

ORIGINAL RESEARCH

'I am part of the community but...' The changing context of rural living for persons with advanced cancer and their families

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ABSTRACT

Introduction: Older rural persons who are receiving palliative care experience multiple co-existing transitions that can be distressing. These transitions do not occur in a vacuum, but occur in a context that reflects the uniqueness of rural living and the complexities of end of life in rural settings. The context or situation (geographical, physical, and social) in which an experience occurs influences the way people view and interpret the world around them; this contextual perspective contributes greatly to perceptions held by rural residents. Purpose: The purpose of this study was to explore the context in which older rural patients receiving palliative care and their families experience transitions. Following a study of the transition experiences of older rural palliative patients, an in-depth interpretive description analysis was conducted specific to the context in which the participants' transitions occurred.

Methods: Twenty-seven open-ended, individual, audio-taped, qualitative interviews were conducted and 4 focus group discussions were held to gather data. Individual audio-taped interviews were conducted with six older rural persons with advanced cancer and 10 bereaved (post-death) family caregivers. Four focus groups were conducted with 12 palliative care healthcare professionals. Participants were recruited from 3 rural health regions in a western Canadian province classified as one of the most



'rural' Canadian provinces. All interviews were transcribed verbatim, coded, and analyzed using Thorne's interpretive description qualitative approach.

Results: From the data analysis four themes emerged: (1) community connectedness/isolation; (2) lack of accessibility to care; (3) communication and information issues; and (4) independence/dependence. Participants described feelings of being connected to the community at the same time as they also reported feeling isolated. They described their value of independence at the same time as finding themselves becoming increasingly dependent on others. At times this value of independence interfered with their seeking and accessing needed health or supportive care. They perceived their lack of access to health care resulted in little or no choice in where they die.

Conclusions: These findings reveal that the rural context has a major impact on the types of community support and healthcare services needed by older persons with advanced disease and their families. With advanced disease, the participants' sense of solitude became one of isolation, and with increasing dependence on others, they needed more connection and support from others. The findings reflected a more complex view of rural aging and dying than has been cited in the literature to date. This study suggests there is a need to renegotiate community supports and the independence available to persons with advanced disease as they undergo multiple transitions near the end of life.

Key words: ageing, Canada, interpretive description, palliative, qualitative, research.

Introduction

I am part of my community but I feel alone. Family and friends come to visit me, but I feel isolated as they are unable to understand what is happening to me and my wife. They are unable to care for me. My cancer has made me weak and dependent on others, although I have always been proud of being independent. I enjoy the peace and solitude of my home, yet I am so far from a pharmacy or my cancer doctor or help. My wife carries the burden now of caring for me and the farm. There is no one else. Yet this is my home.

The exemplar above reflects the impact of the rural context on the older person and their family as they experience multiple transitions associated with the progression of advanced disease. These transitions or significant changes are often changes in: (i) environment; (ii) roles and relationships; (iii) physical and mental health; and (iv) activities of daily living¹. They do not occur in a vacuum, but occur in a context that reflects the complexities and diversities of end of life experiences and the unique nature of aging in rural Canada. 'Context' is the situation (geographical, physical, and social) in which an experience

occurs² and it influences how people view and interpret the world around them; this contextual perspective contributes greatly to perceptions that rural residents hold. Keating suggested that research concerning older adults living in rural areas has not critically addressed the ways in which context influences their perceived opportunities and constraints³. Older adults can adapt and reconstruct the environments in which they live. This, however, can be more difficult when they are isolated because of age and living in rural/remote areas.

Rural Canadians experience a great number of health risks compared with their urban counterparts⁴. They report poorer health status, shorter life expectancy, and higher mortality rates than urban Canadians⁵. Williams and Kulig, in a review of the evidence on the impact of living in rural areas on health status, suggested the shortcomings of health services in rural areas play a significant role⁶. Canadian rural settings often lack tertiary and some forms of secondary care, resulting in a decreased capacity to provide quality palliative care⁷. These geographic inequities are expected to rise in conjunction with the projected increase in the population aged over 65 years⁸. The aging population is also expected to increase the prevalence of complex chronic illnesses, thus adding to the challenge of providing integrated palliative



care⁹. Although there is a growing body of literature focusing on the inadequacy of rural palliative care services⁸, there is also a need to understand the context in which rural palliative care occurs. Understanding this context has the potential to inform the future development of rural palliative care services. The purpose of this article is to report an in-depth analysis of the context of transitions for older rural patients receiving palliative care and their families. The data for this analysis were collected as part of a study exploring the transition experience of older rural palliative patients and their families, which is reported elsewhere¹.

