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Citation:

Publisher:
Rural Development Institute, Brandon University.

Editor:
Dr. Doug Ramsey

Open Access Policy:
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ISSN: 1712-8277 © Journal of Rural and Community Development
www.jrcd.ca
Barriers and Enablers to Providing Palliative Care in Rural Communities: A Nursing Perspective

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Abstract

Nursing plays a key role in the coordination and delivery of palliative care services in rural settings. The purpose of this study is to identify barriers and enablers to providing palliative care in rural communities from a nursing perspective. This study utilized a qualitative descriptive design. Findings highlighted that the remoteness, limited access to resources and professional practice barriers created challenges for nurses as they tried to provide quality palliative care to their clients. System-related barriers were identified and included: lack of services, funding issues, and poor continuity of care. Despite these barriers, nurses drew from supports to optimize palliative care such as using a team approach to care,
centers, utilizing local case managers and informal community members, and using palliative care resources. These results may help inform policy decisions around the needs of nurses who practice in rural settings to provide quality care to individuals who are dying and their families.

Keywords: palliative care, rural nursing, community, qualitative

1.0 Introduction

Rural Canadians tend to have poor health outcomes that stem from transportation difficulties, unemployment, personal and community culture and health beliefs, as well as limited access to some essential services including palliative care (Goodridge & Doggleby, 2010; Public Health Agency of Canada, 2006; Senate Committee on Social Affairs, Science and Technology, 2000). These issues can contribute to poor quality care for rural populations. Quality care has been defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcome and are consistent with current professional knowledge” (Goodridge et al., 2010, p. 142).

The shift of palliative care from the hospital setting to home has created increased complexity of care for community nurses, particularly for those working in rural communities (MacLeod, Kulig, Stewart, & Pitblado, 2004; Williams, 1996; Wilson et al., 2009c). The consequences of this shift in terms of nursing care management is important to examine to ensure that individuals are not at risk for uncoordinated and inadequate end-of-life care (Wilson et al., 2008). Goodridge and Duggleby (2010) state that urban patients benefit in ways that rural patients do not because of the uneven access to services outside of urban areas, which can affect the quality of palliative care provided to rural patients. In addition, the provision of quality palliative care can be improved by using specialists in teams, but are largely missing in rural communities (Donovan & Williams, 2012).

Nursing plays a key role in the coordination and delivery of palliative care services in rural settings but they are faced with many challenges in doing so; such as separating their personal and professional lives, working in isolated areas while having little opportunity for continuing education (Hunsberger, Baumann, Blythe, & Crea, 2009; MacLeod, Browne, & Leipert, 1998; MacLeod et al., 2004). Shreiber et al. (2003) reported there is a need to monitor nurses in rural and remote areas to prevent burnout.

Using a survey design, Kaasalainen et al. (2011) examined the differences between rural and urban nurses’ role in providing optimal palliative care to community-dwelling individuals. They found that rural and urban nurses had similar roles in palliative care but rural nurses spent more time travelling and were more confident in their ability to provide palliative care. Moreover, rural nurses reported that the lack of palliative care training for health care providers and poor accessibility of services and equipment impeded their practice in rural communities. Through this work, Kaasalainen et al. determined that further qualitative work was needed to better understand rural nurses’ perceptions of barriers and enablers to providing palliative care.

The purpose of this study is to identify barriers and enablers to providing palliative care in rural communities from a nursing perspective. This study is a follow-up to a previous survey that examined the practice patterns, self-efficacy in providing
palliative care, extent of interdisciplinary collaboration and satisfaction of rural nurses working in Ontario, Canada (Kaasalainen et al., 2011). This follow-up study sought to explore the perceptions of nurses using qualitative methodology to gain a deeper sense of the barriers and enablers that they experienced while they tried to provide palliative care to clients who lived in a rural community.

2.0 Methods

This study utilized a qualitative descriptive design to explore rural nurses’ perceptions of barriers and enablers to providing palliative care in the community (Sandelowski, 2000). This specific qualitative design was appropriate for this study because it facilitated the gathering of rich, contextual data related to rural nurse perceptions of barriers and enablers to providing high quality palliative care to rural clients who receive home-based end-of-life care. This study was approved by a university-affiliated research ethics board and a national nursing organization with whom we partnered to access community nurses.

