Rural Nursing and Quality End-of-Life Care
Palliative Care . . . Palliative Approach . . . or Somewhere In-Between?

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Secondary analysis of data from 2 studies examining palliative care in rural areas was conducted with the aim to better understand how a nursing palliative approach influences quality outcomes at end-of-life. Nurses’ ways of being that brought connection and comfort at end-of-life included paying attention to time, privacy, and family support. The rural context with its geography, relationships, and unique resources influenced nurses’ abilities to enact a palliative approach. Findings demonstrate that urban-centric models of palliative care do not fit well in rural nursing practice and highlight the importance of understanding the rural context.

Key words: end-of-life, nursing, palliative approach, palliative care, rural health services, terminal care

A population aging with multiple chronic illnesses creates unique opportunities and challenges for nurses working to ensure high-quality care. The Canadian Institutes of Health Information estimates that the percentage of seniors in Canada will double and the number of deaths will increase by as much as 65% over the next 3 decades. Furthermore, largely because of advances in medicine and science, many of these individuals are aging with multiple chronic health problems that contribute significantly to the complexity of end-of-life care.

Over the past several decades, palliative care has developed as a specialty and philosophy of care that has been central to developing an informed and compassionate response to dying. However, accessing palliative care can be difficult either because there are no specialized palliative services available or because individuals are not identified as being palliative. Currently, within Canada, it has been estimated that only 5% of the population receives the benefits of integrated and interdisciplinary palliative services. And within British Columbia, the site of this study, it has been estimated that only 27% of individuals who die are identified as being palliative. Many individuals are never recognized as actively dying and so fail to receive many of the benefits associated with palliative care. Moreover, even if these individuals were identified, it is doubtful whether a specialized model of palliative care . . . palliative . . . or somewhere in-between?
palliative care would be sustainable in light of both the current and anticipated demands. The challenges with providing high-quality palliative care in Canada generally are exacerbated in rural areas. In Canada, approximately 20% of citizens reside in rural areas, where the population is generally older than its urban counterparts and yet there are often few formalized palliative services.3 Recent studies of palliative care in rural areas indicate that individuals residing in rural communities have unique ideas about a good death and that rural communities have capacity for high-quality end-of-life care because of inherent accountabilities within the community and a high degree of volunteerism.4,6 However, a number of barriers to high-quality palliative care exist in rural communities including no access to specialized palliative services 24 hours a day/7 days a week, little formal coordination of palliative care, limited options for place of death, and lack of knowledge and understanding of palliative care, both for the community overall and for health care providers.4,5 Overall, this places a heavy burden on family care givers without adequate resources to support them. Nurses play a critical role in offsetting health care resource deficits in rural communities by volunteering time and resources, often at great cost to themselves.7

These realities have led to questions about alternative models for providing high-quality care at end-of-life; one such alternative model has been described as a palliative approach to care.8 This model recognizes that not all dying individuals require the support of specialized palliative services but that all individuals could benefit from a palliative approach to care. This approach seeks to take the important principles of palliative care (eg, early symptom identification and treatment, holistic care, family support, focus on quality of life, and advance care planning) and apply them in an earlier upstream approach across nursing contexts (eg, home care, residential care, acute care) and across chronic disease conditions (eg, dementia, solid organ failure). Whether this approach to care, and more specifically whether a nursing palliative approach, can improve the quality of care for those at end-of-life, is the question being asked by a team of nurses in leadership, education, and practice in British Columbia (see www.ipanel.ca). As part of this investigation, we focused upon palliative care in rural nursing to better understand how a palliative approach might improve the quality of care for those at end-of-life.

Few studies have explored the nursing role in rural areas in the context of palliative care.9,10 Yet, it would seem that rural nursing would have a great deal to teach us about the quality of care at end-of-life using a palliative approach to care. An examination of rural nursing provides somewhat of a living laboratory to view a palliative approach to care when there are limited formal multidisciplinary palliative services.9 Therefore, as a beginning point to answering this question, we sought to conduct a secondary analysis of data obtained from 2 studies that provided an in-depth look at rural palliative care and family caregiving of palliative individuals in rural areas to better understand the nursing role. By better understanding the nature and scope of rural nursing practice in end-of-life care, we can better prepare nurses to make a significant difference in meeting the complex needs of an aging Canadian society.

METHODS

Findings for this article were constructed from a secondary analysis of transcripts from 2 studies examining palliative care in rural areas (see Table 1 for details of the studies). Approval for the secondary analysis was obtained from the Behavioural Research Ethics Board of the university. Our purpose was to better understand a palliative approach to nursing care in rural areas. Two questions guided the analysis: How do nurses enact a

*It is important to note that a palliative approach was not meant to replace specialized palliative services but rather to enhance the care of those who are dying and who might not require specialized services.
palliative approach in rural areas? What contextual factors support or inhibit a palliative approach to nursing care in rural areas? Findings were constructed using Interpretive Description. Data sources included 72 interviews: 26 interviews with nurses and 46 interviews with family caregivers of deceased palliative patients (see Table 2 for demographic information). Nurses were recruited through convenience and snowball sampling, based upon their knowledge of palliative care within their community. Furthermore, they were purposively sampled from residential, community, and acute care contexts. Family

