

Résumé

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## **L'expérience des soignants familiaux en région rurale en matière de transport des patients en soins palliatifs**

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Carole A. Robinson, Barbara Pesut**

Le transport est une question importante pour les patients des régions rurales qui sont atteints de cancer avancé et reçoivent des soins palliatifs. Cette étude qualitative de nature descriptive visait à explorer les expériences des soignantes et soignants familiaux qui s'occupent d'un proche recevant des soins palliatifs avancés dans un centre de traitement régional. On a mené des entrevues auprès de 15 soignantes et soignants (âgés de 27 à 73 ans) qui accompagnent un proche à ses rendez-vous. La vie en région, les multiples responsabilités en matière de soins, la présence d'un réseau social et la culture du centre régional de traitement constituent des facteurs contextuels pertinents. Un grand thème se dégage des entrevues : le souci de faire en sorte que les déplacements soient les plus agréables possibles pour les patients. Parmi les sous-thèmes, soulignons : *la planification requise pour parer à toute éventualité; les expériences sur la route; le fardeau des déplacements pour les soignantes et soignants; la volonté de tirer le meilleur parti de la situation*. Les auteures formulent des recommandations en matière de soins auto-administrés, de prestation des soins infirmiers et de recherche.

Mots clés : cancer, prestation des soins, soins palliatifs, régions rurales

# Experiences of Rural Family Caregivers Who Assist With Commuting for Palliative Care

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Commuting for advanced cancer care is an important option for rural patients who require palliative treatment. The purpose of this qualitative descriptive study was to investigate the experiences of rural family palliative caregivers (FPCs) who supported advanced cancer patients receiving palliative treatment at a regional cancer centre. Semi-structured interviews were conducted with 15 FPCs (27–73 years of age) who commuted with family members. Rural life, the multiple responsibilities borne by FPCs, the availability of support networks, and the culture of the regional cancer centre were all relevant contextual factors. The dedication of FPCs to making the commuting experience as positive as possible for the patient was the central theme. Subthemes were *planning ahead to prepare for all possibilities*, *experiences on the road*, *the toll of commuting on FPCs*, and *making the best of it*. The authors offer recommendations for self-care, nursing practice, and future research.

Keywords: cancer, caregiving, environment and health, family health care, palliative care, rural and remote health care

Studies have been conducted to describe caregivers' perspectives on travelling for cancer care (Longo, Fitch, Deber, & Williams, 2006; McRae, Caty, Nelder, & Picard, 2000). However, the commuting experiences of family palliative caregivers (FPCs) who accompany advanced cancer patients from rural and remote locales for palliative care (PC) is largely uncharted. Palliative caregivers are known to be at risk for physical and psychosocial morbidity and to face economic challenges (Aoun, Kristjanson, Currow, & Hudson, 2005; McRae et al., 2000). Little is known about the effects on FPCs when they take on responsibilities for commuting in addition to other caregiving tasks. This knowledge could be used by nurses and other health professionals to enhance supportive PC for families travelling to access services for their loved ones. In the absence of information on FPC commuting experiences, health-care interventions and supportive measures may fail to address key family needs. The aim of this study was to examine the experiences of FPCs who commute from rural and remote locales with a family member receiving advanced cancer care and to broaden our knowledge about the demands of family caregiving in that context.

## **Literature Review**

Despite attempts to define rurality and take into account relative levels of remoteness, there is a lack of consensus on how rural communities should be classified. For example, the Canadian Rural Information Service defines rural as areas with fewer than 150 people per square kilometre ([www.rural.gc.ca/cris/fac/def\\_e.phtml](http://www.rural.gc.ca/cris/fac/def_e.phtml)) and Statistics Canada defines rural and small towns as communities with populations of under 10,000 (duPlessis, Beshiri, Bollman, & Clemenson, 2002). Nevertheless, the urbanization of Canadian society, with almost 80% of the population living in small or large cities (Statistics Canada, 2008), is a significant factor influencing health services in rural and remote areas. Although PC services in Canada are increasing, as specialist services they tend to be situated in urban centres while in rural and remote communities they are provided by local generalist health-care providers, including community nurses, family doctors, and volunteers. This trend is not likely to change.