This nursing organization is Canada's largest, national, not-for-profit, charitable home and community care organization. In Ontario, the nursing organization offers a variety of services, largely nursing and professional services as well as other community support services, First Nations and Inuit services, volunteer services, and health promotion and education. Nurses who completed the initial survey (N=159) were asked if they would be willing to participate in a follow-up interview. Out of the pool of nurses who agreed (n=35), purposeful and theoretical sampling was used to gain a diverse group of nurses (N=21) with the following characteristics: varied level of involvement in palliative care activities, varied extent of interdisciplinary collaborations, varied job satisfaction, and differences in educational background. The nurses selected for an interview self-designated themselves as being ‘highly rural’; or rather, all of their clients lived in a community that was (a) at least 80 kilometers away from the nearest large city (with a population of 100,000 or more); (b) sparsely inhabited (less than 150 persons per square kilometer); or (c) with a population of 10,000 or less (MacLeod et al., 2004; Wilson et al., 2009b).

Once a consent form was signed by each of the 21 nurses, a telephone interview was scheduled with each at a mutually agreed upon time. A trained interviewer conducted the interviews with each using a semi-structured interview guide (interview guide available upon request). Questions focused on eliciting information on the nurses’ perceptions of barriers and enablers to providing palliative care to rural clients living in the community.

Each interview was recorded and transcribed. Interview data was organized and analyzed using NVivo 8.0 (QSR International Ltd., 2009). Important concepts that emerged from the data were labeled, categorized and coded (Patton, 2002; Sandelowski, 2000). Initial coding of each transcript was done independently by two individuals to foster credibility and dependability. Any discrepancies were reviewed by the two investigators and discussed until consensus was reached.

A number of methods were used to improve the credibility of the findings. Member checking or “recycling interpretation” was done with each participant, whereby after each interview, informants were asked to review a two-page summary of key findings and provide comments relating to the investigators’ interpretation of the interview data (Crabtree & Miller, 1999). Investigator triangulation was used to minimize any idiosyncratic biases.
By the 21st interview, data saturation was reached; that is, no new ideas or themes were emerging through the later interviews. The 21 interviews were consistent with the general guideline for reaching data saturation typically with 20-30 interviews (Strauss & Corbin 1998).

### 3.0 Findings

#### 3.1 Characteristics of the Sample

All of the participants were female, with 90% RNs and 10% RPNs (Table 1). Almost half of the nurses worked part-time (43%) and the majority worked directly with clients (90%). Sixty-seven percent had over 11 years of rural nursing experience and 77% were over 46 years of age. The majority of participants (76%) reported that they had received some training in palliative care.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Rural n= 21</th>
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<tbody>
<tr>
<td>Professional Designation</td>
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<td>Employment Status</td>
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<tr>
<td>Position</td>
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<tr>
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<td>19 (90)</td>
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<tr>
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<tr>
<td>Over 11 yrs</td>
<td>19 (90)</td>
</tr>
<tr>
<td>Years in rural practice</td>
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<tr>
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<tr>
<td>Years in current position</td>
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<td>6 (29)</td>
</tr>
<tr>
<td>≥ 66 yrs</td>
<td>2 (10)</td>
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</table>
Participants were from rural communities across Ontario, Canada; including Grey-Bruce (n=4), Porcupine (n=3), Perth-Huron (n=3), Thunder Bay (n=1), Chatham-Kent (n=3), Hastings-Northumberland-Prince Edward (n=6), and Hamilton (n=1). Their job satisfaction varied from being somewhat dissatisfied to extremely satisfied and the extent to which their practice involved interdisciplinary collaboration ranged from not at all to a very large extent.

3.2 Overview of Findings

Nurses readily identified a number of barriers and supports that influenced the way they provide palliative care to individuals living in rural communities. The nature of the rural communities themselves presented both barriers and enablers to palliative care practices. The remoteness and limited access to services and resources (i.e., spatial-temporal barriers) and professional practice barriers (i.e., lack of specialization in palliative care, attitudes and beliefs of health care providers, working with families, conflict among health care providers) created many challenges for nurses as they tried to provide quality palliative care to their clients. System-related barriers were identified as well; these impeded palliative care practice and included: lack of services or underserviced nature of rural communities, funding issues, and lack of continuity of care. Despite these barriers, nurses drew from supports that were available to optimize palliative care such as using a team approach to care, accessing specialty trained nurses and physicians in palliative care from both rural and urban centers, utilizing local case managers and informal community members, and using palliative care resources (i.e., symptom management kits, tools-for-practice).

