

Developing Rural Communities' Capacity for Palliative Care: a Conceptual Model

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Abstract / The population in Canada and other developing countries is aging, increasing the need for palliative care services. In rural communities, care of dying people is normally provided by health care professionals as part of a generalist practice, not by palliative care specialists. Despite a lack of specialists and resources, some rural communities have developed local palliative care programs. The goal of this research was to conceptualize rural communities' process of developing palliative care programs using a theoretical perspective of community capacity development. Data were from nine focus groups of interdisciplinary rural health care providers who provided palliative care in seven provinces/territories of Canada. The outcome is a theoretical model that conceptualizes the process of developing palliative care programs in four sequential phases: antecedent community conditions, a catalyst, creating the team, and growing the program. The activities of each phase are outlined. This research offers practical and theoretical knowledge to guide practitioners and planners seeking to develop palliative care programs in other rural communities.

Résumé / La population canadienne, tout comme celle d'autres pays, est vieillissante et de ce fait les besoins en soins palliatifs sont de plus en plus élevés. Dans les communautés rurales les soins aux mourants sont généralement prodigués par des professionnels de la santé oeuvrant en pratique générale et non pas par des spécialistes en soins palliatifs. En dépit d'une pénurie de ressources et de spécialistes, certaines communautés rurales ont développé, à l'échelle locale, des programmes de soins palliatifs. Cette recherche avait pour but de concevoir un modèle destiné à aider les communautés rurales à élaborer un tel programme, et ce, dans une perspective théorique fondée sur la capacité de développement de la communauté. Les données ont été recueillies auprès de neuf groupes de discussion ciblés composés de professionnels de la santé issus de diverses disciplines et prodiguant des soins palliatifs dans sept provinces et territoires du Canada. Il en est résulté un modèle théorique qui conçoit le processus de développement d'un programme de soins palliatifs en quatre étapes consécutives : les conditions préalables dans la communauté, la catalyse, la création d'une équipe et le développement du programme. Ce modèle donne également un aperçu des activités devant accompagner chacune des phases. Cette recherche se veut un

¹In this paper, the term rural includes remote.

outil pratique pour aider les professionnels de la santé et les planificateurs à développer un programme de soins palliatifs dans les communautés rurales.

INTRODUCTION

Demand for palliative care is increasing worldwide because the population is aging and more people are living longer with a chronic or terminal illness than at any other time in history (1-3). Most deaths in the developed countries of the world occur in people over the age of 65 years (1). In Canada, more than 200,000 people die annually (4) and 75% of these deaths are of adults aged 65 years and older (5). The three leading causes of death for older Canadians are coronary heart disease, lung cancer, and stroke; typically, older people have end-of-life care needs that meet palliative care criteria (2). Given Canada's aging population and the concurrent rise in age-associated degenerative and chronic illness, the need for access to palliative care services by older people at the end of life is expected to rise steadily.

It has been well documented in Canada, Australia, and England that people who are dying in rural and remote areas have less access to palliative care services than people in urban areas (4,6-8). Although specific definitions vary, rural areas are generally considered to have low population density and remote areas are at a distance from large urban centres¹ (9,10). In Canada, almost nine million people—about 30% of Canada's population—live in rural areas (11) and a growing number of rural Canadians are elderly (12).

Rural health services often suffer from a lack of resources, including health care facilities and a shortage of health care providers (4,13). Notwithstanding this lack of resources, rural people have expressed a preference to receive health care in their home communities; they do not want to travel to urban centres for care when they are dying (14-17). Developing local programs using

a capacity development approach and available community resources is one strategy to improve access to palliative care services for rural people (6,8,18,19). While some important components of rural palliative care services have been described (6,18,20), research on the process of planning and implementing of palliative care programs in rural communities is limited (6). This research begins to address this gap.

This article describes a research-based conceptual model which articulates the change process undertaken by rural communities as they developed their local palliative care programs over several years. The model, thus, has practical application in health planning and services. Several Canadian provinces have launched strategies aimed to improve access to palliative or end-of-life care services; however, models to guide the process of developing rural palliative care programs have been lacking.

RELEVANT LITERATURE

Community Capacity Development

Because this research focused on a process of community development, the literature on community capacity development provided the theoretical perspective. Specifically, the body of literature which focuses on conceptualizing capacity development as a dynamic, social process of change is most relevant to this research. The capacity of interest in this research is the rural community's ability to deliver palliative care.