In the province of British Columbia, evidence suggests that the majority of those who could benefit from hospice PC services do not have direct access to such services (BC Hospice Palliative Care Association, 2005). Access is particularly limited for residents of rural and remote areas. Out of necessity, patients and their families living in rural parts of the province often travel to larger centres in order to access PC services. At present, there is a dearth of research on PC in rural and remote settings (Robinson et al., 2009). In particular, the influence of rurality and the family perspective is underrepresented. Yet family-centred care is one of the foundations of hospice PC (Canadian Hospice Palliative Care Association, 2003), and FPCs are a critical element in PC services in both urban and rural settings because of the role they play in home-based care. Literature reviews on the topic conclude that as caregivers take on more complex care, their ability to meet all demands is challenged (Andershed, 2006; McCorkle & Pasacreta, 2001).

Researchers have described the needs of family caregivers in rural contexts (MacLean & Kelley, 1997; McGrath, 2006; McGrath et al., 2006; McGrath, Ogilvie, Rayner, Holewa, & Patton, 2005; McRae et al., 2000; Wilkes, White, & O'Riordan, 2000; Wilson et al., 2006). In the only two applicable Canadian studies located (MacLean & Kelley, 1997; McRae et al., 2000), accessibility and quality of services are reported to be primary considerations for caregivers. What is poorly understood is the impact of travel on rural FPCs who transport and accompany family members to palliative cancer services in urban centres. There is also a lack of information on how commuting influences the caregiving capacity and well-being of FPCs.

Palliative care studies conducted in rural settings have not always accounted for geography and the influence of other factors related to the place where people reside (Robinson et al., 2009). There is growing acknowledgement that the characteristics of where people live, including geography, climate, the built environment, and socio-economic characteristics, are all factors that have the potential to influence health and that need to be better understood (Solberg & Way, 2007). Understanding the influence of place becomes particularly important when geographical location provides the context for health-related experiences and nursing practice (Bender, Clune, & Guruge, 2007).

As part of a larger study focusing on the needs of rural PC patients and their caregivers served by a regional cancer centre in British Columbia, we interviewed both PC patients and family caregivers who had experience with commuting for PC. We found that commuting presented patients with challenges, including the time and energy needed to prepare for travel (e.g., pain management), to maintain significant relationships, and to deal with anxiety related to the trip (Pesut, Robinson, Bottorff, Fyles, & Broughton, in press). Although commuting was costly, it had significant benefits for patients in terms of supportive relationships and quality of life. In this article, we describe FPCs' perspectives on supporting family members in commuting for advanced cancer care.

## **Method**

A qualitative descriptive design was used for this study (Sandelowski, 2000). The study was conducted in the south central region of British Columbia served by a regional cancer centre adjacent to a tertiary-care facility in a small city. The cancer centre served a health region of approximately 215,000 square kilometres, including many rural communities. Advanced cancer treatment provided at the centre included radiation therapy, chemotherapy, and pain and symptom management as well as support services. A nearby lodge offered affordable accommodation and meals. Ethical approval for human subject research was obtained from the university and the health authority.

## **Sample**

Purposive sampling was used to recruit 15 FPCs who were (a) actively involved in providing care to a family member with advanced cancer, currently or within the previous 2 years; (b) commuting from a rural or remote area for the purpose of accompanying a patient who was receiving advanced cancer care at the regional cancer centre and who had been identified by the centre as palliative; and (c) English-speaking. For the purposes of this study, rural/remote was defined as outside the commut-

ing zone of a “major urban centre” — a community of 10,000 or more people. In the study region, nine centres met the criteria for major urban centre at the time of data collection. Those FPCs who did not reside in one of those nine places were considered to be living in a rural locale. During scheduled clinic visits at the cancer centre, potential participants were flagged by rural or remote postal code. These people were approached by a specially trained cancer centre volunteer, who gave them a pamphlet about the study and invited them to complete a consent-to-contact form. Those who agreed to receive further information were contacted by one of the authors (SL), who provided more information, obtained informed consent, and set a time for an interview.

