specialist in palliative care centered on reducing suffering and providing optimal quality of life for patients and families. Four themes emerged: (1) working collaboratively, (2) sharing information, (3) guiding home care nurses, and (4) being nonjudgmental.

Working Collaboratively

All the nurse-specialists interviewed explained in different ways how they and the home care nurses achieved mutually determined goals through a joint process of communication and decision making. One nurse explained: "We make suggestions to each other, and I say, 'well, what do you think about this?' or they might say, 'what do you think about that?' So we're kind of collaborating as team members" (S1). Another said: "She gives me one piece and I give her the other piece. It's collaboration!" (S3). Working together was described by another nurse participant as follows: "We work as a team; like, for example, I work in [name of city], so [name of home care nurse] will call me, saying, 'We have a palliative care patient we'd like you to share.' So I open the file and then I and [name of home care nurse] work together for this patient" (S5). Another nurse said: "We usually come to an agreement" (S4). Although NOVA-Montréal contributes their expertise to the care of patients, home care nurses contribute the invaluable nursing supplies. "For palliative care service it works very well with CLSC

[community health clinic] being involved because we can give what our experience allows us as far as the palliative aspect is concerned, but CLSC gets all the supplies that we need from the government. We don't get those; we don't get supplied with needles and syringes and dressings and so it's a good partnership, it really seems to be a good way to go" (S2). NOVA-Montréal is a nonprofit organization that does not receive governmental funding.

Sharing Information

Knowledge and information are important determinants of power (Gottlieb & Feeley, 2006). The nurse-specialists were well aware that the palliative care knowledge they held was valuable and select. However, they perceived sharing information with the home care nurses as an essential feature of a collaborative partnership. One nurse-specialist explained: "Giving advice? I would look at it more as sharing information than giving advice, you know" (S2). She continued: "The [home care] nurses that we work with at the moment work closely with us and closely, certainly, with the patients, and so it can be more of a sharing than of a different level of knowledge somehow" (S2). Another nurse explained how she and the home care nurses "exchange information all the time," (S3) whether it is over the phone or in their meetings every 3 weeks.

Guiding Home Care Nurses

One way of delivering high-quality, appropriate, and collaborative care to both palliative patients and families was for NOVA nurses, as nurse-specialists, to guide home care nurses in the care of their patients. Billet (1996) stated that a guided approach to learning that includes modeling and coaching by experts in a secure workplace provides the opportunities for learners to develop the skills necessary to be successful in their tasks, which otherwise could not be accomplished by learners on their own.

One nurse participant explained that, although home care nurses are experienced in delivering home care, they often lack knowledge in palliative care. She said: "There are some that are experienced in home care, but just in nursing and not in palliative care. Because I find there is a big difference between nursing and palliative care" (S5). She continued: "Of the nurses of [name of the organization] many work in palliative care but they are parachuted into palliative care. 'Ah, what am I doing? I don't know!' and they don't know how to deal with death, and they don't know how to deal with home care, which means, we coach them" (S5). Another NOVA nurse noted that "some [home care] nurses have a lot of private care expertise and others don't, so we're often kind of stepping the nurses through what we think would be appropriate care for that patient" (S1). One senior NOVA nurse emphasized that she will always try, if possible, to give the rationale for each intervention she proposes to home care nurses. She states: "If I can back up [the intervention, I will] give the rationale, 'This is what I do because . . .' then of course I'm fairly comfortable" (S4).

Being Nonjudgmental

Being nonjudgmental, which means showing tolerance for another person's beliefs, values, behaviors, or perspectives (Gottlieb & Feeley, 2006), was also seen by the nurses as an essential feature of a collaborative partnership. Sometimes it happens that home care nurses feel threatened by nurse-specialists: "We don't need you [NOVA nurse], we can handle palliative cases by ourselves" (S4). They might not call on the nurse-specialist as a colleague or as someone who can support them in the holistic care of palliative patients because of a fear of being perceived as incompetent or as lacking knowledge. One nurse explained: "There are some nurses [male and female] who are very reluctant because they think that because they need a helping hand that maybe they are incompetent" (S3). Another nurse described the following experience from her practice: "I had someone [home care nurse] say the other day to a family, 'I'm equipment. They're nursing, they're information.' And I found that was so strange" (S2). She explains her role in relation to the home care nurse in the following way: "I usually will explain it in a way like, 'Maybe I have more time than you,' because they are very busy. They see a lot of patients, many many cases in the mornings. And I say that our mission is also to do support visits, we do have time for that, because they don't see that; for them, if they don't have a skill to perform, they don't necessarily feel there's a need for a visit" (S2).