### Table 1. Description of Original Studies

<table>
<thead>
<tr>
<th>Study 1</th>
<th>Study 2</th>
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<tbody>
<tr>
<td>Purpose: To describe good palliative care from rural perspectives</td>
<td>Purpose: To explore the needs of rural family palliative caregivers</td>
</tr>
<tr>
<td>Method: Ethnography</td>
<td>Method: Qualitative descriptive</td>
</tr>
<tr>
<td>Data sources</td>
<td>Data sources: 25 telephone interviews with family caregivers of deceased individuals</td>
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<tr>
<td>95 in-person interviews with family caregivers, nurses, physicians, administrators, volunteers, funeral directors, and allied health care personnel</td>
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<tr>
<td>51 d of fieldwork</td>
<td></td>
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<tr>
<td>74-h participant observation</td>
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### Table 2. Demographic Description of Participants in Secondary Analysis

<table>
<thead>
<tr>
<th>Participants</th>
<th>Demographic Information</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Nurses (n = 26)</td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>26 (100)</td>
</tr>
<tr>
<td></td>
<td>Age, y</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18-35</td>
<td>3 (12)</td>
</tr>
<tr>
<td></td>
<td>36-45</td>
<td>3 (12)</td>
</tr>
<tr>
<td></td>
<td>46-55</td>
<td>7 (27)</td>
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<tr>
<td></td>
<td>56-65</td>
<td>13 (50)</td>
</tr>
<tr>
<td></td>
<td>&gt;65</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Years in community, mean (SD)</td>
<td>21.25 (15.8)</td>
</tr>
<tr>
<td></td>
<td>Years experience in role, mean (SD)</td>
<td>12.1 (9.6)</td>
</tr>
<tr>
<td>Family caregivers (n = 46)</td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>8 (17)</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>38 (83)</td>
</tr>
<tr>
<td></td>
<td>Age, y</td>
<td></td>
</tr>
<tr>
<td></td>
<td>36-45</td>
<td>5 (11)</td>
</tr>
<tr>
<td></td>
<td>46-55</td>
<td>14 (30)</td>
</tr>
<tr>
<td></td>
<td>56-65</td>
<td>9 (20)</td>
</tr>
<tr>
<td></td>
<td>&gt;65</td>
<td>18 (39)</td>
</tr>
<tr>
<td></td>
<td>Years in community, mean (SD)</td>
<td>34.9 (19.6)</td>
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<tr>
<td></td>
<td>Length of time caregiving, mean (SD)</td>
<td>2.4 (3.7)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>2 wk to 20 y</td>
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caregivers in study 1 were recruited through convenience and snowball sampling and were included if their loved one had been deceased for 1 to 3 years. Family caregivers in study 2 were recruited through newspaper advertisements in rural communities and through media stories about the findings of the researchers from study 1. In study 2, there was no time limit set on how long the loved one had been deceased. Participants were enrolled solely upon the criteria of having experience providing care to a dying family member in a rural area. In light of the types of questions that were asked in the original studies, the data from the nurses focused largely on the rural context and how they managed to provide palliative care within that context; the data from the family care providers focused largely on what they expected of nurses (and other health care providers) at end-of-life within a rural context. Interviews had been digitally recorded, transcribed verbatim, checked for accuracy, and entered into qualitative software for analysis.

Throughout the process of secondary analysis, careful attention was paid to the quality of our analysis and to the credibility of our interpretations. For the secondary analysis, an initial coding framework was constructed by 2 investigators after immersion in the data. Data were coded using this framework, and the framework was revised through a number of investigative team meetings. Themes were constructed and revised using constant comparative analysis, and an explanatory account was created. The interpretive validity of our findings is supported by the analytic logic and methodological congruence of the original research designs. For example, in the original studies, data sources were triangulated contributing to the representative credibility of the data (representing >1 perspective on palliative care in rural settings). In addition, interpretive findings are supported by verbatim quotes from participants. Finally, analysis meetings were held to address analytic validity, the team met to ensure consistency, confirmability, and credibility of the findings.

FINDINGS

In keeping with the analytic questions, 2 primary findings were constructed: the nature of rural contexts that require particular skills and competencies from nurses to ensure high-quality care and nurses’ ways of being that connect and comfort at end-of-life (see Table 3). Understanding the contribution that nurses make to a palliative approach is difficult to understand without knowing the context within which they do their work. The nature of the rural context, with its geography, relationships, and lack of resources could be seen as dialing up the intensity on end-of-life care.

Rural contexts: Dialing up the intensity of palliative care

Although the experience of dying is common to all, there are unique factors in the rural context that serve to exacerbate the challenges to high-quality care at end-of-life. Typically, there are no specialized palliative services and distance and geography are barriers to giving and receiving care. These factors can be seen as dialing up the intensity of what is already a difficult experience for patients and families. Nurses’ abilities to problem solve, to navigate the complex system of palliative care, and to strongly advocate for patient and family needs often determines the quality of care experienced by patients and families. Nurses enact these abilities in a context often characterized by fragmentation, without a palliative team to support them, and amidst relationships that have both professional responsibilities and personal accountabilities.