There is general consensus in the literature that community capacity development is a collaborative social process that occurs as people develop their assets and ability to make social change (21). The capacity development perspective argues that communities are able to tackle their problems through natural (informal) helping and collective problem solving (22). The method for change is to enhance existing capacities and not impose solutions from outside. The approach is strengths-based rather than needs- or deficit-oriented.

The features and broad concepts relevant to capacity development are known. Lavergne and Saxby (23) describe capacity development as a process of social transformation with four key features: the notion of embeddedness (capacity cannot be disassociated from its owners, and is not transferable); it builds on existing capacities (not by creating new ones); different levels and forms of capacity are all interconnected in a systemic way; and the focus is on change, not performance. Similarly, Bolger (24) argues capacity development requires broad-based par-

ticipation, building on local capacities, ongoing learning and adaptation, and long-term investment and integration of activities at various levels to address complex problems. Lusthaus (25) says the capacity development process should include: building knowledge and identity; defining membership; leadership; having relationships based on shared norms/values; a feeling of connectedness, trust, and belonging; engaging diversity; managing conflict; building harmony/consensus; engaging people and existing social systems; feeling ownership and responsibility; and taking time. In summary, the dimensions of community capacity include: level of knowledge, skills and resources; the nature of social relationships; structure, mechanisms, and spaces for community dialogue; the quality of leadership and its development; the extent of civic participation; a value system; and a learning culture (22).

Although research exists that discusses capacity development as a process in action, there is no well developed model (21). In reviewing the literature, no model could be located that conceptualized the development of rural health or palliative care programs as an endogenous process of change initiated and undertaken by local providers. Thus, it became the goal of the research to create an original model to conceptualize the process of developing rural palliative care as a process of community capacity development.

Rural Health Services

Palliative care is integrated into rural health services, making it important to understand this context for the research. The most fundamental challenges in providing rural health services are access and quality of care (13,15). These challenges are caused, in large part, by the inability of rural communities to recruit and retain health human resources, and to maintain local hospitals (26).

Rural health care practice, for most disciplines, has been characterized in the literature as generalist, collaborative, and community-focused. "Generalist" connotes a broad scope of practice supported by an equally broad body of knowledge and skills (11). Rural generalists carry a higher level of clinical responsibility with less professional backup than their urban counterparts (27). Because of their professional isolation, rural generalists often collaborate with urban "specialists" for clinical consultation and professional support (28).

Collaborative practice and interdisciplinary teamwork are well documented in research on

rural practice (28). In rural communities, collaboration is partly motivated by the shortage of health human resources and the consequent need to work cooperatively to "get the job done". The typical boundaries of professional roles become blurred since not all disciplines are available and an overlap of skills is required to allow time off for individuals. Teamwork is further encouraged by the small size of rural communities, where people tend to know one another as friends and neighbours. There is often little separation between the personal and professional relationships of rural providers, and little separation between work time and personal time (27).

Rural providers also share a common community identity with their patients and must be sensitive to practising with respect for community norms, values, and existing social networks (29). The close relationships that develop between rural providers and their clients generate a special sense of commitment, accountability, and emotional ownership of their work (30). When rural providers see the results of their work on a daily basis, it also brings them a special sense of pride and accomplishment (31). Knowing their patients outside of the medical clinic further increases the provider's knowledge of the patient and, therefore, enhances their ability to provide individualized care (31).

While rural health studies document specific problems or strategies, the literature does not present a well-defined health systems approach for rural and remote environments. Most literature recommends models of rural service delivery that employ delivery networks, implement primary care models, use technology such as telemedicine, and involve the community in ongoing needs assessments and evaluations (32-40). The American National Rural Health Association conducted pilot projects in rural health and identified the following five factors as critical to the successful planning and implementation of new strategies for rural health: leadership; teamwork; connection to community; connection to outside resources; and history with planning (41). However, it does not provide a model of the process to achieve these ends.