In recognition of the ways in which perceived power imbalances can affect collaboration, nurse-specialists in this study have learned to adopt a nonjudgmental approach to their interactions with home care nurses. One nurse in our sample explained it in this way: "Be never too pushy, because people don't like that. Often human nature does not react very well: We feel defensive" (S1). Working effectively within a collaborative partnership means for the NOVA nurses knowing each other. One nurse said, "I have a lot of different personalities [home care nurses] to deal with, you know? But now they know me" (S4). She continued: "They know I'm not forceful, I'm here to help, I'm a backup, so we have a good relationship" (S4). Another nurse explained: "After the [home care nurses] call us more and they know us they're like 'yes, I'm going to send

you a referral because I know that it's [name of the nurse-specialist]' you know? They know who we are so they don't see us like aliens anymore: 'Look, she's a nurse like me'" (S3).

Teamwork and Implementing Palliative Homecare Teams

Teamwork is vital in the provision of health care (Leggat, 2007). Qaseem's et al. study (2007) identified different attributes that improve job satisfaction such as team collaboration, communication, a good working relationship with team members, emotional support from coworkers, and so forth. The NOVA nurses in this study expressed high job satisfaction and demonstrated all the attributes described by Qaseem et al. (2007). One nurse captures this in the following way: "Yes, but we [NOVA nurses], we see each other. For us it's really important that for 3 hours every 3 weeks we see each other" (S3). She continued: "We talk about our patients—it gives us the chance to share and just to know that others have experienced the same thing, and sometimes say what happened with them—you're transformed a little, and then you can go on".

In light of their positive experience of teamwork within NOVA, it is not surprising that the nurse-specialists believed that dedicated palliative care teams are needed within the different community health and social care organizations in Montréal. In addition to providing support, nurse-specialists believed a dedicated palliative care team would improve patient care. "I would say that the community health clinics should have departments, a reserve of nurses kept solely for palliative care, not mixing them up with nursing home care" (S5). One nurse explained with regards to the situation in certain organizations that "some of the [home care] nurses rotate, you know; they're doing court-terme for a while, and then they're doing whatever, but they're rotating so they're not doing palliative all the time so they're not developing the reflexes and the expertise that someone who's doing it every day does. And I [nurse-specialist] think if in all the [home care organizations] they had defined teams as they do in [name of city], it would be very helpful" (S1). She described the following example from her practice: "And nurses who aren't palliative care trained, you know, they'll go into a home and they won't really see what's happened that day. It's happened that we're [NOVA nurses] called in the same day after a [home care] nurse has gone in and you go in and you say, 'this patient is dying,' but the other nurse didn't see it because she doesn't have the training or the observations skills that were needed. So I think having experienced nurses who are working in the field all the time and who are increasing their experience all the time is very important" (S1).

DISCUSSION

Studies have shown that patients who have a terminal illness and their families value the work of specialized palliative care nurses, particularly for their advice on practical matters, the information they provide about disease, their advice on symptoms, their emotional support, and their help with communication (Corner et al., 2002; Chapple et al., 2006). Also highly regarded was the role of the nurse-specialist in liaising with other health care providers (Lewis & Anthony, 2007). However, in order to ensure that their expertise is used efficiently and effectively, there is a need to clarify the scope of the nurse-specialist's role, attend to issues of team building, and improve the skills of nonspecialist home care nurses in palliative care (Seymour et al., 2002; Canning et al., 2007). Our study contributes to the knowledge base of these three factors by giving voice to nurse-specialists' perspectives. The all-encompassing finding that the personal and formal knowledge held by nurse-specialists can be shared with home care nurses in a context of collaborative partnership warrants further discussion.