Pocketland

The lack of a coordinated system in rural areas for palliative care led one participant to refer to the context of care as “pocketland.” This nurse was describing the patchwork of services, responsibilities, and policies and procedures that had been implemented to deal with the complex process of dying. Physicians,
funeral directors, hospice volunteers, nurses, home support workers, and emergency personnel all have procedures and forms that guide their work and these change depending upon whether one is cared for at home, in a public acute care facility, or in a private residential facility. As an example of this fragmentation, one nurse described the number of forms required to specify levels of intervention as part of advanced care planning:

*Site of care* developed a blue DNR sheet with levels of intervention, but *site of care* has a white form with different levels of intervention, the Ambulance now wants the Provincial form . . . there is a registry for the Health Authority . . . and there’s the palliative benefits program. So now we have five forms instead of two. (N1∗)

This complex environment of politics and paperwork requires highly specialized skills on the part of nurses, both to know what is expected and to know how to best approach families for the decisions required to complete the paperwork. Participants who were family caregivers shared poignant stories of their experiences in making these decisions and how health care providers influenced those experiences, both positively and negatively. In these studies, the rural community health nurses were described as the experts in navigating this landscape but challenges arose when patients and families had to rely on nurses in acute or residential care where palliative care was not a primary focus of their job.

<table>
<thead>
<tr>
<th>Table 3. Qualitative Themes</th>
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<tr>
<td>Rural contexts: Dialing up the intensity of palliative care</td>
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<tr>
<td>Pocketland</td>
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<tr>
<td>No dream team in pocketland</td>
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<td>Professional responsibility . . . personal accountability: “My palliatives”</td>
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<tr>
<td>Ways of being that comfort and connect</td>
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<tr>
<td>Paradoxical time: A day is an eternity in palliative care</td>
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<tr>
<td>Paying attention without intrusion: Attention to dying . . . space for living</td>
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<td>Working with supportive networks: “You don’t even know the questions to ask”</td>
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There had been some standardization of palliative care policies across both urban and rural contexts of the health authority within which these rural communities resided. This was particularly useful in that nurses could draw upon this standard of evidence-based care when contacting physicians for orders. Nurses could refer to these policies when making suggestions for care rather than implying that they were drawing upon their own knowledge and expertise. This was most important when there was no established and/or trusting relationship between the nurse and the physician. The following quote from a nurse describes the gap that these guidelines fill in the absence of palliative expertise:

And so we’re kind of leading them [physicians] down the path a bit . . . some of them know their clients well, way better than we do . . . and some of them do have expertise and so you can kind of trust them. But if you have somebody that is really not meeting the pain needs of their client, we tend to kind of push the guidelines a bit. (N10)

Indeed, experienced nurses in our study who were recognized as palliative care experts described a long-term process of smoothing and cultivating relationships with physicians, relationships that they could then draw upon when they needed something for their patients. This was particularly important when no formal palliative care team existed.

**No dream team in Pocketland**

As one participant in our study described it, there are “no dream teams” for palliative care in rural areas. In our study sites, there
were dedicated groups of palliative champions who, because of additional preparation and a passion for palliative care, often provided expertise. But the degree to which their contributions were recognized and formalized varied. In many cases, this meant that nurses volunteered their time to provide additional education or consultation where required. The most commonly cited drawback of not having a “dream team” was the lack of ability to consult with someone, or get needed orders, outside of regular working hours. In some cases, the primary care physician was either not available for call or did not have the needed expertise. Although a 24/7 consultation line for palliative care existed outside of the community, physician orders could not be obtained through this service. The following quote was made by a nurse who had once worked on a palliative care unit in an urban area but who now found herself communicating with rural physicians primarily through fax machines and thus felt very isolated in her work:

I think that if I had the opportunity to know these doctors better, you know, being able to sit down and talk with them day in and day out, or week in and week out that would change. But it’s just too distant of a relationship. (N21)

The degree to which nurses felt connected to physicians, and thus supported in their work, was highly influenced both by their length of time and history in the rural community and by the degree to which they had personal contact. Where there was no shared location of work, such as a hospital, the degree of distance was felt more acutely.

Nurses often went to extraordinary lengths of advocacy to ensure that patients’ needs were met. As one nurse described it, “We bend every rule in the book.” Nurses spoke of leveraging relationships with physicians from whom they knew they could get orders, working off-hours, and traveling to homes that would not normally be within their jurisdiction to ensure that patient and family needs were met. However, advocacy to this degree was often exhausting for nurses and resulted in a sense of isolation if quality of care could not be maintained despite these efforts or if administrators were not supportive of their efforts. The sense of isolation of not having a team to support their work was often exacerbated by the reality that nurses were often also caring for those who were neighbors and friends. The following quote was made by a nurse after a particularly difficult death:

Like where was the team? Where were the support systems? Even one other person to say ‘you know you are doing the best you can, maybe no one could make this better.’ It gets really hard to rally the troops because sometimes you are the only troop. (N2)