Rural Palliative Care Services

The research on rural palliative care is limited in comparison to other palliative care topics. Just three review articles were located (7,42,43). Evans et al. (7) conducted a systematic review of 26 studies that examined the organization of rural palliative care and the views of professionals in rural areas. The studies focused on

education and training needs of professionals, strategic policy issues, the role of carers, and consultation. They concluded the organization of palliative care for rural populations is a poorly researched topic, and identified a gap in research on how to best organize, support, and develop rural palliative care. Hughes et al. (43) reviewed 20 studies related to rural patient and carer palliative care needs. The review supported the need to improve palliative care services in rural areas and identified the following issues: the role of geographical distance; the need for information; the importance of informal networks; and the burden that informal caregivers may experience. Wilson et al. (42) reviewed 36 articles and identified the following themes: differences between urban and rural end-of-life care; the nature of rural end-of-life care; accessibility and technological assists; assessing the needs and wishes of terminally ill persons and their caregivers; and education for care providers. They concluded that while the research was not extensive, existing literature did serve to highlight the importance of end-of-life care in rural communities, and the importance of developing rural programs to meet the unique needs of communities. None of the reviews identified any research into local community-based processes for developing rural palliative care.

The research on delivering rural palliative care services offers evaluations of local pilot projects (19,44) or elaborates particular strategies such as the use of community hospitals (8), the role of rural nurses (45), or telephone support services (46). There is minimal research on comprehensive approaches to service delivery. One Australian study provides a framework for a regional specialist palliative care service based on a population-based approach and use of primary palliative care services in rural areas (6). Primary care providers receive education, consultation, and share care with regional specialists. Skilbeck and Payne (47) argue the need to provide palliative care at the primary care level so that people who are dying of chronic noncancer conditions, many of whom are elderly, have access.

Two nationwide studies on rural palliative care could be located, one Canadian and one Australian. MacLean and Kelley (18) identified the generic components of a rural palliative care program, stressing that it must be uniquely tailored to the community. They found that rural palliative care in Canada requires: an appropriate philosophy, definition, and guidelines for rural palliative care; maintaining the integrity of the rural community; accessibility

of services; teamwork in its provision; palliative care consultant/specialist support; flexibility in providing services; education for social workers and health care providers; social support for the family and formal care providers; and cultural awareness. Sach (20) outlined resources required to implement palliative care services within existing service delivery systems in Australia. His study identified the following four levels of patient care needs: limited support (such as information); medical and basic home nursing support; medical and high-level nursing when home support is not possible; and complex medical support and high-level nursing. Sach concluded that a comprehensive model of palliative care addresses the full range of palliative care needs although some patients' care needs cannot be met in rural settings, requiring access to speciality care in regional hospitals.

Phillips (6), Sach (20), and MacLean and Kelley (18) all found that rural palliative care providers are generalists, and often lacked experience, knowledge, and skill in palliative care. Developing rural palliative care services, therefore, must include education for providers and access to specialist support from urban areas. The studies identified a strong need for family caregiver support, and identified the importance of a team approach that includes volunteers, social workers, community nurses, general practitioners, and allied health professionals. Problems in providing palliative care related to lack of providers, and lack of access to specialists and tertiary care hospitals.

In summary, the research on rural palliative care reflects the same problems and practices as delivering other rural health services. However, none of the research on rural health or rural palliative care addresses the process of developing palliative care services within rural communities or uses the perspective of community capacity development.

METHOD

The research employed a naturalistic inquiry approach to answer the overall research question: What is the process of developing palliative care in rural communities from the perspective of health care providers? Naturalistic inquiry is interpretive and inductive, and focuses on understanding phenomena in their natural context. Community capacity development was used as a theoretical perspective to frame the research.

The data for the study were derived from nine focus groups held with 66 rural palliative care providers in seven provinces or territories in Canada. Eight focus groups were conducted as

part of a multi-site national study of rural palliative care in 1999 and 2000 at six sites in Canada (18). This research was a second analysis of that data. One additional focus group specific for this research was conducted by the author in 2000 at another site. Key informants in palliative care across Canada assisted in selection of geographic sites, and a purposive sample of experienced and knowledgeable participants was recruited with the help of local key informants.

The focus group participants were health care professionals and hospice volunteers who provided palliative care in rural communities. They represented the following disciplines or roles: nurses (n=25); physicians (n=7); volunteers (n=6); social workers (n=5); chaplains (n=2); rehabilitation therapists (n=2); managers or coordinators in organizations (n=15); researchers/consultants (n=2); pharmacist (n=1) and funeral director (n=1). Participants worked in a variety of care settings: home care, rural hospitals, community-based voluntary organizations, professional associations, long-term care facilities, and regional palliative care consult services. Most participants were frontline providers. The rural communities in which they worked were small in population (i.e., less than 10,000 population) and/or remote from a major urban centre (i.e., outside daily commuting distance to an urban centre). Some communities had established palliative care programs, others were in the process of developing programs.

