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Program Assessment Framework for a Rural Palliative Supportive Service

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Abstract: Although there are a number of quality frameworks available for evaluating palliative services, it is necessary to adapt these frameworks to models of care designed for the rural context. The purpose of this paper was to describe the development of a program assessment framework for evaluating a rural palliative supportive service as part of a community-based research project designed to enhance the quality of care for patients and families living with life-limiting chronic illness. A review of key documents from electronic databases and grey literature resulted in the identification of general principles for high-quality palliative care in rural contexts. These principles were then adapted to provide an assessment framework for the evaluation of the rural palliative supportive service. This framework was evaluated and refined using a community-based advisory committee guiding the development of the service. The resulting program assessment framework includes 48 criteria organized under seven themes: embedded within community; palliative care is timely, comprehensive, and continuous; access to palliative care education and experts; effective teamwork and communication; family partnerships; policies and services that support rural capacity and values; and systematic approach for measuring and improving outcomes of care. It is important to identify essential elements for assessing the quality of services designed to improve rural palliative care, taking into account the strengths of rural communities and addressing common challenges. The program assessment framework has potential to increase the likelihood of desired outcomes in palliative care provisions in rural settings and requires further validation.

Keywords: rural palliative care, quality indicators, quality of care

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Introduction

The need to provide high-quality palliative care to an aging population has resulted in the development of a number of quality frameworks for palliative care. However, evaluating the quality of palliative care is difficult for several reasons including the concurrent goals of supportive and curative care, the potentially competing interests of patients and families, and the emphasis on patient-centered care in an evidence-based environment.¹ No universally agreed upon outcome exists by which the success of palliative care can be judged. Enhanced quality of life and meeting the needs of patients and family are widely accepted outcomes,² but these goals are elusive. Some have argued that because quality of life has no shared or coherent understanding, it should not be used as a quantitative measurement of the outcome of care.^{1,3} Needs are difficult to evaluate because they are typically understood within a context of harm,³ and what constitutes harm when death is the inevitable outcome remains under debate. Further, many indicators used in palliative care lack the sensitivity to show improvements in outcomes under different models of care, particularly when health naturally declines prior to death.^{2,4}

Despite these challenges, there is a need to ensure that services delivered are cost-effective and high-quality. A number of quality frameworks for palliative care have been published and reviewed. Pasman et al⁵ conducted a systematic review of quality frameworks for palliative care published through December 2007. They identified a total of 142 quality criteria from 16 studies which they mapped against the eight domains of the National Consensus Project for palliative care in the United States.⁶ They found that most quality indicators (n = 82) reflected the process of care, with relatively few focusing on structural indicators of care (n = 4). These researchers constructed a set of outcome indicators that would be applicable across contexts of care in the Netherlands resulting in 33 patient-focused and 10 family-focused outcome indicators.⁷ In a German study, Pastrana et al² used focus groups and a nominal group technique to identify 16 themes relevant to outcomes of care. They discovered that although experts generally agreed on the relevant themes (eg, quality of life, needs assessment of patients and relatives, satisfaction of relatives), there was less agreement regarding the

priority given to those themes. In the UK context, the Gold Standards Framework includes structure and process quality indicators for end of life care across contexts. Australia published guidelines for a population based approach to palliative care^{8,9} and guidelines for a palliative approach in community settings.¹⁰ Others have proposed frameworks for specific contexts of care. For example, Schenck et al¹¹ recently constructed quality measures for hospices in the United States; their initial scan of 174 potential measures was reduced by an expert panel to a final set of 34 primarily process measures. Raijmakers et al¹² reported consensus among experts on seven quality indicators for patients with cancer in their last days of life, along with an additional 18 topics for consideration in determining quality indicators for this specific phase of palliative care.

Assessment frameworks for rural palliative care

Despite the growing body of quality frameworks for palliative care, our literature search yielded no frameworks adapted to the rural context. Although the general principles of high-quality palliative care should be similar, rural areas have unique socio-cultural and healthcare needs. There are few specialist palliative services in rural areas and limited healthcare services in general.¹³ Difficult geographic and weather conditions make it challenging for residents to access care.¹⁴ Previous studies in Canada suggest that rural individuals have unique perspectives on quality of care and quality of life at end of life.^{15,16} Evaluative frameworks must account for the rural context.