**Professional responsibility ... personal accountability: “My palliatives”**

One of the unique characteristics of rural nursing is the degree to which health care providers know one another and those who come under their care. In the daily context of work, nurses have friends and family members as part of their professional responsibility. The intense personal accountability that arises from caring for those with whom you will have relationship over the long term is quite different from the contractual relationships that arise with strangers. This was typified in one interview where the nurse continually referred to “my palliatives.” This statement of ownership was not made in a demeaning sense but rather illustrated a profound sense of responsibility for the quality of care received by those under her watch. Rural nurses regularly went beyond the contractual obligations of nursing, going to enormous lengths to ensure high-quality care. One nurse described being called by a neighbor who was palliative in the middle of the night to help relieve her constipation. “Do you say ‘no, pack yourself up and go to the emergency department’ or do you go and get the stuff and deal with her being extremely constipated at home?” When the interviewer questioned whether there was a line where that became inappropriate the nurse replied, “I think as a human it doesn’t” (N2). This nurse
was reflecting on the profound blurring between the personal and professional in the context of rural life. Nurses’ willingness to be available affects their personal relationships and reputation in the community over the long term. However, nurses’ experiences of that accountability varied. For some, it was a rather difficult fact of rural life. For others, it was an intensely rewarding experience and a way to give back to their communities.

As rewarding as this relational obligation was for many nurses, it was also attended by a high cost. Nurses expressed the need for emotional support and had intentional strategies of debriefing (eg, speaking with the community social worker or attending palliative conferences to network). In one rural community where there was a nurse who had distinguished herself as a palliative champion, she spoke of the burden she felt when a patient experienced a difficult death, an occurrence that often became public knowledge in the community. Furthermore, the degree to which nurses were capable of looking after friends and family varied as expressed in the following quote:

> For some nurses if it’s someone they know well they will jump at it saying, “I’ll take care of her” and other nurses will say “please don’t make me, I can’t do that. I’ll just be a bag of jelly in that room. She’s my best friend’s mom.” (N19)

What to disclose and what to keep confidential was particularly challenging. As one nurse described a situation where a friend had a potential cancer diagnosis:

> As my friend and someone I have known for all these years what do you think is going to happen . . . that’s a really heavy spot to be in because you have to tell them the truth out of respect but you have in mind confidentialities and doctors . . . right? (N19)

In summary, the unique nature of the rural context required not only specialized palliative knowledge but also sophisticated advocacy and relational skills to ensure high-quality care. Participants in these studies, particularly family caregiver participants, described nurses’ ways of being that brought connection and comfort at end-of-life.

**Ways of being that connect and comfort**

Nurses and family members had concrete and specific ideas about ways of being on the part of nurses that represented a therapeutic palliative approach to care. Although these ways of being were not necessarily specific to rural nursing, the ability to realize these ways of being was shaped by the rural context and by the nature of rural relationships. Ways of being included understanding time in the context of end-of-life; learning to pay attention without being intrusive; and working with supportive networks.

**Paradoxical time: A day is an eternity in palliative care**

Time takes on new dimensions in the context of a terminal illness. The need to plan life around death was an important factor for families. Family members are conscious of the limited time available to them and have important needs in relation to having some control within the time left. And yet, often they felt they lacked clear guidance about how much time could be expected so that they could plan accordingly. Most did not need specific commitments of time but rather found generalities helpful as articulated by this family care provider:

> He would say, “How much time do I have left?” And the response from the physicians was always “we can’t tell you. Every person is different.” It wasn’t until M said, “You have weeks not months.” And that was when it really hit P that’s where he was. (F19)

The family caregiver in this case reflected on how their decisions might have been different if they had known more about the limited time they had. Participants also desired signposts along the way (eg, physical symptoms of decline or a palliative performance scale) that would help them recognize that a downward trajectory was occurring.
Ironically, having some general indicators of trajectory allowed them to continue living while making realistic decisions about dying. Families also needed time to process transitions, such as the transition to palliative care, and everyone processed these transitions differently. Health care providers who interpreted this processing time as denial were viewed as particularly unhelpful, whereas providers who left choice were viewed more favorably, as articulated by this family caregiver:

Getting [people] on the palliative program is a talent . . . it’s like this isn’t your execution you know, your death warrant. That’s not it. The facts are you have cancer . . . . If you get to this point [dying] and you need some help it’s here. But if you don’t that’s okay. (F13)

One of the ways that family caregivers maintained control over the time that was left was by advocating for particular interventions they felt would extend time. Because they knew their loved ones so well, they sensed that they knew when to treat even better than health care providers. They spoke of having an innate sense of whether this was a symptom that required acute intervention or whether it was a symptom of dying. In some cases, this entailed wanting acute interventions such as diuretics, heart medications, or intravenous fluids. They resisted the idea that a palliative label meant no acute intervention as described by this family member who was advocating for active intervention to treat lung problems, “And we were trying to make her live. I mean she was on this balance scale where she could absolutely walk out of there [hospital]; so we were really trying to create the space for her to live if she chose to” (F15). Nurses who acknowledged and negotiated these needs were viewed as particularly supportive.

Some of the most difficult points of tension arose when health care providers failed to recognize the significance of time. If families had an overwhelming complaint it related to the failure to control symptoms or provide needed care in a timely manner. Loved ones left seizing or in pain, time lags to see a specialist, or wait lists for radiation that exceeded life expectancy were some examples. Even the failure of a home support worker to show up on time left family members feeling vulnerable and wondering whether they could cope alone if that care provider did not show up. Constraints within the rural health care system were often to blame for a failure of timeliness. For example, nurses might have the q 10-minute orders to provide breakthrough pain but not have the staffing levels to permit such intensity of care. Home care nurses might spend 50% of their patient time allotment traveling to reach the patient. Palliative beds were located in long-term care facilities where admission procedures and medication turnaround times took days rather than hours, leading one participant to suggest that “a day is an eternity in palliative care.”