Holistic nursing practice, which takes into account total patient care by considering the physical, social, emotional, and spiritual needs of the patients, requires both theoretical knowledge and clinical practice (Strandberg et al., 2007). Although nurse-specialists in our sample describe drawing on various forms of knowledge to inform their practice, they draw particularly on their "tacit knowledge," also known as personal knowledge (Polanyi, 1962). Hence, their practice of palliative care is guided by their past and cumulative personal experiences, observations, and human interactions. As Kennedy (1998) stated, "Most of the knowledge of experienced palliative care nurses is personal, it involves knowing what to do with a particular patient or relative at a particular moment in time" (p. 242). However, a core function of nurse-specialists is to share this type of knowledge through the avenue of informal teaching (Husband & Kennedy, 2006). Studies have shown that skilled knowledge can be transferred from nurse-specialists to other nurses (Jannings & Armitage, 2001) by the former supporting and empowering the latter rather than by "taking over" some interventions (Seymour et al., 2002). Moreover, the NOVA nurses in our study perceived their role as that of a "guide" in the ongoing care process of a palliative patient. All nurse-specialists interviewed derived a significant amount of job satisfaction from this type of close contact with and informal teaching

of home care nurses. The interactions with the home care nurses were perceived as very rewarding, as it gave the nurse-specialists the opportunity to learn, develop their skills, and grow both personally and professionally.

As supported by Seymour et al.'s (2002) study, several NOVA nurses highlighted the tensions that this type of role modeling could engender, for instance, that some community nurses can feel threatened by the rhetoric of clinical nurse specialism. However, all the NOVA nurses demonstrated an appreciation and enthusiasm for their working relationships with the home care nurses. They saw the home care nurses as "collaborators" who both gave and received clinical information pertaining to patient care management. Decision making was founded on mutual respect. One of the key features of collaborative partnership as described by Gottlieb and Feeley (2006) is "getting to know the person." The more we know a person, the more a personal relationship can gain in strength and depth. The NOVA nurses highlighted the importance of getting to know the different personalities of the home care nurses in order to establish a trust relationship over time. Importantly, palliative care as mentioned by the nurses in our study is characterized by a climate of trust and a sense of presence gained by being with patients rather than merely the performance of caring tasks. Moreover, the nurses emphasized the need to develop dedicated home care teams for the provision of palliative care in other community health centers. The need for knowledgeable and skilled home care nurses who are able to provide high-quality palliative care to patients that includes alleviation of suffering, optimization of quality of life, and provision of compassion in dying (Boston & Mount, 2006) could be met by the establishment of specialized teams and by the increasing the number of nurse-specialists and strengthening their collaboration with home care nurses. It is neither necessary nor feasible for all home care nurses to be specialized in palliative care. So long as they may communicate and collaborate easily with those who are, palliative patients can receive the care they need at home.

CONCLUSION

The knowledge and expertise of nurse-specialists in palliative care is germane to the quality of care a patient and his or her family receives (LaSala et al., 2007). As also stated by Hollis (2005), nurse-specialists are needed to develop nursing practice, direct service development, and guide formal and informal education and training. Moreover, the collaborative partnership approach to care between the NOVA nurse-specialists and the home care nurses has the potential to directly improve the quality of life of palliative patients and their families by increasing home care nurses' knowledge of palliative care, providing more emotional support to patients and families, enhancing coordination, and improving communication and continuity of care. In Jo et al.'s (2007) study, caregivers and patients receiving palliative home care identified many of these aspects of care as important and in need of further emphasis. This study concludes that nurse-specialists, in this case NOVA nurses, play a crucial role in further influencing nursing practice in the field of specialized palliative care in Montréal. Furthermore, the results demonstrate how working in emotionally charged situations on a daily basis need not be overwhelming and, in fact, can be very rewarding when a supportive team and appropriate expertise is in place. The findings from this study cannot be generalized. It is nevertheless reasonable to assume that our findings can be transferred to a similar context. This study's findings could be strengthened by additional exploration into not only the experiences of nurse-specialists, but also into those of home care nurses, patients, and families who interface with nurse-specialists.

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