3.2 Barriers to Providing High Quality Palliative Care to Individuals Living in Rural Communities

The Nature of Rural Communities

The spatial-temporal barriers inherent to rural communities challenged nurses as they tried to care for individuals who were dying at home. They were confronted with the remoteness of communities which contributed to long distances and extended driving times to travel to provide care to individuals who were dying and their family members. Quite often, these conditions put nurses in difficult situations, as one nurse explained,

> If the person wants to die at home but it’s the middle of winter, you can foresee that it may be difficult to get access to the home if the condition is changing and you want to change the care plan. If somebody needs an increase in their analgesic medication or there are complications, uncontrolled pain might be one, a hysterical spouse might be another…the remoteness limits what you can do and the weather, the weather and the location can be limiting to the intervention. Respondent 4

The importance of planning their workday and coordinating travel time amidst patient care was needed to maximize the efficiency of their workday was paramount:

> Even for our scheduling people I have sent them maps and trying to get to the patients, you can drive as much as 360 kilometers in a day and they haven’t got a clue that you are wasting so much time traveling that you
could better have spent in patient care. So again, when you are planning services, the timeline, travel and convenience of travel if you are on a way back country road that isn’t plowed today, it is a barrier. Respondent 12

The long distances were frustrating for nurses and often meant delays in providing care, which was troublesome, especially when there was an acute issue that needed to be managed in a timely fashion, as described by this nurse:

Challenges for me as a nurse? Well the main one is that they are in a rural setting and it’s a geographically isolated distance. Resource people are a distance from them so as a nurse when I have to go see them, it takes time to get to them…and, so let’s say this person calls because they have some major issue, to get to them takes quite a bit of time, it could be one hour and five minutes, something like that. At times it’s very frustrating, and the fact that rural patients mean a great deal of travel time, sometimes it’s hard to get to them in a timely fashion if there is an acute need. Respondent 21

Spatial-temporal barriers were also imposed by the locations of other care providers. Many nurses spoke of the challenges working with specialist physicians who are located in different regions, separated by a great deal of distance from both one another and their rural clients:

There have been many, many players concerning this girl over the years. Some doctors involved with her are in [urban center] and that’s a good three and half hour drive, then we are involved also with [another doctor], and that’s another hour and a half or two hours away. And the providers at those ends are not always readily available. The family physician is still involved but very minimally and she prefers that we utilize the long distance doctors, and it’s a huge challenge. We come in and we’re a palliative care consult team. I have access to the lead physicians and want to bring this little girl before them and want them to do pain and symptom management which would be so much easier for me and for her because they would be more local. But the family at this point doesn’t want to involve another group of people so we’re struggling with the long distance. Respondent 11

Professional Practice Barriers

Many professional practice barriers were also identified related to palliative care, including: nurses working as generalists, accommodating cultural beliefs of clients and family members, attitudes and beliefs of health care providers, working with families, and dealing with conflicts among the health care team.

Rural nurses described clearly how they practice in a generalist role, covering all aspects of nursing care from “helping people come into this world and then leaving it” (Respondent 14; they sometimes found it a challenging to manage their caseload and provide optimal palliative care since “a nurse-is-a-nurse-is-a-nurse in the homecare setting here” (Respondent 7). For example, one nurses stated:
You have somebody who’s really, really not doing well and you know darn well you’ve got less than 24 hours and you are leaving their bedside and then you go and do other things, admissions or whatever. It’s hard to transition from that role to the next role. Respondent 11

Nurses commented on the challenges of working with various different cultural groups in the rural communities; such as Mennonite, Amish, and First Nations. For instance, a nurse reflected on her experiences of working in a Mennonite home with limited services and how she had to adapt to provide quality care to meet the needs of that particular client:

Certainly, in XXX County we have quite a community of Mennonite and some old order Amish as well, so we do see quite a few horse drawn buggies on the roads. And in our settings, there might be some electricity, there might be some running water. But I do have a handful of homes I do go into [where] that’s not the case. For the most part, electricity and running water are taken for granted, in other places you are working with lanterns in the middle of the night. And working around a lack of clean laundry sometimes… I remember the first few times it was a bit of a culture shock for me but I’ve adapted well since then I think. Respondent 8

