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Community Capacity Development in Palliative Care: An Illustrative Case Study in Rural Northwestern Ontario

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Abstract

Despite the increasing need for palliative care, it is well recognized that people who are dying in rural and remote areas have less access to palliative care services than their urban counterparts. Barriers to accessing palliative care for rural residents include geographic isolation, shortage of human resources, and lack of palliative care education and training for rural health care providers. Community capacity development has become an accepted practice approach to developing rural health services, essentially 'building on what already exists'. This case study research conducted in northwestern Ontario, Canada, examined the application of a four phase community capacity development model as an intervention to develop a palliative care program in a rural community. Data were collected over the three-year period using a participatory action research approach. Findings illustrated the applicability of the model to guide rural palliative care development and provided details of the community change process. Conclusions support the applicability of the model for use as a theory of change to guide and evaluate rural palliative care service development.

Keywords: rural health, rural palliative care, palliative care, community capacity development, participatory action research, rural health teamwork, end-of-life care.

1.0 Introduction

Due to the aging population, more people are living longer with chronic and terminal illnesses, and the demand for palliative care is growing steadily (Carstairs, 2005; Davies & Higginson, 2004). In rural areas, there are many recognized access and quality challenges in delivering health services, including palliative care (Ministerial Advisory Council on Rural Health, 2002; Romanow, 2002). Despite the increasing need for palliative care, it is well recognized that people who are dying in rural and remote areas have less access to palliative care services than their urban counterparts (McKee, Kelley & Guirguis-Younger, 2007; Robinson et al., 2009; Wilson et al., 2009). Barriers to accessing palliative care for rural residents include geographic isolation (MacLean & Kelley, 2001), shortage of human resources (O'Toole, Schoo, Stagnitti, & Cuss, 2008), and lack of palliative care education and training for rural health care providers (Habjan, Kortes-Miller, Kelley, Sullivan, & Pisco, 2011; Kortes-Miller, Habjan, Kelley, & Fortier, 2007). Dying at home, among family and friends, is what rural people want (Conley & Burman, 1997; Romanow, 2002), and care closer to home is a rural health policy goal (Ministerial Advisory Council on Rural Health, 2002).

1.1 Developing Rural Palliative Care

Given the geographic isolation and limited resources of many rural communities, capacity development has become an accepted practice approach to developing rural health services, essentially 'building on what already exists' (Kelley, Williams, DeMiglio, & Mettam, 2011). From this perspective, communities are seen to have the capacity to tackle their problems through collective problem solving. Development is seen as an innate and natural process found in communities (Raeburn, Akerman, Chuengsatiansup, Mejia, & Oladepo, 2006). 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 (Horton & MacLeod, 2008).

However, models to guide the development of rural programs have been lacking (Robinson et al., 2009), especially in palliative care services. Using data collected from health care providers in rural communities in seven provinces and territories across Canada in 1999 and 2000, Kelley (2007) created a model to conceptualize the process of developing palliative care program in rural communities. The model called *Developing Rural Palliative Care* illustrates the four-phase process of palliative care development using a growing tree as a metaphor (Figure 1). The first phase of the model focuses on the antecedent conditions that need to be in place in order to facilitate rural palliative care development, while the second phase represents the catalyst that precipitates change in the community's status quo. The catalyst stimulates the creation of the team which is the third phase of the model. The fourth and final phase involves growing the palliative care program through building the expertise of the team and implementing team outreach activities into the community. Each phase has several tasks that must be accomplished, culminating in phase four which is the delivery of a program that provides clinical care, education, advocacy, and is characterized as having created strong linkages both within the community and with outside resources. The model depicts a 'bottom-up' community development approach that builds on existing community resources and remains community focused. It further illustrates how rural providers manage the challenges of lack of resources, community resistance to palliative care, bureaucracy, and the nature of the rural environment (Kelley, 2007).