Background

Rural living is often idealized as including social support from tight knit families, a strong sense of community, and a pace of life that is more peaceful and in tune with nature than urban living¹⁰. For those who are healthy and have readily available resources, aging in rural communities may be experienced within a context of independence and community support³. For those who are without resources, such as physical limitations and financial resources, their experience, in contrast, is often one of isolation¹¹. Isolation is limited contact with others and other resources such as healthcare services.

In addition to aging in rural settings, those who are diagnosed with a terminal illness are also dealing with end of life care issues. For example, these individuals may require highly specialized palliative care services to deal with a myriad of physical, psychological, and existential issues that often occur at the end of life. In a study involving 31 rural formal and informal palliative care providers, Castleden et al suggested that there is a difference between rural life and rural death¹². A sense of solitude can become a sense of isolation for those who are approaching end of life. As well, the caring nature of rural communities is replaced with care providers having to negotiate a lack of access to needed specialized services¹².

Lack of access to specialized palliative care services for rural residents' disease has been identified in several

studies^{8,13,14}. Fewer physician visits are made by rural residents and the likelihood of receiving home care services and professional home care services such as palliative care and physiotherapy is significantly lower for persons in rural/remote locations¹³. As a result fewer rural residents die at home than their urban counterparts as they need to seek health care outside of their community¹⁴.

Palliative patients and their families in rural settings experience significant changes (transitions) with the progression of advanced cancer. During transitions there are losses of networks and social supports, which may marginalize people and render them more vulnerable¹⁵. Research on transitions experienced by rural palliative care patients and their families has generally focused on two areas: (i) the transition from active cure-focused treatment to receiving palliative care^{16,17}; and (ii) the place or location of care transitions^{18,19}.

Two studies have explored the transition experience after a person has become palliative^{1,20}, but only one with older rural palliative care patients and their families¹. The transition experience for older rural palliative patients and their families involved multiple complex transitions in environment, roles/relationships, activities of daily living, and physical and mental health. The paucity of research on the context in which transitions occur for older rural palliative patients and their families leaves many unanswered questions about how the context of aging and dying in a rural environment influence these transitions. The purpose of this study was to explore the context or conditions under which older rural palliative care patients and their families experience transitions. More specifically, what is the geographical, physical and social context of older rural western Canadian palliative patients and their families?

Methods

Design

The findings of this article represent a planned in-depth analysis of data related to context from a grounded theory



study of the transition experience of older rural palliative care patients and their family caregivers¹. Rich data regarding the contextual characteristics emerged through the participants' descriptions of transitions. Using an interpretive description²¹ qualitative approach, an in-depth analysis was conducted on these data. Interpretive description is a useful approach to enhance understanding of phenomena, in this case the context in which persons deal with advanced disease. It acknowledges the constructed and contextual nature of the human experience and values the perspective of those living the experience¹⁶. As the concept of rural involves shared values and culture as well as geographic location²², the participants' self-identification as being 'rural' was the definition used for this study. All participants self-identified as rural. This study was approved by a university behavioural ethics review board.

Sample/setting: Using purposive sampling, 28 participants were enrolled (six older rural persons with advanced cancer receiving palliative care, 10 bereaved family caregivers and 12 rural healthcare professionals). The number of participants was determined by saturation, defined in grounded theory and qualitative research more broadly as when no new properties of the categories or theoretical insights are being gained²¹.

The palliative care coordinators from the 3 rural health regions in western Canada (population densities of 1.7–2.4 persons/km²) contacted potential participants who met inclusion criteria. Inclusion criteria for patients were: (i) 60 years of age and older; (ii) diagnosed with advanced cancer; (iii) self-reported to live in a rural area; and (iv) able to participate as determined by the palliative care coordinator. Bereaved family caregivers were defined broadly as family or friends who met the following inclusion criteria: (i) age 18 years or older; (ii) had experienced the death of an older (≥ 60 years) family member who received palliative care 2 to 12 months previously; (iii) self-reported to live in a rural area; and (iv) had direct contact with the decedent at least once per week in the last month of the decedent's life. Inclusion criteria for palliative healthcare professionals were: (i) age 18 years or older; and

(ii) providing direct care to older palliative care patients in rural settings.