Sometimes attitudes and beliefs of health care providers about various cultures were barriers to care. Another nurse indicated:

The barriers are often… I am on a First Nation [reserve]. I think some of the mindsets about the people reflects some lack of knowledge and prejudice. They assume that the pain issues are not real, they assume that they are drug seeking when they are young people. And I think it’s, that’s the biggest one for me, lack of proper treatment, inadequate. Respondent 11

Nurses also described a number of challenges working with families when a family member is dying, as suggested below:

And sometimes the families are a bit overwhelmed because they really have never been with somebody that has been dying. And they are dealing with the patient on their own …and so they are a bit overwhelmed because…when a client goes on for a couple of months … it’s unpredictable … they find it very stressful. Because they didn’t ever figure that they would be doing the home nursing for a long period of time. Respondent 20

Nurses described other palliative care situations that were challenging as a result of working with families in a rural setting. For example, one nurse stated that working in a rural setting has its own “unique set of challenges, well part of it is distance, part of it is family is not often living nearby but in some communities, the whole family lives in a little village, sometimes that can be challenging too” (Respondent 14).

Alternatively, nurses described how some families are faced with a tough situation when a family member is dying, particularly when he/she is a relatively new member of a rural community:
As the population ages, they move into rural settings and you know what? They don’t have family here. People who choose to retire in a beautiful rural area may wind up without the kind of family support network that previous generations have had or that they might have in an urban area.

Respondent 4

Nurses described how conflict among care providers was, at times, a barrier. This conflict was described as being amongst the interdisciplinary team or just with the physician. The following nurses described such conflict:

I know some of it can be disagreement among the interdisciplinary team on what should be done for them. So you may be the primary nurse and you know what the client is wanting and what their wishes are but they [the team] don’t seem to come on board with that. Respondent 19

Well I asked for a symptom response kit for a client and he [doctor] said no, I couldn’t have one because he may go into the hospital sometime. [That] being said, if something happens tonight or tomorrow or the next night before he goes into the hospital we have nothing so we had to send him to emergency – that just happened yesterday. Respondent 9

You may get the odd, family doc that’s very resistant with any suggestions you might have [for] use of newer drugs if they’re not familiar with them. So you have to handle them with kid gloves sometimes, just say “I think you should do this, it’s been my experience that this and this might work. Or the last conference I was at suggested you could try this,” or that kind of thing. Most people are pretty open. Respondent 18

System Barriers

Nurses articulated a number of system-related barriers to providing palliative care. The majority of nurses described the challenges of working within an underserviced area. One nurse commented about when she took a maternity leave and how her “coworker carried it almost alone up here, up to seven weeks at a time” (Respondent 2). The shortage of both nurses and physicians continues to plaque the health care system in rural communities. One nurse described a particular situation:

And then the doctor situation is always, always a problem up here and right now we’re short of doctors here. And like I say we often end up with patients that don’t really have a family doctor. So you are phoning some doctor trying to order this stuff and they don’t even know this patient, they’ve never even met this patient. So it can be a challenge sometimes. Respondent 10

The lack of physicians not only creates barriers to care but also negatively affects the quality of the dying experience for someone living in a rural community as one nurse explained:

It’s very frustrating…we don’t have the doctors like we used to… so when we work with the locums they won’t order unless they see the client which
means we have to send them in by ambulance or whatever so they can see them...we have to send them up to the hospital and it’s a very traumatic and long-drawn experience because we have to send these clients in and they’re really not up to it. Respondent 7

Nurses also felt that it took more time and energy to organize services and supports for their clients, such as occupational therapy or personal support workers, due to the limited number of these healthcare professionals to draw from.