The work done in this paper arose from a need for an assessment framework for a rural palliative supportive service (RPaSS). RPaSS is a community-based research project designed to enhance the quality of care for patients and families living with life-limiting chronic illness in rural areas. Previous studies have shown that rural family caregivers experience significant challenges in obtaining needed information and resources.¹⁶⁻¹⁸ Care is often fragmented and occurs too late in the palliative trajectory. Through RPaSS, patients with chronic life-limiting illness are identified using an upstream approach when the symptom burden is increasing but when they do not yet require home support services. The RPaSS coordinator maintains regular contact, provides teaching, support,



and referrals, and plays an important integrating and advocacy role during transitions in care. RPaSS is designed to provide high-quality palliative care in an upstream approach within the rural community itself, thereby augmenting options available through the publicly funded healthcare system.^a We describe a program assessment framework that can be used to evaluate a specific rural palliative supportive service. However, the framework is likely applicable to other forms of palliative care services in rural areas.

Methods

We began by gathering key documents describing standards, frameworks, and models for palliative care. Searches were conducted in PubMed, CINAHL, and the grey literature using database-specific terms and key words that represented palliative care and quality indicators. We then supplemented the documents with empirical literature describing palliative care in rural contexts.^{eg,13,19,20} The same databases were searched using database-specific terms and key words that represented palliative care and rural context. Using Kelley's^{21,22} model of capacity building in rural palliative care, we then organized potential quality principles within the four stages of program development: antecedent conditions, critical incidents, creating a team, and growing a program. A conceptual process map was created by organizing the principles into general themes. Although this map represented the ideal scenario for growing a rural palliative care team, RPaSS is a supportive service meant to augment the healthcare services that currently exist in the community. It was important for us to obtain program-specific evaluation criteria. Two members of the investigative team then identified and organized the principles most appropriate to the nature of RPaSS. These principles were evaluated and refined by a community-based advisory committee, which included key stakeholders in the community who are guiding the development of the RPaSS. Table 1 shows the general quality principles derived from the literature and the specific RPaSS assessment framework by which we evaluate development of the service.

^aIn British Columbia funding for healthcare comes to rural communities through centralized Health Authorities that have jurisdiction over large geographic areas.

Results

The principles for the RPaSS program assessment framework are discussed in terms of the following seven themes: embedded within the community; timely, comprehensive, and continuous care; access to palliative care education and experts; effective teamwork and communication; family partnerships; policies and services that support rural capacity and values; and systematic approach to measuring and improving outcomes of care. Under each theme, the principles that constitute high-quality palliative care from the rural palliative literature are discussed, followed by a description of the strategies RPaSS employs within the assessment framework.

Embedded within the community

Previous studies pointed to important antecedent conditions for rural communities to develop palliative care capacity.^{21,22} Capacities include “abilities, skills, understandings, attitudes, values, relationships, behaviours, motivations, resources, or conditions that are essential in enabling individuals, organizations, and communities to carry out functions and achieve their developmental objectives.”^{23(p118)} Capacity building is a manner in which communities problem solve complex issues through enhancing existing capacities²³ and is an important strategy for program development in rural communities where formal healthcare resources are limited.²³ Building upon inherent capacity is particularly important for ensuring that programs are embedded within the community and less vulnerable to the rapid cycles of change that are typical of modern healthcare. Previous research has illustrated how healthcare restructuring can have negative unintended consequences on palliative care capacity in rural communities.^{16,24}

Important principles for rural capacity building include the following: based upon a community assessment;²⁰ vision generated from the community;²⁰ broad-based community support;^{25–28} involvement of leaders;^{15,16} and public visibility.^{17,27} Important antecedent conditions for a successful rural palliative care program include adequate community healthcare infrastructure, integrated and generalist healthcare practices, and a shared vision for change as well as sense of community empowerment.^{21,22} Broad-based community support is essential. Unlike urban areas where services (eg, healthcare, transportation,