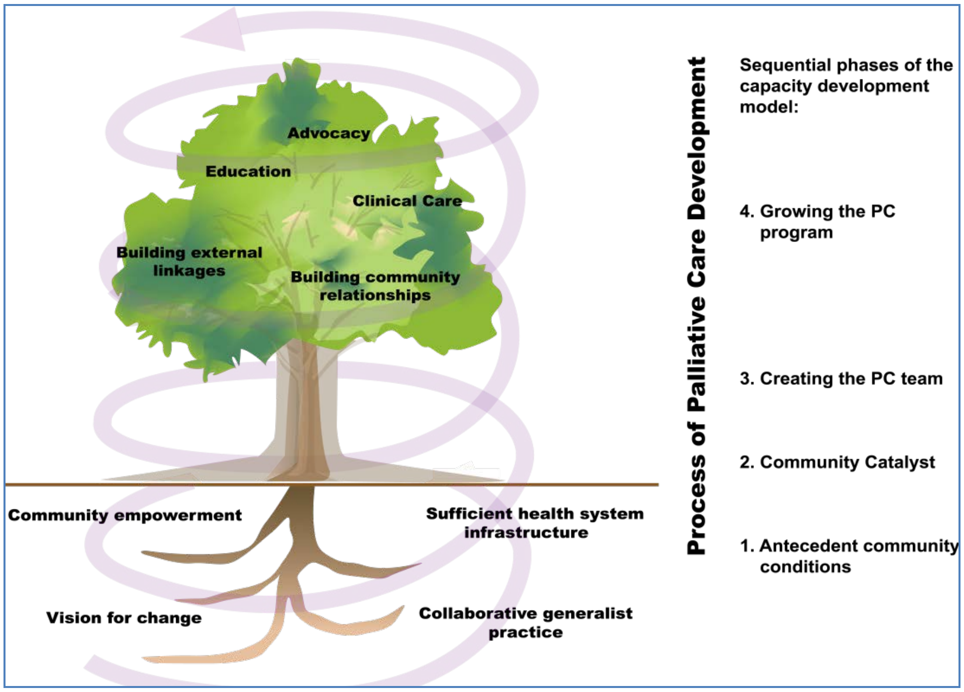

Figure 1. Developing Rural Palliative Care

The *Developing Rural Palliative Care* model demonstrates the principles of capacity development: change is incremental in phases but dynamic; the change process takes time; development builds on existing resources; development cannot be imposed from outside; and development is ongoing. The model offers service providers and health planners a different approach to rural palliative care program development (Kelley, 2007).

Additional research, conducted in 2007 and 2008 with health care providers in seven rural communities within two provinces, validated and further refined the model (Kelley et al., 2011). Through the validation process, an additional antecedent condition was uncovered: the need for a sense of community empowerment. Three dynamic processes were elaborated within rural palliative care development: 1) palliative care development adapts to internal and external forces such as health care restructuring; 2) the progress of palliative care development is non-linear in nature; and 3) the catalyst process is ongoing during all phases of the project, and it is not confined to Phase 2. This validation research affirmed that the model can be used to predict and explain palliative care development in rural communities (Kelley et al., 2011). The case study presented herein examines the practical application of the model in all its stages.

1.2 Rural Case Study Context

The case study was done in northwestern region of Ontario which can be defined as rural and remote as per DesMeules et al's (2012) definition of rural and small town. Northwestern Ontario is comprised of the districts of Kenora, Rainy River and Thunder Bay (Figure 2). It covers approximately 60% of the landmass of the province, but contains only 2% of its total population. The rural and remote areas include numerous small towns and First Nations communities. The distance between eastern and western boundaries is slightly over 1,000 kilometres, with a population density of 0.5 persons per square kilometre. The only major urban community in the region, Thunder Bay, has a population of 109,000 and is considered remote in relation to Ontario's major population areas in the southern part of the province (Northwestern Ontario District Health Council, 2001).