Lack of funding for services, including nurse salaries, as well as other supports for people who are dying in a rural community was endorsed by many of the nurses. In particular, nurses identified lack of equipment, medications, 24-hour nursing or personal support worker care as being major barriers to providing quality palliative care in a rural community. Nurses stated, “I think enough PSW support for the family, that’s probably what’s not out there.” (Respondent 4); “the equipment - it does get here eventually but if they want it earlier they have to pay” (Respondent 11); and “there’s very few services that are offered here and the ones we have they are threatening to close them [due to financial constraints]” (Respondent 13). Another nurse elaborated:

The pharmacies are small here, we would have people that suddenly changed from oral medications to other medications [but the medications were not] not stocked at the pharmacy here. So we would wait for two days before [the medications] are shipped from the city. And then we would have to go over to the hospital and make arrangements to borrow it from the hospital. Respondent 10

Many of the nurses interviewed claimed that the lack of funding for nurses in particular or poor pay for rural nurses working in the community has led to high nurse turnover, which has led to poor continuity of care for some people who are dying at home. Lack of continuity of care was highly endorsed by nurses as a barrier to providing quality care in rural communities. Some nurses stated that “people being cared for in their home could see as many as 12 different care providers in the course of a week” (Respondent 11). Another nurse added, “the difficult part is that I may see a patient three visits in a row and then it may go to other nurses, so it’s kind of a continuity [issue]” (Respondent 18). This was troubling for some nurses as described by this one:

I’m finding it very different here, we have our set of patients, but we get assigned in a willy-nilly sort of way. I never know for sure if I’m going to have the same follow-up on a patient. So it doesn’t really feel like the patients are managed, so that’s a barrier for me. Respondent 14

Continuity of care is challenged further for nurses who have many “working stations”, including their office, clinics, hospitals, and patient’s homes; all these stations are separated by much distance, requiring nurses to be very organized. However, problems ensue when unexpected issues arise as this nurse explained:

…the whole rural thing, our faxes are in the home room, and we get our charts forms from an hour away, then the charts are in the home, well we have to try to carry all our different filing with us wherever we go. And then the CCAC [Community Care Access Center] can be complaining we
didn’t fill out a requisition. But the requisition could be at the clinic and the hospital and our fax machines at home, so we have a lot of logistics just with homecare. Respondent 5

3.3 Enablers to Providing High Quality Palliative Care to Individuals Living in Rural Communities

Nurses identified a number of enablers or supports that helped them overcome barriers and provide quality palliative care to people dying in rural communities; specifically support from community members, local case managers, and palliative care experts from local and urban centers. Nurses also stated that having practice tools, ‘symptom control kits’, and optimizing a team approach to care improved their palliative care practices.

Support from Community Members

The majority of nurses described how rural communities take care of themselves, offering support to other members when needed since “some of these older people who have been in a church family for probably 20 years or 25 years” (Respondent 2). A nurse elaborated further:

Friends and neighbours in the area, there’s often a lot of support from neighbours because they have grown up [together], there are five generations in the area. So we get a lot of support from the locals, the friends, the neighbours, where I am not sure that would happen in the city. Respondent 2

When a community member is dying or has died, then much support is garnered from the community to help families out; rural members feel this is an integral part of their way of living and take great pride in it, as one nurse highlighted:

In rural settings sometimes, well it is very rewarding. Because I think in rural settings when you do have the supports, everybody is a very close-knit community. I mean everybody knows everybody and it seems like maybe once they have passed on, everybody is there to support whoever is left. Where sometimes I find in urbanized areas your neighbors really don’t care. Respondent 19

Support from Other Team Members

Rural nurses found the support from local case managers to be very helpful in the provision of palliative care, especially when patients were transitioning from hospital to home. A nurse explained, “I think the greatest facilitator when they go home from the hospital is the case manager that works at the hospital, she sets it all up” Respondent 1

Nurses described the case managers as being “pitbulls for their clients” (Respondent 15), teaching nurses how to work within the constraints of the system to meet the needs of clients “showing us [nurses] how to go around something to get something done” (Respondent 20). Nurses also described how they rely on the case managers to “pull it altogether” (Respondent 1), as one nurse explained:

The case manager in this area is quite on board with making sure that the services are in place. She has the capacity to get a hospital bed, often times
it’s from the local Legion or the Lions Club, and if [the case manager calls] the people from that service club they will actually bring the bed and deliver it [to the patient] Respondent 3

Nurses also found access to palliative care specialists (both nurses and physicians) very helpful. In particular, nurses commented on the benefits of having CAPCE (Comprehensive Advanced Palliative Care Education) trained persons in terms of providing advice and mentorship relating to managing challenging palliative care issues. One nurse stated:

If it were up to me the CAPCE course would be mandatory for all. Because when you are the nurse in the rural setting you can’t just go and say ‘well the nurse on the next shift will, that’s their specialty’. So to me I would make that [CAPCE training] mandatory so we can provide excellent palliative care in the home. Respondent 8

One of the rural nurses stated that she had CAPCE training and then described the added benefits of her role with this training, “I was a CAPCE trained nurse so I mean I would help with medications, consult with pain specialists if they were having pain issues or with the family doctor helping them to adjust the medications that way.” (Respondent 9)

In addition, nurses often consulted with specialists from urban centers to help solve clinical issues that could not be managed effectively through local resources since “they’re always there at the other end of the line to help us out if we call down” (Respondent 3); this was viewed as an enabler in providing quality palliative care in rural communities. One nurse described a specific example:

I would phone, I’m not that shy so, we had a man in a rural setting, he was on continuous chemo[therapy] and we ran into the odd snag. So I had phoned right down to [urban center] and got the oncology floor. Oh, I know another time, one of the PICC [Peripherally Inserted Central Catheter] lines clogged up and I wasn’t quite sure what I should be doing with this because this usually happens on a weekend. I just phoned right to the actually oncology floors…another time I phoned the chemo specialist down there and just left a message with the secretary. Respondent 5

However, nurses emphasized the importance of meeting face-to-face as well but sometimes this is not always possible. One nurse stated:

I like to have a lot of in-services, I like to see who the players are, I can see who my pain and symptom control person is because they are coming to give us an in-service. So it’s easier than to pick up the phone and call them up. I would love to be able to meet some of the people down in [urban center] that I have been on the phone with. Respondent 2

Nurses also described the benefits of using a team approach to care in many different ways, including how an interdisciplinary team provides care holistically within a palliative care focus. One nurse emphasized:

[working on an interdisciplinary team] has broadened my knowledge of what these people [other interdisciplinary members] actually do. It helps to
collaborate because I don’t always think of everything. And they come up with some pretty darn good stuff. So it just helps to have more ears and more minds involved. Respondent 11

A nurse described the importance of a team approach to care that occurs within the home setting as well, sharing care at the bedside to optimize the skill set of different health care providers, especially physicians.

So I think the biggest enabler is the doctors who are willing to come out to the home to assess the patient even if it’s for a little bit, so they can make sure that what they are providing is on target for what the patient needs at that point. Respondent 12

3.4 Tools That Facilitate the Delivery of Palliative Care

Tools for practice, such as the ESAS (Edmonton Symptom Assessment Scale) or the PPS (Palliative Performance Scale) were identified by many nurses as being helpful in their practice when caring for clients who were dying in rural communities. In addition, many nurses stated that they use ‘symptom management kits’ which include a set list of medications that we anticipate we might need in palliative settings or “need something in the middle of the night” (Respondent 12). Another nurse added:

We still have to call the doctor in the middle of the night [to use the medications in the symptom control kit] and that’s sometimes a problem. But I think that has been fairly good and that’s working with the pharmacy and the case manager and the doctor to get all of that sent onto the client. Respondent 9

4.0 Discussion

The findings from this qualitative study highlight the barriers and enablers that rural home care nurses describe as influencing the way they attempt to provide quality palliative care to individuals living in rural communities. These findings are important to gain a deeper understanding of the challenges and supports that face rural nurses so that efforts can be directed at addressing some of these barriers to improve, not only nurses’ quality of their work life, but also the quality of palliative care to individuals living in rural communities together with their family members.

Some of the professional practice barriers that the nurses describe are not unique to rural settings (i.e., working with families, conflict among health care team) but are still important to consider when developing interventions to support rural nurses in their practice. Since family members are often the primary caregiver for a dying relative, nurses need to work closely with them optimize care processes. Novik and MacLean (2012) found that effective communication among palliative care providers, the patient, and the family member was critical to providing high quality care in remote communities. Otherwise, communication issues will negatively impact the ability to care for those with a terminal illness (Ingleton, 2000).