**Table 1.** Program assessment framework for a rural palliative supportive service (RPaSS).

Quality principles for rural palliative care from the literature	RPaSS assessment framework: strategies
<p>Embedded within community</p> <ul style="list-style-type: none"> • Based on a community assessment. • Vision generated from community. • Involves champions in the community. • Is publicly visible. • Broad-based community support. <p>Palliative care is timely, comprehensive and continuous</p> <ul style="list-style-type: none"> • Timely designation occurs for those who may benefit from palliative care. • Designation is comprehensive and dependent on need rather than prognosis. • Palliative care is available for any life-limiting illness and in an upstream approach. • Palliative care may be provided in conjunction with life-prolonging treatments. • Patients and families have access to services 24 hours a day, 7 days a week for basic to advanced palliative care. • Case management supports continuity of care to help integrate transitions for patients and families between care settings (eg, home, hospitals, residential facilities and urban relocations). <p>Access to palliative care education and experts</p> <ul style="list-style-type: none"> • Continuing palliative care education is available for primary health care providers. • Primary care physicians and nurses with palliative expertise are utilized in the community and can undertake direct care of the patient if needed. • Palliative care experts are available as back-up (eg, Telehealth). <p>Effective teamwork and communication</p> <ul style="list-style-type: none"> • Clear leadership structure. • Regular team meetings to discuss, plan and evaluate care and initiatives. • Formal communication plan. • Registry of palliative individuals. • Peer support for team members. • Builds connections in community between volunteer/paid/formal/informal healthcare providers. 	<ul style="list-style-type: none"> • Advisory committee with broad stakeholder representation. • Regular advisory meetings to report on activities and solicit feedback. • Media strategy for reporting. • Website. • Active community referrals. • Yearly environmental scan and strategic planning. <ul style="list-style-type: none"> • Referrals received for patients who have not yet received a palliative benefits designation. • Referrals received from patients with a variety of chronic life limiting conditions. • A RPaSS coordinator maintains regular contact with registrants throughout all transitions in care. • Treatments are discussed and negotiated on a regular basis with registrants. • Documentation of physical, psychosocial and spiritual needs of registrants. • Documentation of care delivered through the RPaSS. • Access 24/7 to healthcare providers with palliative expertise. • Physician orders to treat symptoms available with no undue delays. <ul style="list-style-type: none"> • RPaSS coordinator provides evidence of his/her continuing PC education. • RPaSS coordinator documents educational needs encountered in care and reports to advisory committee. • RPaSS coordinator documents continuing education opportunities offered within the community. • All appropriate registrants aware of provincial palliative care nurse referral line and usage of service documented. • Expert physician resource available in rural community. <ul style="list-style-type: none"> • Advisory committee with terms of reference. • Care committee with terms of reference. • RPaSS care plan created, regularly updated and left in registrant home as a means of communication for other care providers. • Registrants sign a release allowing information to be shared between RPaSS coordinator and other care providers. • Comprehensive RPaSS communication plan constructed and reviewed annually. • Registration database created for RPaSS. • Registrants screened and educated regarding hospice services. • Registrants screened and educated regarding spiritual/religious care services.

(Continued)



Table 1 (Continued)

Quality principles for rural palliative care from the literature	RPaSS assessment framework: strategies
<p>Family partnerships</p> <ul style="list-style-type: none"> • An inventory of local and regional bereavement services available to health care providers and bereaved family members. • Needs and roles are negotiated and re-negotiated on an ongoing basis. • Receive anticipatory and timely teaching and guidance based upon needs. • Participates in choices around place of care. • Bereavement care available through a variety of approaches. <p>Policies and services that support rural capacity and values</p> <ul style="list-style-type: none"> • Policies of agencies providing palliative care are supportive of rural values and needs. • Advance care planning occurs and is revisited when a disease is recognized that is life-limiting. • Necessary benefits and services are available and accessible in a timely manner. • Persons are aware of available benefits and services. • Desired place of death is discussed and meets the realistic expectations of the patient. <p>Systematic approach to measuring and improving outcomes of care</p> <ul style="list-style-type: none"> • Accountability cycle with feedback to stakeholders. • Validated patient and family outcome measurements. • Built upon research and translation of best practice guidelines. 	<ul style="list-style-type: none"> • Designated family registrants. • Family registrants receive resource binder. • Family registrants complete Robinson et al caregiving decision aid regarding location of care and discussion occurs regarding identified needs. • Family registrant involved in advance care planning. • Family registrant participates in care conferences. • Family registrants regularly assessed regarding satisfaction with RPaSS care and caregiver burden. • Family registrant participates in bereavement visits × 2. • Documentation of the effects of policies that hinder and facilitate high-quality palliative care with a feedback loop to advisory committee, ministry of health and health authority. • Registrants will be aware of My Voice, engage in conversations about advance care planning and have someone to whom they can make their wishes known. • Resource inventory for rural communities updated yearly. • Documentation of benefits and services obtained through RPaSS coordinator. • Preference for place of death recorded. • Needs assessment performed of feasibility of preferred place of death. • Family caregivers complete Robinson et al decision making tool and discussion occurs regarding identified needs. • Documentation of gaps in care (eg, failure to control symptoms or unavailable services). • Regular feedback loops about quality of care to care committee, advisory committee and community. • Registrants complete quality of life tools. • Family registrants complete satisfaction with care provided by RPaSS and caregiving burden tools. • Bereaved family registrants complete satisfaction with care and grief tools. • RPaSS coordinator completes healthcare utilization index. • Knowledge integration plan in place for RPaSS.

volunteer organizations) exist in silos, in rural areas there must be cooperation across sectors due to limited resources. For example, with limited transportation options, the location of healthcare services plays an essential role in accessibility. Despite the close knit nature of rural communities, it can be difficult to make services visible and to disseminate information. Patients and families need to know the nature of

palliative care, common issues they may encounter, and available services and supports. Community leaders who are passionate about palliative care and devote time and energy toward improving services are an important part of community capacity. Dissatisfaction with the status quo, often arising from critical incidents, provides an impetus for these leaders to work for change. These leaders work to



integrate services, to enhance visibility of the services, and to provide access to information, thus generating community support.