An overview of the sample is provided in Table 1. The average commuting distance was 177 kilometres each way. Although the majority of FPCs returned to their own homes on the same day, some stayed in town because of the time required to travel long distances, frequency of appointments, illness of the patient, or weather conditions. Four participants made use of the nearby lodge for overnight stays and meals.

<b>Table 1 Characteristics of Sample (n = 15)<sup>1</sup></b>	
<b>Gender</b>	
Male	6
Female	9
<b>Age (years)</b>	Average = 55 (range = 27–73)
<b>Education</b>	
High school diploma	3
Technical/trade diploma	7
University degree	4
<b>Marital status</b>	
Married or living with a partner	11
Not married or living with a partner	3
<b>Residency status with regard to patient</b>	
Living in same household	12
Living in same community	1
Living in different community	1
<b>Income</b>	
\$11,000–24,000	2
\$25,000–49,000	4
\$50,000 or higher	6
Don't know/prefer not to answer	2
<sup>1</sup> Demographic data missing for one participant.	

### ***Data Collection***

A demographic questionnaire, together with an in-depth semi-structured interview, was the primary means of data collection. The majority of interviews were conducted face-to-face in participants' homes or at the cancer centre. At their own request, one third of FPCs were interviewed by telephone. Interviews were digitally audiorecorded and ranged in length from 30 minutes to almost 3 hours. Open-ended questions were used to invite participants to share the experiences and concerns they deemed most important. Field notes were recorded (Morse & Field, 1995); these included information on locale and the interviewer's initial impressions of the interview. An honorarium of \$20 was provided to FPCs in acknowledgement of their contribution to the research.

Five FPCs were interviewed following their first commute for advanced cancer care. Among the remaining participants, commuting experiences ranged from three visits to numerous visits over an extended period. Several participants accompanied family members who were in a fragile state; increased pain and unpleasant symptoms made travel even more difficult towards the end-stage of the illness.

### ***Data Analysis***

The initial transcripts were read several times and open-coded independently by the authors. At team meetings, observations of the data were discussed and a preliminary coding framework was developed to capture salient ideas and themes. Coding then proceeded using NVivo data-management software. As additional transcripts were reviewed, new categories were added to the coding framework and some codes and their definitions were revised. Additional questions that surfaced during data analysis were incorporated into subsequent interviews. Once coding of the interviews was completed, data for each category were retrieved and constant comparison was used to identify and refine themes and sub-themes.

Methodological rigour was strengthened through verification strategies, clarification of the disclosures, identification of experiences common to all families or unique to particular families, the gathering of additional details to enrich descriptions, and analysis concurrent with data collection. An ongoing process of discussion and revision of coding served as one component of the internal audit. An electronic audit trail of procedures, decisions, possible thematic development, and sources of bias was initiated at the beginning of the study and continued until the study was complete.

## Findings

### *Context of Commuting for Care*

The commuting experiences of FPCs were influenced by four contextual factors. The first was rural life. Although rural living was highly valued by participants, it came with a price. Experience had taught FPCs to expect challenges in commuting long distances, whether related to weather, road conditions, traffic problems, accidents, road construction, or vehicle breakdowns. Goods and services are more expensive in rural communities than in larger towns and there are costs associated with travel (e.g., gas, meals, and accommodation). For the group as a whole, the weighing and consideration of expenses was a preoccupation. Commuting added to the financial strain, particularly for those with fixed incomes or reduced employment incomes as a result of caregiving. One FPC knew she could fall back on family members to help out if she found herself “completely tapped for cash,” but at the same time she worried about “taking away” their financial resources:

*It's a lot more stress, you know, because . . . I'm on [employment] leave so my income isn't high, and when you're paying 60 bucks in gas to go out, it gets pricey.*

The second contextual factor influencing commuting was the busyness of FPCs' lives and the added burden associated with commuting. Participants fulfilled a range of roles and responsibilities at home and in their communities, as parents, employees, volunteers, and community members. Layered upon these was their role as a palliative caregiver and their responsibilities related to commuting. The burden of commuting was heavier because of these multiple commitments.

The third contextual factor related to the strong social networks that are characteristic of some rural communities. Commuting experiences were therefore influenced by the availability of support in rural settings, as well as whether FPCs accepted the support that was offered to them, as evident in a comment provided by one FPC:

*Early on, we felt it was something the two of us could do with no help. [laughs] . . . you're married 43 years, you figure, well, okay, you can do this.*

The majority of FPCs did not have close relatives living nearby and thus relied primarily on friends or neighbours. When family members did live nearby, they were usually involved in the commuting experience.

Finally, the regional cancer centre and services represented an important contextual influence. Participants spoke of the staff, including volunteers and receptionists, as providing compassionate care. They noted in

particular that the friendly and encouraging manner of the staff serve to create a community of support. The majority of participants described visits that included good humour, smiles, and a sense of being remembered between appointments by staff and volunteers at the cancer centre and the lodge. In summary, the nature of rural life, the multiple responsibilities borne by FPCs, the availability of social networks, and the culture of the regional cancer centre all provided context for how FPCs experienced commuting.

### ***Family Palliative Caregivers' Experiences of Commuting***

Family caregivers took their responsibility to support commuting seriously and were committed to doing everything in their power to ensure that their family members received the treatments they needed. A 36-year-old FPC who drove his mother in for care stated, "Whatever you have to do, you make . . . it happen . . . with work or anything . . . family is everything." Four themes capture important aspects of FPCs' experiences of commuting: *planning ahead to prepare for all possibilities*, *experiences on the road*, *the toll of commuting*, and *making the best of it*.

***Planning ahead to prepare for all possibilities.*** Planning and preparation were key to ensuring that the commute went as smoothly as possible and that appointments were not missed and that they were flexible for rescheduling. Family palliative caregivers had to attend to every detail. Preparations included a number of strategies. The first involved attention to a range of practical issues: getting time off work; making sure the car was in excellent running order; packing clothes, medications, and equipment for the trip; occasionally arranging for a second driver; and monitoring weather and highway conditions. The participants not only needed to consider the possibility of traffic delays or poor road or weather conditions, but also had to plan for contingencies in case of breakdowns or other problems:

*If you go off the road or hit a deer, then you've got to be prepared . . . because then you have to take into consideration the person with you is [in a] compromised [condition] . . . in general, so they get cold faster . . . they need their medicine . . . they're just not able to do the hike or walk that far, or stand for 3 hours hitchhiking, or whatever the case may be . . . So you always want to make sure that if that happened, . . . one person was able to stay in the vehicle and stay warm, then the other person could go for help or gas or whatever.*

Anticipating the needs of the family member was the second major planning strategy used by FPCs, to be sure the person was as comfortable as possible during commutes. They had to ensure that even when the patient was not well they would both be prepared to take the trip. One



FPC observed, “That’s not really conducive to cancer treatment at all . . . you know, he’s throwing up on the road or whatever, you still have to go.” The potential for changes in level of debility over the course of the treatment challenged FPCs to engage in monitoring before each trip. They watched over family members to assess their sleep, activity and energy levels, changes in appetite and associated changes in weight, and adherence to medication regimes. Assessing pain was one of the more difficult monitoring tasks that FPCs took on to guide their planning: “It’s tough . . . [the] physical . . . also mental [pain] . . . [and] taking inventory as to where the pains are.” One caregiver described pain control as “big” and said that it was important to “take lots of breakthrough doses” for the trip. Packing analgesics and other supplies in a “just in case” bag was common practice, to be prepared for any unexpected changes or events during the trip.