Potential participants were asked if they could be contacted by a research assistant to discuss possible participation in the study. If they agreed, a study package which included study information and consent forms was mailed to potential participants. Data collection began once signed written informed consents were returned. Written informed consents for palliative care patient participants by trained research assistants were obtained at a visit to their homes at a time that was convenient for them.

Data collection: For all study participants, data collection involved completing a demographic form and open-ended audio-taped interviews using an open-ended interview guide focusing on transitions. Additional questions were adapted to the participants' responses. Although the questions were focused on transitions, data on the context in which the transitions occurred were explored in depth by the trained interviewer because a description of the context was a specific aim of the original study. To add to and clarify what was said in the first interview, whenever possible participants were interviewed twice. Based on the responses and ongoing data analysis, adapted interview questions were used in the second interview.

Twenty-seven open-ended individual audio-taped qualitative interviews and 4 focus group interviews were conducted by telephone. Telephone interviews were chosen because of the wide geographical distribution of study participants across a large western Canadian province. Although there are some limitations of telephone interviews, the advantages of this method are numerous²³. This method provides vast geographical coverage²⁴, increased time effectiveness²⁵, the development of positive relationships between researchers and participants²⁶, improved quality of data²⁶, and is particularly useful where key individuals are targeted based on their experience or knowledge of a specific subject area²⁴. Seven in-depth face-to-face, open-ended, audio-taped interviews were completed with six palliative patients of 30–60 min duration. Only one of the six patients was



interviewed twice: three participants died shortly after the first interview and two were too ill to be interviewed a second time. Twenty open-ended, in-depth audio-taped telephone interviews were conducted with 10 bereaved family caregivers of approximately 50-70 min duration. All caregivers were interviewed twice. Two focus groups of four to six rural healthcare professionals were interviewed twice by telephone. Eleven female palliative register nurses and one female social worker participated in the focus groups of 50-70 min duration.

Data analysis

All interviews were transcribed verbatim, coded, and analyzed. Transcripts were checked for congruency with the audiotapes then entered into QRS International N6 software (www.qsrinternational.com). Initially transcripts from each group (patients, bereaved family caregivers and healthcare providers) were analyzed separately on an individual level for patients and bereaved family caregivers, and at a group level for healthcare providers. However, as similar themes describing the context emerged all data were integrated into themes. Using interpretive description data analysis²¹, initial codes were developed by collecting data bits with similar properties. These initial codes were then developed into themes and potential subthemes. Associated themes were placed together and coded. The data were re-analyzed until no new themes could be identified. Constant comparative analysis was also used to ensure that data were examined thoroughly for similarities and differences with the data from all participants.

Scientific rigor: Rigor was established by gathering rich data from a number of different sources²¹. In this study, data were collected from patients, bereaved family caregivers and healthcare professionals. Thorne suggests that it is in triangulation of data sources that representative credibility will occur in interpretive description²¹. Representative credibility was achieved through multiple perspectives confirming the interpretation of the event. Direct quotes from study participants were used to represent themes as much as possible. Researchers continually checked that the

findings reflected the data gathered to achieve interpretive authority. Further, an audit trail was kept with The researcher will keep a detailed audit trail that follows a logical sequence where the reasoning behind each decision.

Results

Sample

A total of 28 individuals participated in the study. The six older rural palliative care patients (two male and four female) had a mean age of 73 years (SD 7.403 years) and were diagnosed with a variety of cancers (three had lung cancer, two stomach cancer and one pancreatic cancer). Ten family members were within the first year of bereavement after providing care to a family member with advanced cancer. They were predominately older females (eight female, two male; mean age 62 years; SD11.24) and had a mean length of care-giving time of 19.7 months (SD 20). The focus groups consisted of 12 (female) palliative healthcare professionals (mean length of time working in palliative care 11.3 years; SD 7.14).