It was not uncommon to hear stories such as the one where a husband was left in pain for 4 hours while a nurse was waiting to get a medication rather than being more assertive in her advocacy. “So it took over four hours for her [the nurse] to get that drip in and he was suffering. I didn’t want to talk to her after that anymore” (F11). The family caregiver in this case, although she was a nurse, experienced a profound alienation from the nurses. Family members also reiterated times when health care providers, whether unintended or not, communicated to them that their loved one was not dying soon enough. This included offhand comments overheard at the nursing station such as “is that palliative still alive” or the withdrawal or transitioning of services (eg, from acute to residential care) if someone did not die within an expected time frame. Situations such as this left family members struggling with an already fragile sense of time.

Paying attention without intrusion: Attention to dying . . . space for living

Issues of privacy are central in rural areas where life, death, and bereavement are played out in the public arena, in which individuals often know each other well. Family
participants in these studies talked about their loss of privacy during the dying process, “We just couldn’t take people coming and going continually from the house. It was as if we’d lost not only our mother’s good health but lost all semblance of privacy, all semblance of a home” (F8). This invasion of privacy was exacerbated if the family caregiver found themselves in the position of entertaining multiple visitors while providing care. This loss of privacy was offset when there were consistent health care providers who knew how to attend without being intrusive and who knew how to navigate and respect boundaries if personal and professional relationships coexisted. The types of experiences that were experienced as intrusive were interesting. For example, in one situation, a home support worker was only needed for several minutes to assist with turning but, by policy, was required to spend a set amount of time in the home. Policy further did not permit this worker from doing some of the needed tasks such as running errands.

How nurses were able to make themselves available without being intrusive was complex. Some suggested that it was related to the experience and age of the nurse and that some nurses simply had more of a “heart” for those who were dying. Nurses too spoke of developing this heart: “From the very first time as a student nurse you see a death and that marks you. It sort of tattoos you. And to watch the family and know that geez I’d like to help them more” (N5). When participants spoke of competence in palliative care, it was often related to giving palliative patients priority and being somewhat relaxed, humorous, and capable of treating death like an everyday experience. In other words, a nurse who was available without being intrusive was one who was inherently comfortable with death.

Family members talked about how important it was for the nurse to check in on a regular basis, whether the care context was home, residential, or acute medicine. Nurses who checked in routinely and who inquired about family member’s well-being were viewed as supportive. Furthermore, there was a way of checking in that was particularly supportive and nonintrusive; it entailed not rushing, giving the impression of availability, and not just being present but being interested in the humanizing details. One family member described the nurse as leaving the impression that “we were treated in a sense, as if, when the nurse was in our room, we were the only people she had to deal with, which was wonderful” (F1). When nurses did not check in routinely, family members felt abandoned and spoke of having to face the dying process alone.

Here I am inside this institution in a little room where my mom’s supposed to be dying unto myself. I’m an entity unto myself with my mother. I’m left alone to make decisions, I’m left alone to decide whether or not she’s dying. (F14)

This sense of isolation was exacerbated by the reality that palliative beds were often placed in more isolated locations of care in rural areas (eg, at the end of a hallway on a busy medical unit or apart from the regular population in residential care). Family members felt particularly vulnerable to being alone when there was cognitive decline in their loved one, when patients or family members had been labeled as difficult by health care providers, or when the death was imminent. One family caregiver pondered the strangeness of being abandoned at the very end when her mother had been known as a resident in the facility for many years. In some cases, this sense of being alone led to a hypervigilance on the part of family members; they recognized that if they were present and paying attention, there would be a line of accountability.

Family has to show that this person has people. This person in that bed is a mother, is an aunt, is a lover, is someone who is loved . . . and I don’t think a lot of people in these facilities actually see them as people. They see them as dying people and I think they treat them differently. (F14)
Working with supportive networks: “You don’t even know the questions to ask”

If there was a common lament across rural family caregivers, it was “I am not a nurse,” “the learning curve was steep,” and “I wish I knew then what I know now.” One family caregiver said, “You don’t know what you don’t know until you discover you didn’t know it” (F4). There was a sense of regret when family members learned things after the death of their loved ones that would have helped during the process. Often they learned these things by stumbling across Internet sites after death. Examples of this type of learning were basic care, feeding, recognizing levels of decline, and what to expect around death. One participant talked about not having the time to sit in a chair and read through all the material, but rather needing the “Coles” notes or “palliative care for dummies” (F2). One participant identified the most basic questions as being important, such as if he stops breathing will he start again? Another expressed fear when turning the oxygen tank on wondering whether it would explode. Participants suggested that sometimes health care providers overestimated their level of knowledge. They kept saying you can have hospice if you want hospice. But no one ever told me what hospice was. I knew it had something to do with dead people . . . . I didn’t know what it was and I didn’t have time to seek it out. (F22)