Managing time was the third strategy used by FPCs. A high degree of flexibility and planning was needed to be sure that there was sufficient time to make all arrangements and get to appointments on time. Participants reported that they always planned to leave early in order to build a cushion of time into each trip. They also found that they needed to anticipate changes in appointment times and the possibility of unexpected wait times. The participants needed to plan for “an all-day affair” as well as very short radiation treatments. In the case of brief appointments, the FPC barely had time for a hot drink before heading out on the road again. Unlike paid caregivers, FPCs did not get breaks from the responsibilities associated with commuting. The concepts of time and time management as discrete knowable entities were replaced by the idea of time as a fluid commodity. In summary, planning ahead required considerable effort on the part of FPCs.

***Experiences on the road.*** For FPCs, the demands of commuting were most clearly reflected in their experiences on the road, where they not only took responsibility for driving and getting their family member to appointments safely and on time, but also managed other caregiving responsibilities. Their experiences are captured in three subthemes: *doing double duty*, *getting into a routine*, and *dealing with unfamiliar territory*.

The multiple roles that FPCs took on while travelling can be described as doing double duty. Caregivers needed to be particularly cautious with their driving, especially when patients found it difficult to sit in the car for long intervals due to pain or when their discomfort was aggravated by rough roads. Assessing the person’s physical tolerance for the trip was an important part of commuting — a part of the job that became more difficult as the disease progressed and the patient suffered increasing pain and fatigue as well as other effects of the disease or side effects of the treatments. Some caregivers found it hard to motivate the

person to make the trip in for more treatment when he or she was experiencing nausea and vomiting that might be made worse by a long car ride. Managing the range of emotions experienced by the ill person in relation to commuting for cancer care was also a challenge. While driving, FPCs responded to the person's anxieties related to upcoming appointments, reluctance to travel, disappointment at having to return for additional treatments, and loss of independence associated with the advancing disease. The range of support provided by FPCs is illustrated in the account of a participant who found himself coaching his wife during the commute on how to manage her claustrophobia during radiation treatments. He suggested she use images to distract herself:

*Trying to imagine what it was going to feel like lying there. You know, when you can't move your head, right? And what sort of things can you see that are going to help you deal with that? So we talked about what she would try and imagine. Like her garden . . . or, on a particularly nice day in the fall, walking the dog . . . and it's nice and the colours are out and it's cool and sunny.*

Getting into a routine, the second subtheme capturing FPCs' experiences on the road, was a common experience among those who commuted frequently. These participants began to feel as though they were "on autopilot." One man commented, "There [were] days . . . holy cats, here we go again! . . . Pretty soon the truck would go by itself." Although being "on autopilot" helped FPCs manage the additional responsibilities associated with frequent commuting, over time the trips became tiring. In addition, routines were disrupted sometimes, such as when appointments were unexpectedly changed.

Dealing with unfamiliar territory was the third subtheme identified in the FPCs' commuting experiences. The additional stress and numerous arrangements required when accompanying a palliative patient took commuting outside the realm of customary travel. A few FPCs were unaccustomed to long-distance driving and city traffic. The role reversal from secondary to primary driver created a stressful trip to the city for one wife, who had never driven such a long distance before. She opted to leave home a day early to avoid heavy traffic.