Themes

The findings of the study reflected the complexity of end of life care and the unique nature of the rural context. Four overall themes relating to context were found reflecting the rural geographical, physical and social context: (i) community connectedness/isolation; (ii) lack of accessibility to care; (iii) communication/information issues; and (iv) independence/dependence.

Community connectedness/isolation: Overall, participants described feeling connected to their community as part of the social context. For rural healthcare providers, this sense of connectedness resulted from living and working with people they knew both personally and professionally. With respect to patients and family members, this related to feeling connected to people (ie friends, neighbours, family members) within their community, as well as the support



they received from these individuals. Further, connectedness for patients and family members referred to the closeness they felt toward their formal healthcare providers (especially the unique bonds developed with the palliative care coordinators). Examples of the data reflecting this theme are:

And I think on the farms people know more about each other than in the city. You make friends in the city, so fine but, on the farm...in our area especially, if somebody was in... in some kind of problems...neighbours were there to help... So may, maybe a more of a sense of community there. (Family caregiver)

...they connect you up and then they seem at peace because they're so used to living and dealing in a rural and small town community and you're a part of that community... you're almost part of an extended family...it's kind of like you're taking care of your own. (Healthcare professional)

...really great support from our church and the community too... They're just coming more often and I think that's just a comfort thing... (Palliative patient)

Community connectedness was seen as both emotional and spiritual support from their friends in rural areas, often through 'visiting and sympathy'. Evidences of physical support included delivery of groceries, bringing food, and driving to appointments. Their support networks changed with transitions and, as one healthcare professional suggested:

...need to renegotiate their support systems - there are different times... depending what they are dealing with. They may need to use resources they never thought they would need.

As their illness progressed, the participants also noted that although they felt supported by their community, they also felt isolated. Examples of the data reflecting this theme are:

Well all the responsibility was on me. That's the way I felt... But they were basically just coming here to take his blood pressure and to see how he was feeling today. But everything else was, was in my hands to look after him. I just felt so alone in this situation that I had... I really struggled with it. (Family caregiver)

I think one of the biggest fears that I've heard is being alone. (Healthcare professional)

...so I guess in that way I suppose you're isolated a bit. (Palliative patient)

Isolation reflected the social as well as physical and geographical context and was strongly tied to living in rural, and especially remote, areas where distances to resources limited access.

Lack of accessibility to care: Lack of accessibility to care was described as a lack of access to palliative care services, and lack of continuity of care. The care received was often fragmented because of having to see many different healthcare providers across a number of care settings. For example, if there were problems after 17.00, patients had to go to hospital emergency departments to access care. As one participant said: 'And then... when you needed somebody after 5:00... you had to go to the hospital... to see a doctor.' (Family caregiver)

Lack of access to palliative care and fragmented care resulted in a sense that there was limited continuity in the care that was received/given on a daily basis. This led to many older rural palliative care patients having to: seek care outside of their community; see numerous doctors; wait long hours in hospital waiting rooms; drive long distances; manage transportation issues, and; have no choice for location of care/death. Lack of accessibility to health care reflected both the geographical and physical nature of their context. Data examples from transcripts reflecting this theme include:

...we were three and a half hours away from his physicians... so the local physicians... you know, they



looked after him to the best of their ability, the problem there was that our physicians change so quickly... I believe in an eight month period we actually had three physicians come and go and then there was a fourth one... so there was really no continuity to his care at home... (Family caregiver)

...they have to go; so some of our clients have had to go outside of their community - a considerable distance to where they don't know anybody. (Healthcare provider)

...we have to go to [name of town], they have a doctor and pharmacy there... it's quite a ways to go. (Palliative patient)

...my father was afraid of seeking care, as he was afraid of not being able to come home... and he didn't... (Family caregiver)

Communication/information issues: An additional theme that stemmed from having a sense of isolation and not being able to access adequate resources was issues with communication and relaying of information. Participants described poor communication with healthcare providers and, in general, communication patterns reflected a lack of respect. Examples of this theme from the data are:

I guess he opened the file, he saw that she was terminal, she was stage 4, he pulled the file, and said, 'There, there's really nothing we can do'. They said to send her out the door. My brother almost flipped. Because like, that was not treating uh, my mother with respect. (Family caregiver)

As you probably realize, like... the doctors really don't level with you. Like I... you know, they don't tell you what to expect. (Family caregiver)