One of the enablers that was highly endorsed by nurses was their high regard for Comprehensive Advanced Palliative Care Education (CAPCE) training for nurses. CAPCE is a program that was developed by the Palliative Pain and Symptom
Management Consultation Program of South-western Ontario, Canada and funded by the Ontario Ministry of Health and Long Term Care (Harris, Hillier, & Keat, 2007). It includes training for both registered nurses and registered practical nurses with the aim of providing both education and support to nurses, focusing on optimizing workplace resources and fostering practice change. Training is facilitated through a regional Palliative Pain and Symptom Management consultant (PPSM). Evaluation of the CAPCE program indicates many positive effects, including enhanced palliative pain and symptom management, staff education, and development of care policies and guidelines (Harris et al., 2007; Hillier, 2009). More opportunities are needed for rural nurses to participate in CAPCE training to build capacity within rural nursing to provide effective palliative care. In doing so, the quality of work life for nurses may also improve as Hunsberger and colleagues (2009) have shown that providing rural nurses with continuing education and support for roles that are demanding, increases both their job satisfaction and retention in the rural workforce.

Findings from this study related to the spatial-temporal barriers that exist for nurses are characteristic of rural communities and present many challenges for nurses in organizing and managing palliative care for clients who quite often may not have predictable trajectories in their care management. Other studies have found similar findings; that is, in rural geographies, the most commonly reported barrier to providing optimal palliative care was the large distances involved and time required for visiting patients in their homes, which is often exacerbated by poor weather conditions (Fillion, Viellette, Wilson, Dumonte, & Lavoie, 2009; Kaasalainen et al., 2011; MacLeod et al., 1998; Robinson, Pesut, & Bottorff, 2010; Veillette, Fillion, Wilson, Thomas, & Dumonte, 2010; Wilson et al., 2009a; Wilson et al., 2009b).

Nonetheless, these study findings highlight the benefits of working in rural communities for nurses, and the cohesive community supports that exist for individuals and their family members throughout their dying experience. Goodridge et al. (2010) found that rural communities had more patient-centred care as many of the relationships between health care providers, family members and patients had existed long before the patient required palliative care, established relationships which contributed to better outcomes. The sense of community and cohesiveness within rural geographies clearly has an impact on both the quality of living and quality of dying for its members.

These study findings also highlight the importance of providing culturally-sensitive care, as nurses described the challenges that they faced across differing cultural or ethnic groups. Novik et al. (2012) previously suggested that health care providers need to have cultural awareness to provide quality palliative care in rural and remote communities; where cultural differences can impact (a) decision-making processes related to palliative care, (b) family involvement in the process, and (c) the communication styles among health care providers, family members and their relative who is dying. For the most part, nurses are not trained in how to provide culturally sensitive care but, based on the findings of our study, they seemed to ‘learn on the fly’ and creatively adapt their care practices to accommodate the conditions that they worked in while trying to maintain safe and effective care for individuals dying in their home environment.

Clearly, rural nurses relied on many supports to help them provide quality care to community members. In particular, access to palliative care specialists in urban centers was mentioned repeatedly in the interviews with collective agreement that this support was indeed helpful to them. Robinson et al. (2010) found similar
results; it was interesting to note, however, that they found generalist rural clinicians resisted specialized rural palliative care teams. Further work is needed to build stronger supportive networks between rural clinicians and specialized palliative care clinicians, both among rural and urban communities.

There are limitations to this study. First, data was collected in one province of Canada so results may be different in other locations. This study addressed the perspective of nurses only. Future work is needed to explore perceptions of personal support workers, physicians and other care providers in terms of what they identify as barriers and enablers to providing high quality palliative care to individuals living in rural communities. Also, nurses were sampled from only one nursing agency with a particular and solid culture of community involvement of its own; hence the results may not be reflective of all community nurses who work in rural areas.

5.0 Conclusion

In summary, the findings from this study add to the growing body of literature on the experiences of health care providers working in rural communities in terms of the barriers and enablers that affect the provision of palliative care. Nurses described how these barriers or enablers affected their practice and ultimately the clients that they care for. These findings are important since nurses play a major role in caring for community-dwelling clients who are dying. As such they need to be equipped with the knowledge, tools, and skill sets to provide optimal palliative care to their clients and their clients’ family members. Moreover, they need to be supported within an interdisciplinary approach of care. These results may help inform policy decisions around the needs of nurses who practice in rural settings and the adequacy of the current system to provide quality care to individuals who are dying and their families.

6.0 Acknowledgements


7.0 References