***The toll of commuting.*** For most of the FPCs, commuting for advanced cancer care had implications for their own health. As their family member's disease progressed, seven of the FPCs experienced a range of health impacts related to commuting, including the stress of driving, increased worry, anxiety and tearfulness, fatigue, exacerbation of chronic health conditions leading to physical discomfort, and altered sleep and eating patterns. A few FPCs who could not remain in town during treatments because of commitments at home found that they

were unhappy being home alone and worried about the ill person. Anxiety about what would occur at the cancer centre and concern about the patient's well-being often obscured their own health issues. In one case, an FPC omitted her regular prescribed medications because she was concerned they would make her an unsafe driver. Some FPCs admitted that they would forget to take their pills and would put themselves "on hold" or "on the back burner" during the commuting period. Two FPCs reported that pre-existing chronic conditions worsened and caused them physical discomfort during the commute. Despite these health issues, FPCs never wavered in their commitment to supporting family members on their commute for care.

***Making the best of it.*** Practical-minded FPCs took advantage of the travel to a larger centre to do errands and shop for items that were not available in their own community. Participants also focused on making the commute as pleasurable as possible. There was a strong consensus that commuting for advanced cancer care should be combined with enjoyable pursuits. The overall commuting time was valued by many as an opportunity for meaningful conversation. Discussions about goals, asset protection, or relationships, or just enjoyable private chats, seem to have been facilitated by the close quarters of the car, motel, lodge, or airplane. One FPC noted:

*I think people just find it easier to talk in a small space . . . you have that extra time that's just there, just for you . . . that few hours that you're taking to drive in or out. I think it becomes important.*

The idea of the car as an intimate space played out for other families as well. Married couples sometimes became closer because of the commuting experience. One FPC explained, "We're near the end of where we need to — where we are — and so every time for us together is important . . . we need the time together."

There were also examples of taking advantage of the travel to renew connections with relatives and friends and to do something different or special (e.g., have a meal at a new restaurant) or to fit in some shopping. Some FPCs found it difficult to find a balance between supporting the family members' engagement in these activities and preventing them from doing too much.

### ***Family Palliative Caregivers' Recommendations for Commuting***

Participants had a number of recommendations for families in similar circumstances and for health-care providers. Their recommendations centred on various strategies for maintaining overall health and building endurance for travelling in these particular circumstances. One spouse

used sombre tones in describing what he thought other FPCs should be told:

*Take what you think [is] the worst thing [that could] happen to your partner and double it, triple it, in terms of how they're going to feel. Because it really is quite scary, in terms of how physically beat up individuals get. . . . And they can say, "Yeah, you're doing fine" . . . and you look at this individual who is just hardly anything there. And there's no energy . . . It's just . . . it's an eye opener. . . . Take the good stuff [out of the situation] that you can. Certainly, don't dwell on the down side of it. Enjoy the time with your partner.*

Being well organized, getting ready well in advance, and being prepared for unexpected events were reiterated by the FPCs as important strategies. In addition, participants emphasized the importance of asking for driving assistance. Self-care suggestions were what most FPCs wanted to pass along to others who might need to commute with a family member in the future. The most endorsed recommendation was that FPCs and patients arrange to stay over in the city or town during treatment, to reduce the strains associated with travel.

The participants stressed the link between how cancer care is provided and positive commuting experiences. Their expectations of health-care providers included good communication, clear information, acknowledgement of the prognosis, appreciation of the demands of commuting, permission for FPCs to observe treatment whenever possible, weekend support by volunteers, caregiver support groups, and a social services liaison. One FPC was returning to the cancer centre with his mother after 2 years away:

*I think the most important thing is that when you arrive, you have a good experience from the doctors . . . no matter what's happening with . . . the cancer. Like, you don't want to drive all that way and go away . . . disappointed.*

To address the financial implications of commuting, FPCs advocated for "compassionate pricing," rebates for travel costs associated with commuting, and ready sources of funding to cover basic commuting costs that ought to be available right at the cancer centre.