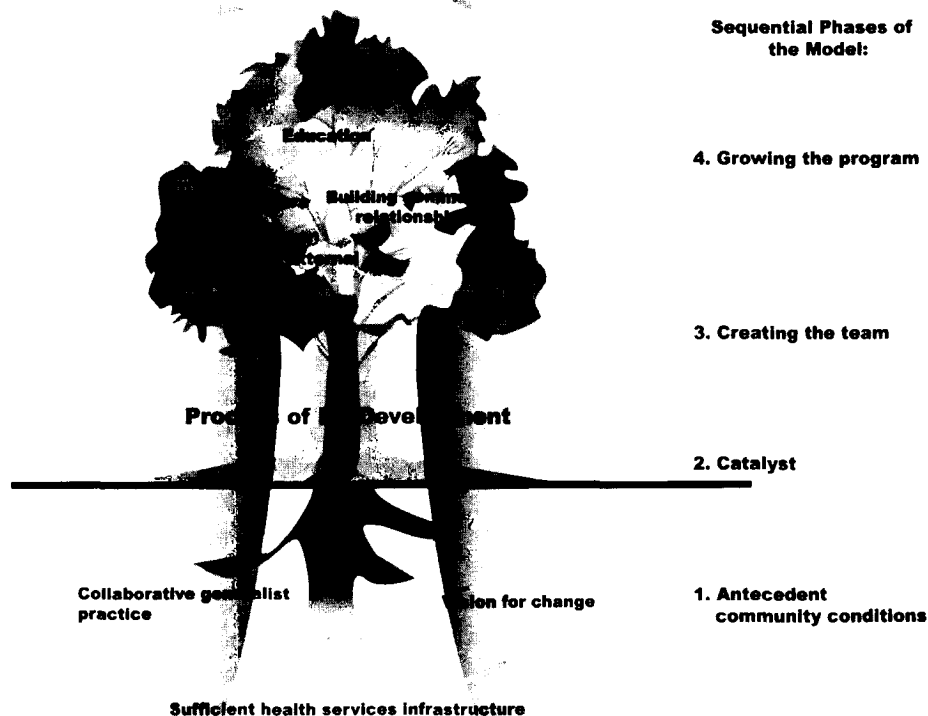
All focus groups were audio taped, transcribed verbatim, and checked for accuracy. The original transcripts were imported into the NVivo software program for storage, coding, and analysis. Throughout the analysis, ideas of community capacity development provided a way of looking at the data. Rigour was ensured by the richness and breath of the dataset, maintenance of a detailed audit trail, reflexivity on the part of the researcher, peer review of the results by rural palliative care providers at three palliative care conferences, and triangulation of findings with the literature.

RESEARCH RESULTS

The outcome of the research is an original model, called "Developing Rural Palliative Care", which conceptualizes the process of developing palliative care using four sequential phases. This section presents an overview of the model, depicted in Figure 1.

The model uses the metaphor of a growing tree to represent the change process while developing palliative care in a rural community. The model has four phases: antecedent com-

Figure 1 / DEVELOPING RURAL PALLIATIVE CARE



PC=palliative care

munity conditions; catalyst; creating the team; and growing the program. The phases represent a sequential, yet gradual transformative process over time. Each phase includes a number of activities or processes that grow out of and build upon those of the previous phase; however, work in all phases is ongoing. Thus, the model represents a dynamic, evolutionary process of change that has no end.

A tree is an appropriate metaphor for several reasons. Tree growth requires antecedent conditions such as fertile soil and healthy seed; its growth occurs slowly, and is influenced by environmental conditions such as weather and pollution; and its healthy maturity can be recognized by its dense foliage. Inadequate conditions or a noxious environment will have a negative effect on a tree's development. Conversely, optimum environmental conditions will produce a robust tree.

In the model, the foliage of the mature tree represents palliative care activities taking place in the rural community such as: providing clinical care; educating providers, patients, families, and community members; building community relationships; advocating for palliative care resources; and building external linkages. Just as the tree's foliage increases as it grows over time,

palliative care activities are associated with the last phase, growing the program. In the model, palliative care activities are integrated into the developmental process. The model does not consider palliative care services or activities separately as an outcome of development. The remainder of this section describes each phase of the model in detail, presenting the themes and supporting data.