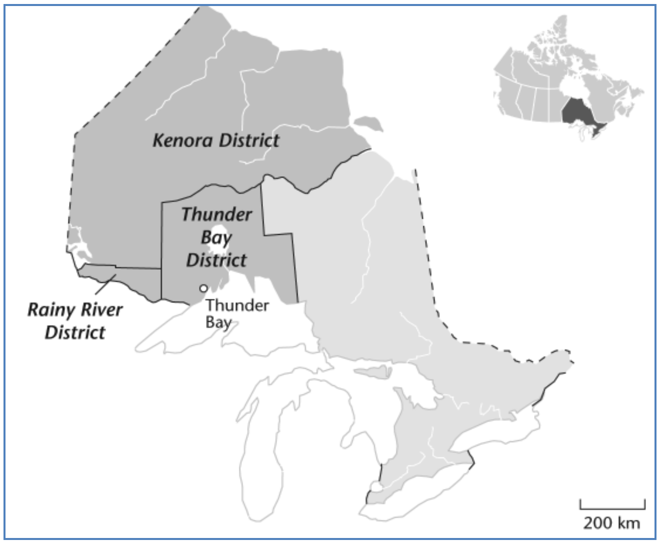

Figure 2. Map of Northwestern Ontario, with districts

The case study took place in two small adjacent communities in Northwestern Ontario (Community A and Community B) that share health care services, health care providers, and a number of support programs. A fully accredited acute care hospital, a multidisciplinary Family Health Team and a medical centre are part of the shared resources. Community A has a population of 1,625, with 13.5% of residents being over the age of 65, and Community B has 901 people, with 16.1% being aged 65 or over, compared to Canadian average of 13.7% (Statistics Canada, 2006). These two communities are located approximately 200 km from the closest urban centre. Due to geographic proximity and development of a joint palliative care program, the two communities will be addressed as 'the Community' for the purpose of this study. Community is therefore defined and understood in this paper as a geographically delineated area comprised of the two communities described above. Within this macro-community exists the palliative care team, made up of a wide range of individuals who represent the health, social, economic and political spheres of this larger geographical community.

2.0 Methodology

The goal of the study was to examine the practical application of Kelley's model (Kelley, 2007; Kelley et al., 2011) to create new palliative care programs in a rural community. The research was explicitly community-based and emerged from the community’s initiative. Data were collected over the three-year period (2007-2010) in a case study design (Yin, 2009), using a participatory action research (PAR) approach.

Community-based, participatory research is appropriate for developing rural health programs (Flicker & Savan, 2006; Lyons & Gardner, 2001). PAR calls for doing research in partnership with the community and for the community's benefit; it focuses on working with local people to identify their practice problems, implement solutions, monitor the process of change, and assess outcomes (Kemmis & McTaggart, 2005). Collaboration, education, and action are the three key elements of PAR, reflected in the role of the researcher as observer, facilitator, and consultant (Ramsden, 2003). The researcher facilitates and supports the development process, and the research plan is constantly evolving based on current experience (Minkler, Breckwich, Mansoureh, & Peterson, 2008). Thus, unlike other methodologies, knowledge is embedded in the process rather than viewed as an outcome of the research. It is the evolutionary process of change that is documented by the researcher.

Qualitative data were collected from various sources in order to gain an in-depth understanding of the process of palliative care development from the multiple perspectives of those involved in the delivery of palliative care within the community. Data collection involved annual site visits to attend palliative care community team meetings (4), observing a two day workshop about palliative care attended by health providers, review of team meeting minutes (8) as well as telephone interviews with the chairperson of the palliative care team approximately every six months (8) who volunteered to work with the researchers to facilitate the community development process and data collection. The nominated chairperson was a community palliative care team member who had been nominated by her colleagues to coordinate their team meetings and liaise with the researchers as a key informant in between face to face research meetings. The ongoing participation of the researchers provided palliative care team members greater opportunity for self-reflection on their process and this self-reflection further validated their efforts and progress over time. Three focus group interviews also took place with the community’s palliative care team in 2007, 2008 and 2010, consisting of 12, 6 and 13 participants respectively. Focus group questions are outlined in Table 1. Focus group participants were invited by purposive selection and included health care professionals and volunteers involved in palliative care. Some participants took part in all focus group interviews, while others participated only in some due to their availability or changes in local health human resources that impacted team membership.

Table 1. *Focus Group Interview Schedule*

Question	Probes
1. How has palliative care in your community changed in the last 6 months?	
2. What has influenced/contributed to the change?	
3. What were your successes in developing palliative care in the last six months?	(a) What were the keys to your successes?
4. In the last six months, what were your challenges/obstacles in developing palliative care?	(a) How did you overcome those obstacles?
5. What are your future goals for developing palliative care in your community?	(a) What strategies ill you use? (b) What resources will you need?
6. How does your community's experience developing palliative care compare with the developmental process depicted in the model (Figure 1)?	(a) How would you compare them?
7. How is the model used/useful in facilitating your palliative care development?	