Participants reflected back on how useful it was, or would have been, to have a single care provider to whom they could have addressed their questions or fears; someone who would know them well and be able to anticipate the questions they could not articulate. “That one person knows where all the balls are flying through the air and helps connect them with each other if they need to be connected” (F4). Much of this family teaching and support came through home support workers or volunteers. Whereas nurses could only teach in blocks of time, family members spoke of the continuous nature of their learning needs, and how often they needed repetition because of the amount of information they forgot. Furthermore, they were sometimes confused by what to them appeared to be conflicting goals of care. For example, one woman pondered why her physician was pursuing an active course of therapy for tuberculosis while abruptly stopping steroid therapy. Her experience had taught her that steroids required weaning and she could not figure out why this lapse occurred. The risk was that these inactions were misconstrued as a failure to pay attention because the person was dying anyway. Families attributed a variety of reasons for why they got conflicting or inadequate messages from a belief that health care providers did not know them well enough, to not having the time, to wanting to “cover their butts.” What family members desired was a sense of confidence that they were providing high-quality care and reinforcement for the good job they were doing. By instilling this confidence, nurses made a substantial contribution to how families felt about the caregiving process during bereavement.

DISCUSSION

Findings from this analysis help deepen understandings of a palliative approach to care in rural areas and the contributions of rural nurses to outcomes of care at end-of-life. The inclusion of family caregivers strengthens the analysis by anchoring these understandings within the perspectives of the recipients of care. However, a limitation of this study is the nature of secondary analysis whereby one cannot go back and deepen understandings around questions that arose during the analysis. There were a number of times when the investigative team would have liked to probe deeper, particularly around how expert nurses were able to accomplish what family care providers found particularly important to outcomes of care. These questions are areas for further research. Findings from this study reveal nurses’ ways of being in a rural context that families find therapeutic and the high levels of advocacy, interpersonal skills,
and knowledge of the context that facilitate quality outcomes. However, the challenge of being an expert generalist within a context where at times the outcomes of care were beyond the nurses’ control illustrate some of the unique strains of rural nursing. In this analysis, nurses and family caregivers identified 3 primary areas for consideration when reflecting on nurses’ contributions to a palliative approach in rural areas: rural nurses’ disjunctures in time, rural nurses’ ownership in paying attention, and rural nurses’ knowing and advocacy. Overall, what these findings highlight are how urban-centric models of generalist versus specialist palliative care do not fit well with rural nursing practice. There is a need to think more carefully about rural-specific models.

**Rural nurses’ disjunctures in time**

From nurses’ perspectives, the need to simply be with patients at end-of-life out of respect for their limited time and the need to do this within contexts that were typically time pressured created a sense of disjuncture. From family caregiver perspectives, important aspects of time were the need to have some sense of the amount of the time left so that informed decisions could be made and the need to have timely attention to care so that the time left could be optimized.

The challenges of decision making in light of illness progression is frequently acknowledged in the palliative literature and is an area where nurses often feel the need for further education. Furthermore, in this study, family caregivers expressed the need for nurses to stay in sync with their decisions in relation to time and treatment. Some nurses were able to do this better than others.

However, what this study illuminated more was the nature of time in the context of terminal illness and how acutely family caregivers felt delays in the treatment of symptoms. Actions or inactions were evaluated by family caregivers through the lens of the time that was left; a delay that might be tolerated in the context of a reversible illness was experienced acutely in the context of a terminal illness. This altered sense of time perception has been found in other studies. Van Laarhoven et al studied time perception in patients with cancer who were disease free in comparison with those who had advanced cancer. Patients with advanced cancer tended to have a present-oriented focus in comparison with a future-oriented focus for those who were disease free. Furthermore, if time was perceived to be moving slowly, this was correlated with distress, although it is important to note that this could be a reciprocal relationship whereby time moving slowly causes distress whereas distress causes time to move slowly. This would lend insight into why timely attention to needs was of such significance in this study.

Several studies have examined time in the context of palliative nursing. Dalgaard and Delmar used grounded theory and philosophic inquiry to better understand the role of time in palliative nursing practice. Beginning from the assumption that time can be conceptualized as either objective clock time or subjective personal time, they suggested that when there is insufficient clock time for the nurse to do his or her job, the nurse attempts to maintain control in 1 of 3 ways: through finding a fixed rhythm that emphasizes routine versus individual care, through racing against the clock in a way that emphasizes doing versus being, and through pointing out time thieves such as those patients who demand more time. In contrast, when nurses perceived clock time to be sufficient, they were more likely to be with patients and remain responsive to their needs.

These studies lend insight into the challenges of time in a rural context. Palliative care is delivered largely within settings where time pressure is the norm. Dedicated palliative beds are often located on busy medical units or residential care facilities where staffing is based upon the normal day-to-day flow of care. When extra time is required, such as it is at end-of-life, to maintain control nurses may fall to a form of care that is the antithesis of the waiting and being...
inherent in a palliative approach to care. Or they may routinize care, like the example provided of the nurse who waited for the medication to arrive from pharmacy, an action typical of medical surgical nursing, rather than going to pick it up so that symptoms would be relieved more quickly. Meanwhile, patients and families were experiencing an altered sense of time, and distress was created when symptoms were not attended to in the present. This also helps explain the behavior of nurses who made comments about patients who did not die within an expected time; these were the “time wasters.” The nurse is perceived to be uncaring and or irresponsible when indeed they are striving to maintain some sense of control in a disjuncture between their experiences of subjective and objective time.