Phase 1: Antecedent Community Conditions

The first phase of the model represents the community conditions that pre-exist and facilitate the development of palliative care. Participants indicated palliative care services were built on existing resources in their rural communities. "We didn't create a lot more new positions to do this," said one participant. "Everybody was already there.... We did it with what we had...[and] we were quite proud of that." Another participant felt it was important to make use of local wisdom.

In the model, antecedent conditions are metaphorical nutrients in the soil. They affect the community's potential to develop palliative care. The data revealed three types of antecedent community conditions: sufficient health services infrastructure; the nature of rural health care practice; and a vision for improving care to dying people.

These antecedent conditions interact and operate simultaneously within the model. Collectively, these antecedent conditions are the foundation for subsequent phases of development.

Sufficient Health Services Infrastructure. Data indicated that developing palliative care involves building on existing resources, which requires a sufficient number and type of local community providers and organizations. Participants identified no specific organization as essential; however, most communities had a local hospital or health centre, a home care or home support program, and long-term care facility or personal care home. Participants stressed the need for access to home care services. Access to a hospital was also viewed as important. Participants identified a shortage of local providers as a challenge, particularly the lack of physicians and social workers. Difficulty accessing medications was another important resource issue. Despite identifying these rural resource shortages, participants did not talk about them as preventing development of palliative care. Rather, lack of resources was considered a challenge to be managed throughout the development process.

The Nature of Rural Health Care Practice. The nature of rural health care practice involves three characteristics that serve as antecedent community conditions: providers' collaborative and generalist approach; the necessity to perform multiple roles; and the overlap of personal and professional relationships. Data indicated that high levels of cooperation already existed between providers prior to developing palliative care and this was an advantage. Participants emphasized that, "prior to having the palliative care team established, there was already a good working relationship with the hospital, with the personal care home, and with the community." People on the palliative care team indicated they could "pick up the phone and call each other and bounce ideas off of each other because we know each other so well".

Rural palliative care was provided by generalists, who considered palliative care to fall within the scope of their practice. The provision of palliative care by local generalists was appropriate because the numbers of dying people were small and varied in communities. Rural providers also frequently performed multiple roles in the service delivery system because there were so few providers. For example, a physician worked in the hospital, a community practice, and the long-term care facility.

There was also overlap between personal and professional relationships. Members of one palliative care team described how closely their

personal lives, palliative care work, and other professional activities were intertwined:

[The palliative care coordinator] is in the hospital all the time and so am I, and if I see somebody in emerg, I can kick it around with him in the morning, and...he does the same with me if he's seen somebody in the office. And [name] and I live together. We talk about patients in the hot tub at night and, [name] and [name] and [name] all work in the same office, in the same building, and [name] is...on our extended care unit, so she knows the people that we've got.

Overlapping relationships served to strengthen commitments among providers. The influence of close relationships in the rural community was illustrated in an interview in which a participant talked about how the palliative care team heard "everything through the grapevine..." Another said, "In the culture of the rural community, dying in hospital is like dying at home because people have a very different feeling about the hospital. It's very much part of the community and the people who work there are your friends and neighbours and relatives."

A Vision for Improving Care to Dying People. Vision for improving care to dying people served as the metaphorical seed for developing palliative care. Vision often grew from personal experiences with the illness or death of a family member. Sometimes dying could be a positive experience for those involved and providers wanted to help others by doing palliative care.

[Dying] doesn't have to be a difficult, a bad situation necessarily. It can be probably one of the best experiences of your life if you can help people come to grips with some things before that person dies. They die comfortably. If you've been able to be a part of that, you cry with those people and you're sad with them, and you go through a lot of the grieving that they're going through too, and there's nothing wrong with that. It helps us all grow in ourselves as well, and how we're going to be faced with our own death down the road, or the death of our families.

Alternatively, a vision for improving care was sometimes based on a family member's negative encounter with the health care system while dealing with a life-threatening illness. That was the case for this physician participant:

My wife had cancer, and I saw how she was treated and I got bloody mad. It was really intensive, cruel, and unusual punishment. She wasn't dying but...when the opportunity [to join the palliative care team] came rolling, [name] asked me if I'd be interested and I literally jumped at the chance.