Focus groups were semi-structured and facilitated discussion around the participants' experience of palliative care in their community, in relation to each phase of the model. All focus group interviews were audio-recorded with the participants' permission and transcribed verbatim by members of the research team. Focus groups were held in the community at a time and place arranged by the membership, for example over lunch in the community centre or in the local hospital meeting room. The transcripts from the focus group interviews were reviewed independently line by line by two members of the research team. The coding of data was conducted manually in a two-stage process. The first stage involved using the validated model as a framework to organize the focus group data into descriptive codes (Cope, 2010), based on the four phases of the model and their key components. The second stage involved articulating common themes within each phase using excerpts from the focus group data. When analysis was complete after each focus group, researchers returned to the community and met with the participants to share their findings. Participants always welcomed the researchers' visits as the researchers' observations and analysis of the team development provided them with an empowering perspective. Ethical approval was granted by the Research Ethics Board of Lakehead University and McMaster University.

3.0 Process and Outcomes: A Case Study in Capacity Development

The analysis of data revealed that Kelley's conceptual model is consistent with the practical experience of palliative care capacity development in rural communities and can be used as a guide for local palliative care committees or teams. This case study also highlights key components addressed in the model, such as: the importance of a sense of local empowerment; the ongoing nature of the catalyst; the non-linear development process, and; the role of internal and external forces.

The case study confirms that contextual differences in rural communities impact the development of palliative care programs.

Each phase of the model is examined using data from the case study. Applicable excerpts from the focus group interviews are used to demonstrate the key components and themes within each of the four phases of the model.

3.1 Phase 1: Antecedent Community Conditions

The palliative care team, represented by the focus group participants, recognized they have a strong foundation of antecedent conditions that allows them to develop a palliative care program for their residents. These include: **sufficient local health care infrastructure; collaborative generalist practice; sense of community empowerment and control; and a vision to improve care of the dying.**

Participants identified a **variety of available health services**, both through the hospital and home care services. Among these are a multidisciplinary Family Health Team[1], home care through Community Care Access Centre[2], and hospice volunteers. There is also a strong informal network of family and friends who provide care for those who are dying in the community. As one person stated,

> "I think that shows us what strong antecedent conditions we have, what a strong community force we have, what strong family and friends support we do have for some of these people." (FG3)

Members of the palliative care team illustrate **collaborative generalist practice** since they are willing to take on responsibility and work together to move forward in developing a program. They mentioned how, as generalists, they work with palliative care patients when palliative care is not their speciality. They fill multiple roles in different settings, supporting the collaborative generalist practice aspect of the model. Participants mentioned the many layers of skills and resources that can be tapped into if needed.

> "We're a pretty well-qualified group here, you know, a pretty diverse group, so we have the infrastructure and we sort of have government agencies backing us, so I think all the ground work is there." (FG1)

Participants identified that 'knowing your resources' is important in the creation of a team. Service providers were already working together and they know each other. As one participant shared:

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[1] Family Health Teams are health care organizations that include a team of family physicians, nurse practitioners, registered nurses, social workers, dieticians, and other professionals who work together to provide health care for their community (Ontario Ministry of Health and Long-Term Care, http://www.health.gov.on.ca/en/).

[2] Community Care Access Centres are the local organizations established by the Ontario Ministry of Health and Long-Term Care to provide access to government-funded home and community services and long-term care homes (Ontario Ministry of Health and Long-Term Care: http://www.health.gov.on.ca/en/).

> "I think the most important thing is that people are aware of all the different agencies that are out there...in a community that you have resources there, it's able to grow." (FG2)

Community empowerment and control was evident. Participants recognized that the community has specific needs and a strong community force that is already working and caring for the dying. Many regional policies and practices are influencing rural communities. However, participants stressed the importance of community ownership of their new palliative care program, while staying consistent with regionally based services, policies and procedures.

From the beginning of the study it was evident that participants had a **strong vision to improve care for dying people** and this vision spurred them forward with goals and action steps: "I don't want to wait for a crisis before someone decides to change the status quo" (FG1). The following interconnected characteristics of their vision come through in the focus group data: community support; working together; and breaking the barriers with support of community and education. Each of these characteristics is described in detail below.