## **Discussion**

This study is one of the few to describe in detail FPCs' commuting experiences for advanced cancer care and the investment of time and energy entailed in taking on this responsibility. For FPCs, the commute involved much more than simply driving. Their dedication to making the

commuting experience as positive as possible for the family member underpinned their extensive preparations for the trips, precautions taken to ensure safe travel regardless of weather and road conditions, efforts to continuously monitor the impact of travel, and provision of comfort and support during commutes. These activities demonstrate the extra work that FPCs put in on a regular basis to support commutes — work that sometimes pushed them beyond their limits of endurance. Moreover, the financial burden of commuting was a significant worry for some. Despite these challenges, FPCs discovered unexpected benefits to commuting.

The study's findings are influenced by the particular characteristics of the setting and how cancer services are provided there. The experience could differ for FPCs who live in very remote settings, have greater responsibilities associated with rural life (e.g., farming duties), have inadequate financial resources, or have limited access to reliable transportation. The experience could also differ when the person who commutes with the patient is not a family member. This study did not capture the experiences of those FPCs who had to stop commuting because the travel could no longer be managed, by either the FPC or the ill person, or of those FPCs who chose not to commute at all. The relatively small sample may not have captured the full range of FPC experiences. Despite these limitations, the interviews produced a rich data set that provides important insights into FPCs' experiences of commuting and that extends our understanding of an important dimension of PC in rural settings.

Although other studies describe the needs of family caregivers in rural contexts (McGrath, 2006; McGrath et al., 2006; McGrath, Ogilvie, Rayner, Holewa, & Patton, 2005; McRae et al., 2000; Wilkes et al., 2000; Wilson et al., 2006), our study included a more detailed examination of the influence of the rural environment on the experiences of FCGs. The importance of taking into consideration complex rural dimensions of health experiences has been recognized (Harvey, 2007). However, a focus on the social and economic hardships of rural life has often directed attention away from the positive aspects of rural life (Rogers-Clark, 2002) and tensions inherent in rural life (e.g., tension between social isolation and sense of belonging) (Harvey, 2007). In this study, rurality influenced family caregiver experiences in complex ways that both enabled commuting and made it particularly challenging.

Since rural environments influence the way people relate to one another and are often characterized by strong social networks, it is not surprising that FPCs benefited from local instrumental and emotional support that directly influenced the commuting experience. However, there were also many instances of FPCs declining or not asking for assistance. While the independent nature of many rural dwellers might be an

explanation, there were hints that FPCs wanted to protect their privacy and the personal time they had available to spend with their family member. It is possible that FPCs perceived that those less familiar with their family member's condition would not be able to take on the additional caregiving responsibilities they associated with commuting and that it would be too much to ask of them. Most of the FPCs chose to make the journey alone with the patient, and few asked another person to go along, either as an extra driver or as a companion. This position is illustrated in their descriptions of the intimacy afforded by the drive to and from the cancer centre as well as the complexities of managing pain and other side effects during commutes. These are features of commuting that have not been systematically described, and they point to potential drawbacks of depending on volunteer drivers. An added advantage for FPCs and patients when they travelled together was the opportunity to engage in interactions infused with meaning. This is an important observation. These types of interactions have been noted as essential for family well-being (Syren, Saveman, & Benzein, 2006).

Commuting is generally an accepted part of rural life and the familiar routines of travel prepared FPCs to assess and modify the commuting approach when palliative caregiving was needed. However, the findings highlight the additional responsibilities and stressors that result when travel is needed due to advanced cancer care for family members. In particular, the FPCs' experiences were influenced by pressures caused by their growing awareness of the family member's nearing the end of life and increasing difficulty coping with the travel. The pain, exhaustion, or other side effects experienced by ill family members were concerns that affected FPCs while commuting. The tiring and stressful effects of commuting had a direct effect on caregivers' own health. Researchers have described the psychological, occupational, and economic aspects of caregiving in this context. For example, Grunfeld et al. (2004) report substantial increases in caregiver anxiety and depression as family members enter palliative and then terminal phases of their illness. The present findings suggest that the physical, psychological, and economic impacts on FPCs are magnified when commuting responsibilities for PC are added to their already difficult caregiving roles. The challenges of pain and symptom management and provision of psychological support during commutes need to be considered as important aspects of caregiving in rural contexts.