It's how do we approach this - the topic, if the physician doesn't... (Healthcare professional)

Poor communication also resulted in palliative patients and their family members perceiving that they were lacking important information regarding their care. Participants

especially felt that patients and family members were not being informed about the specific condition and what to expect as the disease progressed. Examples of the data reflecting this theme are:

We actually picked him up and put him in the car and took him back to the hospital because, you know, 'cause mom felt something had to be done, she didn't realize that he was dying, do you know what I mean? (Family caregiver)

None of that information was given. (Family caregiver)

...but nobody tells me anything... even the doctors. (Palliative patient)

...if I'm not aware of that person being out there, then I have no idea that they're out there on their own and [are] not connected yet... (Healthcare professional).

Independence/dependence: Regardless of limited access to resources and issues with communication and information, there was a shared sense that palliative patients, together with their informal and formal caregivers, felt the need for retaining the patient's sense of independence as they became more dependent on others. The physical changes related to their illness reflected the physical dimension of context. Examples of the data reflecting this theme are:

He was very determined to do things for himself. (Family caregiver)

I think that's the key there too, is dealing with them as individuals and, and you know remembering that everybody is different... (Healthcare professional)

I deal with the changes by being me... by continuing to be independent as possible. (Palliative patient)

At times their independence made them reluctant to ask for help. As one caregiver said: '...have always been independent... was reluctant to ask'. Their valuing of independence was compounded by the fact that they were



dealing with extreme fatigue and complex symptoms that necessitated a reliance on assistance from others: 'I was really exhausted...' (family caregiver) and '...no I don't feel well. I'm tired' (palliative patient). As a result, participants experienced a tension between wanting to be independent, yet becoming more dependent. For patients this was felt most as their disease progressed; for caregivers, this tension escalated as they became more fatigued and stressed with the strain of care giving.

Discussion

The findings of this study reflect a critical understanding of how context (geographical, physical and social) influence the experience of living with advanced disease in a rural setting. Tensions were found between feeling connected with the community while also feeling isolated from much needed resources and still having the freedom to control their level of independence, and being functionally dependent on others for assistance. It was evident in this study that having a sense of community and support from others within their community setting were key aspects of the psycho-social and physical context of rural palliative care for older adults. Social community networks provided psycho-social support to older adults and their family members. Older adults in rural communities have been found to describe higher satisfaction with family contacts and community integration compared with their urban counterparts²⁷. In a longitudinal study following older rural adults over 20 years, Wenger and Keating described how rural social networks evolve over time, often becoming less diverse and declining with negative changes in health status¹¹. Specifically, with age, social networks were found to become smaller and more family-dependent. In addition, as rural communities changed and populations decreased, there was a similar decrease in available services and resources which provided physical as well as psychosocial support. Although data collected did not allow exploration of whether resources and services in the rural area were declining, it did underscore the increasing need for services and resources with the progression of the advanced disease.

In the present study, the participants were experiencing significant changes in their mental and physical health. It may be that these changes resulted in diverse and complex care needs, which an already declining rural psychosocial and physical support network would have difficulty meeting. With the resulting lack of access to resources and absence of continuity of care participants felt isolated.

Although the participants in the present study described feeling isolated (physically and socially), they also simultaneously described a sense of connectedness and feeling psycho-socially supported by their community. A perception of high levels of community support has been described in other studies of rural persons with advanced disease²⁸. However, these studies did not describe the simultaneous feelings of isolation, both social and physical.

The study participants described a sense of connectedness particularly with their formal care providers. In a sense, the participants in the present study viewed their formal care providers as their friends and neighbours, and as integral parts of their community network. Social networks and feeling connected were very important to the participants, so while there were losses in this regard, there were also opportunities to expand their networks to include others (eg formal caregivers, neighbours) that were not previously part of their network. The idea of renegotiating their social/support networks, as posed by the study participants, may have an impact on decreasing the sense of isolation that was described. Future research is necessary to determine if this is the case.