Participants highlighted a need for support from a broader community. Obtaining this support is seen as a challenge because: "Unless it is affecting them personally or until it does, they don't deal with it until it hits home" (FG1). Having broader community support and awareness would enable those involved with a patient and their family to be able to meet their needs in a time of crisis. Participants envisioned inclusive education around palliative care that reaches beyond hospital walls and health care professionals, and saw the potential for wide ranging community impact. A participant noted that palliative care "is a huge kind of under-represented area that we don't have knowledge of or want to increase our knowledge of" (FG1). Being able to recognize, think about and be a part of the palliative process could be difficult, especially when "a lot of them [community members] don't even want to talk about it" (FG 1). The participants acknowledged that a great deal of community education would be required to gain their support.

One of the strongest aspects of the vision was for the community to work together, and for different care providers to communicate with each other and work in a consistent manner.

> "I think it is important to educate people that it is easier to work together than work in silos" (FG1).

Participants wanted to move beyond the common perception that care providers could do it on their own. A stronger relationship and more understanding between palliative care providers and other community services could help create more integrated care:

> "…there needs to be some connection to the hospital that makes us all on the same plate or on the same page…" (FG 1).

Participants saw a need to disrupt the hierarchy of services and the 'silo-ed'[3] way of working, recognizing that community education, communication and working together all had to happen in unison in order to improve care for the dying.

Many of the specific goals that participants talked about correlated to breaking down the barriers that stand in the way of fulfilling their vision, such as the 'if it's not broke, don't fix it' mentality. One participant commented, "We aren't sure how to get [the Community] to understand that palliative care can't stay as a status quo and get them to buy into it" (FG 3). Participants had a vision to be innovative and provide more solid support for people while there were others in the community comfortable with the way things were. Overcoming this barrier has remained an ongoing challenge and part of the participants' vision.

3.2 Phase 2: Community catalyst

Several catalysts to growing the palliative care program were observed throughout the duration of the case study research.

The first identified catalyst was the primary researcher (ML Kelley) who introduced the developing of palliative care model to the community. Participants highlighted her first visit to the community as the beginning of the formation of their team and the palliative care program. She was seen as an external facilitator that brought them all together to start the process of learning about the model, building a vision to improve care and taking steps to form a team and start a program.

Another catalyst was palliative care education that was offered in their community in Year 2. The Centre for Education and Research on Aging and Health at Lakehead University, Thunder Bay (http://cerah.lakeheadu.ca/), held an onsite interdisciplinary 2-day workshop for all interested health care providers and hospice volunteers. Approximately 25 people attended this work shop, including all the physicians practicing there (N=4), nurses from the hospital, family health team and home care, and hospice volunteers. This palliative care training that was offered in the community facilitated and encouraged connections among different health care providers and served to engage the broader community in understanding the work and goals of the newly formed palliative care team.

In Year 3, the provincial call for end-of-life care funding proposals was another catalyst to push the team forward in reaching their goal in developing a palliative care program within the community. Funding was obtained and another local palliative care workshop focusing on grief took place. The timing was crucial since several deaths were experienced in a short period of time, bringing the end-of-life issues into the community's forefront. One participant commented on the value of this grief workshop:

> "The workshop...was probably driven because we had such a huge number of expected and unexpected deaths in the community, but it brought the

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[3] Government intervenes in a number of ways at the local level; however, rarely are these interventions co-ordinated effectively, creating the notion of "silos". Such divisions are often taken for granted, blamed on historical working relationships and organizational cultures (Froy & Giguère, 2010).

> education program I guess as a stronger force in our group. And it brought quite a few different people, in terms of collaboration, together." (FG3)

As demonstrated in the model, catalysts are ongoing and are important throughput the development process, coming from both internal and external forces (Kelley et al., 2011); this was demonstrated in the case study. Catalysts can be direct community events such as multiple deaths within short time period, or larger forces such as the health care policy and palliative care discourse that has entered into the Canadian health care system over recent years (Carstairs, 2005).

3.3 Phase 3: Creating the palliative care team

Participants identified various facets that were important in both creating and maintaining the palliative care team, including having the right voices and people involved, having a team facilitator, and maintaining commitment of members.