This finding would be relevant for any context where it is important to implement a palliative approach outside of dedicated palliative units. Can nurses care within a palliative philosophy while attending to the normal workload and time pressures of regular nursing contexts? Some studies have suggested that the failure to take time is not purely a phenomenon of the context of care. Haraldsdottir19 examined the art of “being with” in a hospice setting and discovered that even within dedicated palliative settings care could become ordinary, matter of fact, and routinized in such a way that the emotional engagement of being with was never realized; time pressures were not the only relevant factors. Similarly, Georges and Grypdonck20 studied the meaning palliative nurses assigned to their care of patients and found that nurses tended to take 1 of 2 divergent approaches: either that of a well organized, purposeful approach or that of a patient well-being approach. The patient well-being approach was more conducive to a palliative philosophy of care. In light of these time challenges, it was revealing to see how many rural nurses were still able to pay attention. These were the nurses whom family members said they gave the impression of having all the time in the world.

Rural nurse’s ownership in paying attention

In this study, family caregivers described a delicate balance between attention and intrusion on the part of nurses. This was particularly relevant in the rural context where maintaining privacy can be a challenge. They described how nurses contributed to high-quality care by having a comfort with death and by simply checking in with them frequently to ensure that all was well, particularly as the end got closer. Family caregivers felt acute abandonment when this did not happen. Nurses’ ability to pay attention both to family caregivers and to subtle cues about how much assistance was desired has been found in other studies of palliative care both in the hospital21 and home care22 settings. The idea of intrusion is one that has been described within the home care literature, although not specific to palliative care.23,24 Other studies have found similar findings in that the personality of the community palliative nurse and his or her technical skills, knowledge, and experience has the capacity to improve health and well-being in clients.25 But what was interesting from these findings was to see how the entwined professional and personal responsibilities characteristic of the rural nursing role played into how the nurse paid attention. Nurses demonstrated a strong sense of ownership over those under their care and a direct accountability whereby they knew that the quality of care they provided would become part of a public knowing and memory that would influence their standing within the community. As such, they went above and beyond to provide the type of paying attention desired by rural family caregivers. In the absence of a formal palliative team, they were diligent advocates in pursuing orders and bending the rules to obtain the support required by patients and families. Furthermore, they often knew their own limits in terms of their involvement with those whom they had close ties. This natural accountability meant that nurses were heavily invested in insuring a high quality of care for
those under their care, but it was also risky in the sense that if quality care was not possible under the constraints, they would own those outcomes as well. Not having a team to support them was felt most acutely when things did not go well.

The realities of dual relationships and burnout are well documented in the rural health care literature. This study contributes to that body of knowledge by illustrating in more depth how that plays out for rural nurses engaging in end-of-life care. Nurses felt a profound sense of responsibility for the quality of care for “their palliatives” and also derived a great sense of satisfaction in their work when they were able to make a positive contribution. Indeed, there is evidence in the literature that nurses working in rural and remote areas derive great satisfaction in their work and perhaps more so than their urban hospital-based counterparts. However, in this secondary analysis, we were left with questions about how nurses made their decisions related to involvement with patients and the impact of those decisions on their work and personal lives. Further research is required to better understand how this intrinsic accountability affects quality of care and quality of life, both for nurses and for patients.

Rural nurse’s knowing and advocacy

A common finding across the palliative family caregiving literature is a feeling of inadequacy on the part of family caregivers and the need for consistent support and information. Findings were similar in these data. Family caregivers’ ability to confidently provide care was supported by someone who could anticipate their needs, find resources, and steer them through unknown territory. Previous research has highlighted the central role that home care nurses in particular play in facilitating family access to resources and how that is influenced by the relationship between the nurse and the family caregiver. Rural nurses who knew their clients and families well were ideally situated to do this work. However, to do this work well required a high level of knowledge, skill, and advocacy. Nurses in this study needed to know the complex landscape of paperwork and policies associated with palliative care and they needed to know the resources available in the community. Above all, they needed to have the ability to foster and smooth diplomatic relationships with physicians so that they could call upon those physicians when needed. When they could not get the medical backup they needed, they required strong advocacy skills and a willingness to take risks and bend the rules. Most of all, they had to do this in a somewhat fragmented health care system characterized as “pocketland” and without a dream team with palliative expertise to back them up. Only then, could they adequately support families in their caregiving tasks.

The importance of being able to establish long-term trusting relationships with physicians and to mobilize support from them when required has been found in other studies of rural nursing in specialty areas. MacKinnon studied maternity nursing in a rural context, and Kidd within a rural emergency context. In both studies the ability, or perhaps more specifically the inability, to get medical support when required was critical to achieving high-quality care. Nurses described knowing who they could and could not draw upon to get the help they required and the careful negotiation of accessing support. In this study, nurses had Health Authority sanctioned, evidence-based palliative care protocols to draw upon to remove some of the tensions of nurses being seen to order treatments. But the challenges of knowing there were some physicians that they could not rely upon, and that there was no formal palliative team to back them up, often left them to their own resources. When nurses were unable to mobilize the support they required, they were left with a sense of personal failure. The ability to mobilize assistance was also dependent upon an intimate knowledge of the resources available. MacKinnon’s work also illustrated the same need for mastery of a complicated set of details evident in
this study, although in the context of maternity, those details were related to the logistics of mobilizing emergency systems should women need them.