Participants were independent, self-reliant, and dependable when it came to commuting, and were highly committed to being there at all costs for their family member. The result is that in some instances they may have encouraged patients to travel for advanced cancer care when this might not have been in their best interests. There has been a general

lack of recognition of the complexity of decisions and preparations for commuting in the context of advanced cancer care. Participants did the best they could with the information they had. The vital role played by family caregivers of those with life-limiting illness is recognized (Andershed, 2006). Extending adequate support to FPCs can serve to improve the quality of life of palliative patients.

In summary, although participants viewed the rural environment as an important resource, rural living presented significant challenges that underpinned their commuting experiences. Despite many demands related to caregiving and commuting, FPCs strove to “make the best of it” in multiple ways. Hudson (2004) notes that it is important for health professionals to help caregivers realize the benefits in their role; it appears that these FPCs were able to do so on their own. These findings add to a growing body of literature supporting the need to recognize the tensions inherent in rural life, as well as the influence of rural environment, distance, and climate (Keating, 2008).

### **Recommendations**

The augmenting of PC services in rural communities is now under way, but it is likely that for some types of treatment (e.g., radiation therapy) commuting for advanced cancer care will continue to be a part of the experience of many patients and their families. The findings provide some direction for practice, policy, and future research. In relation to practice, nurses and other health professionals at all levels need to be aware of the potential challenges that FPCs face when they take on commuting responsibilities in addition to significant caregiving, employment, and family commitments, and the complex work that this involves. The health effects for FPCs of commuting for advanced cancer care cannot be ignored or underestimated. Efforts should be directed at providing FPCs with guidance for pain and symptom management while travelling, decision-making support related to commuting, and regular assessments of FPC well-being and support needs. Reducing the number of commuting days for rural and remote palliative families by coordinating appointments for diagnostics, treatment, and consultation should be a priority, to minimize the need for travel and associated costs. Advocating for policy changes to address the financial burden associated with commuting for PC is also clearly required.

The provision of effective support will ultimately depend on a more thorough understanding of the needs of FPCs who commute from outlying areas to regional centres. Further research is needed to deepen our understanding of the factors that influence the experiences of commuting FPCs, in order to develop effective support and respite measures that

will minimize the health risks associated with caregiving. Examining the influence of the frequency and duration of commuting on FPCs' experiences and health outcomes is also important, as well as the influence of diversity in terms of ethnocultural groups, gender, and socio-economic status as they relate to the commuting experience. Finally, through the extension of research initiatives to other rural populations who also commute for advanced cancer care, our knowledge of how rural contexts influence commuting experiences will be enhanced. The results of this research could also provide direction for improvements in the provision of PC services in these locales.

### **Conclusion**

The findings of this study hold particular significance for those who work with patients/families from rural and remote communities, especially given the trend towards the centralization of health services and expected increases in the numbers of individuals requiring PC associated with demographic trends in Canada. The insights into the experiences of rural FPCs who commute with a relative for palliative cancer care highlight a dimension of rural PC that is in need of greater attention. The results add to our understanding of the needs, challenges, and quality-of-life issues facing FPCs and suggest ways that nurses and other health professionals can support family providers of palliative care in rural areas.

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### **Acknowledgements**

This study was part of an investigation supported by a grant awarded to the Principal Investigator, Dr. Carole A. Robinson, by the BC Cancer Foundation – Southern Interior. The research was also supported by the Bryce Carnine Memorial Prize and a British Columbia Rural and Remote Health Research Travel Bursary awarded to Ms. Lockie.

Other team members who supported this work include co-investigators Dr. G. Fyles and Ms. Sandra Broughton.

There are no conflicts of interest or financial disclosures to declare.

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