A vision for change provided the seed for growing the palliative care program in the commu-

nity. This seed was embedded in the communities' existing health services infrastructure and the nature of rural practice. Together, these three antecedent conditions provided the foundation for the remaining three phases of the model.

Phase 2: Catalyst

A community catalyst is a person or event that disrupts, creates discomfort, and stimulates change within the community because current ways of providing care are now judged to be inadequate. In the model, the catalyst triggers community action to improve care to dying people and transforms the vision for change into action. The catalyst provides the motivation and momentum for community providers to move to the next phase of the model: creating the team.

In the research, catalysts included: a bad death, a local champion, palliative care education, or government project funding. A powerful example of a catalyst was provided in one focus group. The events surrounding this death are described:

The lady died in hospital several months after we were all introduced to her...she died a miserable death. We all felt like we really missed the boat with her....She had so many end-of-life issues that we couldn't even begin to deal with. We didn't know how to, we didn't have the resources, and we really felt like she dropped through the cracks and we just, you know, dumped her really. We felt awful about it and we didn't ever want that to happen again. But we didn't know what to do about it. So the three of us and the long-term care assessor at the time and the coordinator for [hospice volunteer program] got together...at the picnic table outside one day and said, 'You know, let's do something about this.'

In another community, the catalyst was a physician who became a local champion after doing volunteer work with the Canadian Cancer Society. Generally, catalysts originated inside the rural community, although events outside the community could become a catalyst if they resulted in local action. That the catalyst is not imposed is an important aspect of the model, and is consistent with the perspective of capacity development.

According to the model, after experiencing a catalyst for change in their community, health care providers progress to the next phase: creating the team. Traditional processes of caring for dying people have been disrupted and providers are ready to reorganize themselves to change how they care for dying people.

Phase 3: Creating the Team

The third phase occurs when community providers join together to collectively pursue their

vision of improving care to dying people, transforming individual action into collective action. For example, one participant said that, although there were palliative care services available, "everybody was doing their own thing and nobody was coming together to discuss issues or to have each other for support." Further, those who initiated the formation of the team "recognized that we could improve the services that we were providing if we worked together."

The term "team" is used in the model because participants used it most often to describe themselves as a group. Creating the team involves two interrelated themes: having dedicated providers and getting the right people involved. Although these two themes are discussed separately, they occur simultaneously.

Having Dedicated Providers. Participants identified the dedication of local providers as the most important factor in creating the team. Participants referred to this dedication as commitment and passion. "The key to our success [on the team] has been that people have been very dedicated and very committed to see this through," said one participant. In the model, dedication is foundational for future palliative care development. The theme of dedication remains strong into the final phase of the model.

Getting the Right People Involved. Participants noted the value of having team members who are influential in the health care system and community. Having physician involvement was viewed as particularly important.

Our...doctor...isn't the palliative care doctor for every client; everybody has their own physician.... He...help[s] us with the [palliative care] issues that we're talking about...and to act as our liaison with the other physicians....We have sent him on missions from time to time, [laughing] when we need him for that kind of thing.

Team members felt the physician on the team played an important role in influencing other physicians, thus helping to engage the community.

Getting the right people on the team also meant having members from all relevant disciplines and health care organizations in the community. Team members who participated in the study included physicians, nurses, social workers, pharmacists, spiritual caregivers, and hospice volunteers who were typically employed in local organizations that provided care to dying people. The actual membership of each palliative care team differed by community and most teams did not have all disciplines represented. Membership depended on antecedent community conditions, specifically,

which local providers were available in the community and interested.

Professionals not traditionally associated with palliative care were also part of the rural teams. For example, participants included a speech pathologist, a staff development coordinator who was also an infection control nurse, a long-term care case manager, and hospice volunteers. Rural palliative care teams also included community members who played an important role in the care of dying people but were not health care professionals (e.g., funeral director).

Having the right members involved was more important than the size of the team. Participating teams ranged from seven to 17 people. Team membership appeared open and inclusive, which is consistent with the collaborative nature of generalist rural practice, discussed in antecedent community conditions. The work of the palliative care team becomes a natural extension of providers' daily interactions. According to the model, dedicated providers who are the right people form the team and now focus on growing the program.