The model includes 'having the right people involved' and 'having dedicated providers' as essential aspects of creating the team (Kelley, 2007). The participants expressed the importance of multiple voices, and discussed whose voice should be included on the team and in program development. According to participants, important voices include those who work directly in palliative care, such as hospital nurses, hospice staff, and home care providers. It was deemed important to gather input from patients' family members, as well as to involve both clinical health care providers and other members of the larger service landscape from a variety of disciplines that could play a role in advocacy, education, and building community relationships. Participants articulated the importance of engaging people with “knowledge about how health care works” (FG1), in order to determine what works, what does not work, and how to strengthen supports. Physician involvement is generally seen to be an important aspect in formation of the palliative care team, and the team of concern herein found it fortunate they were able to secure family physician involvement from the start of team development. As previously mentioned, one of the local team members was nominated by her peers to be the team chair. Her role was to facilitate communication, organize meetings and liaise with the research team. This facilitator was a key role in the capacity development process and it was important to choose the “right” person. In this case, the facilitator was an experienced and well respected social worker who worked in the community health clinic.

By Year 2, palliative care team had met regularly, and team members felt they had been able to affect change within their organizations and larger community. They had developed an organizational chart for their program, terms of reference for the team and a path of care specific to palliative care that included a common assessment tool to be used by the hospital, family health team and home care program. The team also created a palliative care program pamphlet and had an information session to promote their work.

However, barriers to effective team functioning were identified, including problems in communication:

> "I think we had the discussion before about barriers, and in terms of the [organizational issues] confidentiality becomes a barrier very frequently, and communication between CCAC [Community Care Access Centre], the

> hospital, the family health team. Some physicians don't know that CCAC is involved in and vice versa."

In addition, some organizations placed little value on palliative care, and obtaining needed education was still seen as a barrier for some providers. Some challenges to maintaining and strengthening the team were noted, such as: time constraints and availability of team members (since some were hospice volunteers in addition to working full time); and, a lack of administrative support. However, in Year 3 and forward, the team members reported they have stronger support from their agencies to be members of the palliative care team, and to work within the palliative care field.

3.4 Phase 4: Growing the palliative care program

When the third focus group interview took place, the team evaluated their own progress and placed themselves in Phase 4 of the model. They recognized that the creation and development of a palliative care program is a non-linear process, as elaborated in the model validation research.

> “I think we kind of have leapt back and forth sometimes between the different levels that you have listed here. Creating the team, we’ve kind of done [it]. People move in and move out… growing the program… it seems that we’re kind of new in some areas, where we’re moving ahead in some areas where we’re a bit further behind”. (FG3)

Several aspects of growing the palliative care program were observed: **strengthening the team; engaging the community; and sustaining palliative care**. Each of these aspects are described in detail below through the experience of the team.

Within the focus group interviews, several messages came through that demonstrate the inherent **strength and confidence of team members**. The team reported sharing knowledge, skills and information with each other. They were 'learning by doing', such as making community presentations of the in-home charting process, and planning a local workshop. These actions increased team members' self-confidence and also strengthened group dynamics.

They also started to create linkages outside of the community, such as partnering with other rural communities to apply for program funding and organizing an educational workshop together. A strong relationship has also begun between the team, the Northwestern Ontario End-of-Life Care Network and, more specifically, the Network's palliative pain and symptom management consultant.[4]

One of the first active steps the team took to **engage the community** was developing an educational pamphlet about multi-disciplinary palliative care

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[4] The Northwestern Ontario End-of-Life Care Network is a non-profit organization that is committed to advancing end-of-life care in Northwestern Ontario. Palliative Pain and Symptom Management Consultant supports service providers by providing access to consultation, education, mentorship and linkages to palliative care resources across the continuum of care (http://www.nwoendoflifecare.ca/).

services that are available in the community. At this early part in the team's development, a participant identified the following:

> "The community is more empowered in the sense that they've become more aware of palliative care and have a little bit of an understanding of it". (FG2)

Other team-led initiatives included: developing and implementing palliative tools for care; providing family education on palliative care; and, offering education and support for other service providers. The team's future goals are to develop stronger and more diverse community relationships and encourage palliative care, for example, by participating in a health fair at a local First Nations community.