In this rural context, family members suggested that much of their information came from home support workers (also known as nursing care aides) and hospice volunteers rather than registered nurses. The important role of the hospice volunteer in palliative care is widely acknowledged, particularly in rural areas where they tend to fill in the gaps in care.\(^{38,39}\) However, less is known about the role of the rural home support worker.\(^{40}\) Denham et al\(^{41}\) conducted a study of rural nurse aides’ knowledge about end-of-life care in residential settings, using focus groups in 6 rural counties across 5 American states. Their findings suggested that formal preparation in end-of-life care for nurse aides was inadequate and much of their learning was a socialization process on the job. Furthermore, their relationships with professional nurses often determined their ability to report the subtle changes that they were well positioned to recognize—an interpersonal dynamic that is similar to that described between nurses and physicians in this study. Similar results were obtained by Devlin and McIlfatrick\(^{42}\) in a UK-based study but with a sample of home-care workers involved in end-of-life care that was not rural specific. Home support workers played an essential role in end-of-life care at home but did so with minimal preparation and varying levels of support by other team members. In light of the central role that nursing home support workers and aides play in supporting families providing palliative care in rural areas, there is an urgent need to understand their experiences better and to provide them with education and support equivalent to the essential role they are being asked to fulfill.

**Palliative care . . . palliative approach . . . or somewhere in-between?**

What this study highlights are the very real tensions between the ideal of specialized palliative care and the more indistinct gray zone of a palliative approach to care that exists in rural areas. Over the past several decades, with the rise of the palliative movement, palliative care has become increasingly specialized. This has been reflected in specialized nursing standards, competencies, and curricula primarily designed for continuing education after basic preparation of nurses.\(^{33-45}\) However, recognition of the shortcomings of a purely specialist model has resulted in a refocusing toward a palliative approach whereby nurses take the important principles of palliative care and enact them within nonpalliative-specific contexts such as residential care, acute medicine, and home care. The assumption within the palliative approach is that specialized palliative care services will be available for the small percentage of the population that would benefit from it.

However, the idea of generalist and specialist preparation of nurses, whether that is within palliative care, maternity care, or intensive care, reflects an urban-centric model of nursing that may not serve rural nurses well. This study that examined palliative care in rural nursing without the benefits of specialized palliative teams or services illustrates the risks of this urban-centric model. Nurses in this study were aware of the standards for hospice palliative nursing and indeed many of them had received advanced preparation in palliative care. However, their ability to realize this ideal was shaped by the rural context. In some ways, this context facilitated achievement of the ideal as nurses drew upon the social capital of knowing their patients, coworkers, and community and went above and beyond the contractual obligations of nursing to provide highly skilled care. In other situations, however, when the urban-centric ideal of palliative care could not be realized, it put nurses in a difficult position. The most common example in these data was the failure to control symptoms, either because the nurse did not have the time to focus on that patient or because nurses could not get appropriate backup because of a lack of a palliative team. However, the ideal also extends to having a
dedicated hospice house and a full multidisciplinary team educated within a palliative philosophy.

Outcomes were often beyond nurses’ control. When the outcomes were good, nurses derived a sense of great satisfaction in their work. When the outcomes were poor, nurses experienced a sense of moral distress that carried an inordinate amount of personal responsibility for that outcome. This work of stepping in to fill in the gaps to ensure quality care in rural areas results in a dynamic that has been referred to as “emotional toil” in the literature, a toil that can have impact on the nurses’ well-being over the long term. Clearly, there is a need to think through the ideal of palliative care within rural contexts and to work out standards and models of delivery that are uniquely suited to that context. Minimally, this should entails providing appropriate staffing levels for those beds that are designated palliative and medical backups for palliative orders when required. The willingness to care and inherent accountability that pervades palliative care in rural areas needs to be augmented by appropriate education and support. The depth of palliative nursing expertise that was apparent in this study suggests that the required education and mentorship may exist already in these communities but needs to be drawn upon more purposefully. If palliative expertise does not exist within the community, distance technology could be used to create links to that expertise. Distance technology could also be used to support communities of practice where nurses can connect to others facing similar challenges. These initiatives should include home support workers in acknowledgement of their essential role on the team.

CONCLUSION

This study highlights the link between quality outcomes for families and how nurses practice within a rural context. As expert generalists providing palliative care to patients within their communities, rural nurses were required to be strong advocates, often in a fragmented system, and without a palliative team for support. Advocacy in fragmented systems or “pocketland” entailed nurses navigating complex policies and paperwork. To meet patient and family needs as they arose, nurses would “bend every rule in the book,” actions that stemmed from nurses feeling professionally accountable and personally responsible. Ways of being in which a nurse could provide comfort and connection at end-of-life included appreciating an altered sense of time; paying attention without being intrusive; and working with supportive networks. Families appreciated nurses who cared for their loved one with the awareness that they were in a limited time frame, who knew how to “check in” on patients and families without intruding into their privacy, and who provided the necessary teaching so that they could feel confident that they were doing a good job of providing care. The findings of this study help contribute to a deeper understanding of how nurses provide a palliative approach in a rural context and how the rural context itself shapes nurses’ abilities to enact this palliative approach.

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