Phase 4: Growing the Program

During the fourth phase, providers focus their energy on delivering palliative care in their local community. Activities included: clinical care; educating providers, patients, families, and community members; building community relationships; advocating for palliative care resources; and building external linkages. The team's ability to carry out these activities gradually increased over time as they engaged in three interrelated processes: strengthening the team, engaging the community, and sustaining palliative care. During this phase of the model, team members managed challenges common in rural health such as the shortage of resources.

Strengthening the Team. The community team is gradually strengthened by developing members' expertise and self-confidence in palliative care. Developing expertise is accomplished in three ways: by sharing existing knowledge and skills among group members; by creating linkages with experts outside the community for education and consultation; and through learning by doing. Participants spoke about knowing they could count on other team members to assist them when they lacked knowledge or skills. One said, "I never feel that I am alone out there", and having the support of the team was a relief because it meant "I don't feel like I've got to know it all...I couldn't". Team members supported one another in face-to-face interactions and on the telephone.

Rural teams formed linkages with experts outside the community who could advise them. Their need for external linkages was articulated by one participant who said, "[Be]cause we are rural, we are out here on our own. We really need to have links with other people out there who've either been through it or can serve as a resource for us." Specialized palliative care units in urban centres played important roles in supporting rural providers with education and clinical consultation.

In spite of ongoing efforts to prepare themselves, most learning about rural palliative care happened while doing the work itself. Participants spoke of the importance of "not being afraid of jumping in and doing it". They understood learning by doing involved taking risks and viewed this as an essential part of strengthening their team. Teams became stronger as members built self-confidence. Over time, other health care providers acknowledged the expertise of team members; dying people and their families also expressed gratitude for their care. "Success is the key to success." said one participant, "It just helps fuel the team and fuel what you're doing and...your desire to do better."

Engaging the Community. Palliative care teams engaged their communities in developing palliative care by three simultaneous and interrelated means: changing clinical practices; educating and supporting community providers; and building community relationships to improve service delivery.

Changing clinical practice involved developing tools for care such as drug boxes, specialized health care records, and assessment tools. Specialized health care records and screening tools provide clinical direction for providers who lack experience in palliative care by drawing their attention to issues they should be addressing. The team also created care plans or protocols (e.g. use of subcutaneous butterflies to administer pain medication in long-term care facilities) that helped educate and support families, as well as guide health care professionals.

Teams provided education and support to other health care professionals, especially front-line workers in home care and long-term care. Participants considered physicians an important target audience for education because they control much of the decision making about patient care. Education focused on the philosophy of palliative care, and the specifics of pain and symptom management. Educating and supporting staff was the strongest theme in engaging in the community.

Within their communities, providers identified the importance of developing linkages so dy-

ing people would experience continuity of care between the hospital, home care, and long-term care settings. Team members who had influence within local health services often worked to create needed linkages. Providers identified working in a small community and working together collaboratively as success factors for developing rural palliative care. Palliative care teams did not often meet formally, yet team members interacted in the course of their normal daily activities.

Providers used existing resources to do their work. Where resources were lacking, team members relied on providers' cooperation, personal relationships, and creative problem solving. "We try to do the best we can with our clients with what we have," said one participant. "I think that is a great asset to us because we have such good communication and a great team of people we work with in the community, who are very interested and caring." One participant described the ingenuity of rural providers: "They're the most creative bunch of people that I've ever met in terms of figuring out how to make the system work on their behalf....And they don't look at a situation and say, 'Oh we can't do that.' The question they ask is, 'Oh, how are we going to do that?'"

Sustaining Palliative Care. As the community engaged in delivering palliative care, palliative care providers recognized the need to sustain their new services. Palliative care teams developed through volunteerism, and their work was based on using existing community resources. While volunteerism remained important in sustaining rural palliative care, providers identified the need to secure additional staff and resources, and to develop policy and procedures that formalized their work.

Although palliative care was not formally identified as part of their role, dedicated rural providers voluntarily incorporated it into their work as generalists. Participants emphasized the value of having their managers' support for their palliative care work. Having palliative care delivered through professional volunteerism, however, limited palliative care development. Some participants described spending vacation days attending palliative care meetings. They also described how this sort of professional volunteerism can lead to overwork and burnout among rural providers.