By Year 3 of the case study, team members recognized they were in the midst of the "Growing the Program" phase and were aware of important aspects that would be required to **sustain the program**. These included: developing policies and procedures; communication and advocacy; external linkages; and, sustaining the team's emotional and mental health needs. Each of these aspects are seen by the team as next steps in growing the palliative care program, described below.

4.0 Limitations

Outside the inherent limitations of a case study approach which is time limited, there are a number of shortcomings that need to be mentioned. There was a number of inconsistencies with respect to who participated in each of the three focus groups, as well as the time period between focus groups. For example, although scheduled ahead of time, one of the focus groups had to be post-phoned due to the HINI concern; this monopolized all community resources, including the availability of the palliative care team. These inconsistencies may have resulted in lost representation, with respect to team members, as well as lost opportunities with respect to recall of information pertinent to the research objective. This was partially mitigated through a telephone interview with one of the primary members of the team.

5.0 Discussion and Next Steps

Across the span of data collection, the palliative care team accomplished many goals but also recognized a need to develop a more formalized process that would assist them in coordinated 'care planning', a goal they have not yet reached. They often communicate informally and continue to evolve organically. Although they already have some policies and procedures in place, the development of a coordinated process for palliative care has remained a long-term goal.

According to the model, an important aspect of sustaining palliative care program is communication and advocacy. Team members found there was a lack of communication and continuity of care between different health care services, such as the regional cancer centre and the local hospital, and they have identified improved communication as a goal for sustaining their program. The team is also working on their connection to the hospital by engaging in continuous communication with hospital staff.

There is a strong desire to work with other small communities in the region that are similarly trying to develop and sustain their own palliative care programs.

Participants thought it important that these communities know they are not working in isolation. One participant had this vision:

> "Maybe once a year everyone could get together and say this is what's going on in our community, these have been our successes, if it does develop then that could be a next step". (FG3).

The palliative care team is already a part of the region's End-of-Life Care Network which is seen as a connecting body between communities in Northwestern Ontario.

With all of the formal aspects of developing a palliative care program, a consistent message throughout all of the focus group interviews has been the significant impact of end-of-life care on the emotional and mental health of patients, family members and friends, and the team members themselves. Sustaining end-of-life care is about sustaining *people* as well as sustaining the *program*. People need to be supported through these often emotionally intense experiences. One participant expressed this need:

> "What about when we work with palliative clients and there's no recognition of that need as providers of any type of health care. How do you nourish your own soul? And I think that's highly, highly underrated". (FG2)

There was significant discussion amongst team members about the need for "debriefing" after the death of a patient, which would involve bringing everyone together who was involved with the deceased. One participant shared a particularly valuable discussion she took part in:

> "People came away from that and went, 'Wow, we really needed that. That was so invaluable to me as a person.' And it was very much the type of discussion that you would have in a debriefing after you lose a member of your community...we not only know the clients in the hospital, we know them for years, you know?" (FG2)

Care providers get attached to those they are supporting, especially in a small community. Support for the ability to process the events leading up to and at the point of death is seen as a condition for sustainability of palliative care programs.

6.0 Conclusion

This case study suggests the continuous evolution of rural palliative care development. The practical experience of palliative care program development follows the conceptual model of palliative care development (Kelley et al., 2011), while also providing further insight into the practical aspects of the model. These research findings support earlier conclusions that the model has applicability for use as a theory of change to guide and evaluate rural palliative care service development (Kelley, Sletmoen, Williams, Nadin, & Puiras, 2012). In our study, team members experienced the model as very helpful in forming their team and growing the program. One participant enthusiastically expressed, "It shows us where we started and where we've come to, and where we need to go next, and I just found that very, very useful" (FG3). It prompted them to examine the model and relate it to their own work, and it also empowered them to identify what they had achieved and where they still need to go. The team members are looking to further define substantial goals to work towards as they carry on their journey of palliative care capacity development.

The team demonstrated that they are a resourceful group who base their actions on the needs of their community, beginning from the ground up, with the patients and families they serve. Given the non-linear nature of palliative care development, it is inevitable that the community will need to respond to their rural contextual heterogeneity (Williams & Cutchin, 2002) as they continue to move forward. Future research will be useful to examine specific contextual factors that contribute to the palliative care development, and there will be a need for ongoing evaluation as programs move towards long-term sustainability.

7.0 Acknowledgements

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