Although our participants suggested that the community provided emotional and some physical help, the family caregivers felt completely alone in providing the physical care needed as the palliative patient's illness progressed. Castleton et al's findings in their study of the rural experience of living with advanced disease described how a sense of solitude from rural living may become a sense of isolation from others along with an increased need of formal healthcare services¹². Their findings are similar to the findings of the present study as participants described the



lack of access to services needed, specifically around symptom control at home. They often had to leave their communities to receive the care they needed. Issues of rural persons' access to needed healthcare services has been well established in the literature⁸. As the participants described, these issues had an impact on the location of their death. Rural palliative patients perceive they have little or no choice in where they die⁹. As well, rural cancer patients are less likely than their urban counterparts to die out of hospital¹⁴. More research is needed to explore ways to support older rural persons and their families so that they are able to choose where they die.

The participants in this study described how they valued independence and individuality in their daily lives. However, at times these beliefs resulted in their reluctance to seek help. The beliefs of independence and self-reliance by older rural persons and their families have been noted in other research²⁹⁻³¹. Similar to the present findings, these studies revealed that valuing independence and self-reliance resulted in delayed help-seeking³¹. Future research with rural older adults should explore how attending to these values can provide opportunities and support, as well as exploring way to overcome reluctance to seek assistance.

Factors influencing the study

There are several factors influencing this study. The inclusion and integration of data from multiple perspectives – patients, bereaved family caregivers, and healthcare professionals – in identifying the context of transitions could be problematic. In a study of transitions for persons with advanced cancer and chronic obstructive pulmonary disease, healthcare professionals were found to identify different transitions than patients and families²⁰. However, the themes identified in our study were found in the data across all participant groups. As noted, Thorne suggests that multiple perspectives help to capture the experience and facilitate a deeper understanding²¹. Another limitation may be that the researchers were unable to share the findings of this in-depth analysis with the study participants to confirm that it represented their views.

Other limitations relate to the characteristics of study participants, such as gender, geographic location, type/stage of terminal illness, and cancer sites. Further research is also needed to determine if the findings would differ in locations other than rural western Canada. Rural settings are diverse⁶. For example, different rural settings will have differing access to resources which would potentially change the findings. As well, the study participants included both genders, had been diagnosed with advanced cancer, and had a range of primary cancer sites. As men and women may experience rural aging differently, the findings may have been different if only one gender were selected to participate. Palliative populations, such as those with non-cancer diagnoses, may also have different experiences in rural settings. Thus, future research is needed to determine if the findings would vary with different populations.

Implications

Although there are limitations to the study, the findings have several potential implications for improving healthcare delivery with older rural persons with advanced disease and their family. Without a doubt the current rural health delivery systems for this population are insufficient. Models of palliative health delivery should incorporate mechanisms for improved communication and information as well as 24 hour access to specialists. Any healthcare delivery model does need to consider building on the rural community strength of support and independence.

As this is an exploratory study, research with older rural persons with advanced disease and their families should also critically examine the context of the experience. This will potentially build on the findings of this study to determine if there are similar findings with other rural populations and in other geographical areas. The findings raise many questions. For example are there situations when solitude does not become isolation or where independence is maintained? Is it possible to renegotiate the social/support networks in rural communities?



Conclusion

The findings provide insight into the lives and values of rural older adults who are receiving palliative care services. Participants described feeling connected to the community while simultaneously feeling isolated. They also described valuing their independence at the same time as being increasingly dependent on others. With the increasing dependence upon others, they needed to connect and have more support. The findings reflect a more complex view of aging with advanced disease within a rural context than have been cited in the previous literature.

The findings of this study suggested that having community support (psychosocial and physical) and independence were important to older rural people. However, the type of support and the need for independence often changed with progressive terminal illness in rural settings. These changes resulted in an increasing need for: information; 24 hour access to specialized palliative care services to help control symptoms; and supportive services to provide physical care in the home.

With the current healthcare delivery system in rural areas participants felt they had limited choices in their location of death. This has implications for rural health delivery models which should include mechanisms for provision of timely information, 24 hour access and additional ways to provide physical and psychological support in rural areas.

The findings also suggest there are opportunities to improve the experience of rural older persons and their caregivers. The process of renegotiating support networks as terminal illness progresses may foster new ways to support rural persons with advanced disease. As well, exploring ways to build on the values of community connectedness and independence within a rural context may provide some insights to improve the quality of palliative care services in these settings. As this is an exploratory study, the findings are not conclusive; however, they provide important ideas for future research.

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