To compensate staff appropriately and to avoid burnout, participants identified the need for additional staff and resources to do palliative care. Resources became an issue when the palliative care program grew beyond the ability of existing resources and the volunteerism of

providers to meet demands for service. In effect, additional resources—staff and money to pay for equipment and education—were required because providers had successfully engaged the community in providing palliative care.

Palliative care providers also spoke about the importance of policy development to sustain palliative care. Participants considered policy development important at both the local and provincial level to legitimize the work in the health care system, help secure needed resources from government sources, and improve care for dying people by ensuring access and consistency of approach. In particular, one participant noted "the need to recognize palliative care as a program in and of itself....If we could make that policy shift, then that, in turn, means that necessary resources have to be dedicated to the program, such as the training, the medication when a person is not in an acute setting. And that has a whole pile of legal and practical, as well as financial implications."

While volunteerism among providers remained important in the growing-the-program phase of the model, participants recognized that volunteerism was not sufficient to sustain palliative care. Providers worked to obtain staff and resources, and to develop policy to support the work of the palliative care team.

The process of developing palliative care, as presented in the model, is a transformative process that builds on and gradually formalizes existing informal community processes that exist as antecedent conditions in the rural community. Time is an important element, as data indicated that program development took six to 10 years. Providers emphasized the importance of keeping the program simple, flexible, and community-focused. Working together and building on existing resources were important; however, additional resources and policy were needed once the new program became more established in the community.

DISCUSSION

The model presented for developing rural palliative care clearly demonstrates the principles of capacity development: change is incremental in phases, but nonlinear and dynamic; the change process takes time; development is essentially about developing people; development builds on existing resources; development cannot be imposed from outside; and development is ongoing. Conventional approaches often focus on the delivery of resources from outside the rural community. The model offers service providers and health planners a different approach to thinking

about rural palliative care program development. Just as the stages of change model in health psychology (48) offered practitioners an explanation of individual behaviour change in a manner that facilitated planning appropriate interventions, so this community change model has potential to guide community program development.

The model addresses a gap in the literature in both rural palliative care and rural health services in that no models of a process of rural community development could be located. Each phase of the model, however, is supported by the existing research on rural health, rural palliative care, or community capacity development. In the first phase of the model, antecedent community conditions, the importance of having local health services infrastructure and a generalist, collaborative practice is consistent with the rural health literature. The need for a local vision for change and internal catalyst is foundational in the capacity development literature. The phase of creating the team is consistent with the literature in rural health and rural palliative care, which documents the importance of teamwork; and in the capacity development literature, which emphasizes the social relationships and connectedness of members, and the importance of cooperation, participation, and learning. The activities of providers and themes of development identified in the final phase of the model, growing the program, are consistent with the needs of rural palliative care patients and families for services, information, and support in the literature, as well as the needs of rural providers for education and linkages with experts for clinical consultation. This final phase incorporates the capacity development research on developing knowledge, skills, resources, and leadership.

The strength of this research was the richness and diversity of the dataset. The data were collected nationally from rural health care providers who worked in communities of different sizes and types, located within different health policy environments. This allowed for development of a model that was applicable in diverse contexts. A limitation of the research was that the use of an existing dataset did not allow the researcher to probe for more detailed information on some aspects of program development. Taking the model to a diverse group of rural communities in Canada and elsewhere for model validation, then applying the model prospectively to develop palliative care programs in rural communities where none exists is the next phase of the research. Given the urgency of creating access to palliative care in rural commu-

nities, it will be important to program planners to know if use of the model can accelerate the development process.

CONCLUSION

The purpose of the research was to conceptualize the process of developing palliative care in rural communities using the theoretical perspective of community capacity development. The research used national data from Canadian rural palliative care providers, and created an explanatory conceptual model that takes the form of four dynamic and sequential phases: antecedent community conditions; a community catalyst; creating the team; and growing the community program. The activities associated with each phase of the developmental process are described in considerable detail, as they provide the strategies to facilitate program development. The model makes a unique contribution to palliative care and rural health services literature, since no models of rural community capacity development were located. Although the model has not been applied internationally to date, doing so is possible because it conceptualizes a developmental process that is independent of any particular sociocultural context. In fact, according to the model, development grows out of the specific antecedent conditions of rural communities, and builds on the capacities of local health care providers and resources. This community change model has the potential to guide community program development, and offers service providers and health planners a different approach to developing rural palliative care programs. Developing local programs in rural communities will improve access to palliative care services for an aging population.

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