Based upon these principles, RPaSS includes an advisory committee, a communication plan, a yearly environmental scan, and monitoring of community referrals. The service is supported by an advisory committee with strategic representation from relevant community stakeholders. The committee meets regularly to receive reports on the activities of the service, to provide advice, and to communicate information back to their constituency. RPaSS is supported by a communication plan that includes a media strategy promoting a continuing presence in the community. One of the specific ways that RPaSS tracks broad-based community support is through the presence of referrals from healthcare providers and from self-referrals of patients and families.

Timely, comprehensive, and continuous care

Palliative care should be available in an upstream approach for any life-limiting illness.²⁹ The provision of palliative care, including palliative care provided in rural settings, such as palliative home care, should be based upon the principles of need and benefit, rather than upon guidelines that target specific time frames until death (eg, 6-month prognosis),³⁰ regardless of the geographic location of care recipients. This means that the line between chronic illness management and palliative care may initially be blurred and that the transition to primarily palliative care will be seamless. The potential for concurrent palliative and life-prolonging treatments must exist. As the burden of chronic disease increases, rural-dwelling patients and families should have continuous access to palliative services, and this access should be available 24 hours per day, 7 days per week when near the end of life.^{26,30} A case management model can support the continuity of care and help to ease transitions for patients and families across illnesses, geographies, and institutions.^{26,30,31} Rural care, based upon a generalist model, is ideally suited to such an approach. The high degree of connection between providers in rural communities has the potential to support person- and family-centered care.^{15,16,19} However, previous studies have indicated that challenges occur around providing 24/7 access and thus symptoms may not be treated

in a timely manner. Further, gaps in care may occur when persons commute outside of their communities for care or when they transition between settings (eg, acute to residential care).^{17,18}

The RPaSS assessment framework monitors the unique contributions of the service to timely, comprehensive, and continuous care. The timeliness of referral is monitored by registering patients who have a chronic life-limiting condition with increasing symptom burden but who have not yet received a formal palliative designation. A chronic life-limiting condition is defined broadly to include any individual for whom a healthcare provider would not be surprised to have death occur within the next year. Once on the service, participants receive regular contact from the coordinator for care, support, education, and referral based on identified needs. Supportive needs and the plan of care are documented so that these needs can be tracked over time. Although registrants must be residing at home when recruited, once on the service, the coordinator follows them throughout transitions in care to ensure that support remains continuous, regardless of place of care. Registrants on the service have access to this support 24 hours per day, seven days per week. This model of care is unique because it provides a supportive and knowledgeable individual for patients and families early in the palliative trajectory who help them to integrate and navigate the other services provided by the formal healthcare system.

Access to palliative care education and experts

Specialist, multidisciplinary teams characterize palliative care in urban areas, a model that many rural communities hold as ideal. However, rural healthcare is characterized by a generalist model whereby practitioners must become expert generalists. Rural healthcare providers often feel they lack the required specialized palliative knowledge,^{13,32} particularly when difficult symptoms or psychosocial issues arise. Rural primary healthcare providers require access to continuing palliative care education^{27,33} and understanding of the philosophy of palliative care.¹⁹ Further, there should be expert resources available outside of the community for consultation.^{20,28,30,33} This expert should be able to undertake direct care of the patient if necessary.²⁶



As RPaSS is a community-based supportive service meant to augment healthcare, the role of the service in relation to educating providers is limited to providing a profile for palliative care in the community and a clearing house for palliative information. The coordinator provides evidence of his or her continuing education, makes educational opportunities visible to the community, and documents community-based educational needs that he or she observes in the context of care. These needs are referred to an advisory committee as part of an ongoing accountability cycle in the community. A palliative nurse referral line is available in British Columbia to family members who have been designated as palliative by the formal healthcare system. The RPaSS coordinator informs participants of this line and documents usage of the line. This is important because RPaSS is a time limited research project; although participants have access to RPaSS on a 24-hour basis, it is important to ensure that they know the options available at the conclusion of the project. At this time in British Columbia, there is no expert outside of the community that can undertake direct care for rural individuals if the primary care physician is unavailable or lacks the required expertise. Therefore, the RPaSS is supported by a general practitioner and nurse practitioner in the community who have palliative expertise.

Effective teamwork and communication

Rural teams function best when there are appropriate resources for administration, when providers are involved across settings of care (home, acute, residential), and when leadership is delegated by tasks rather than teams.²⁷ Adequate time to discuss, plan, implement, and evaluate care is important. Formal communication systems including a common patient chart, care plan, referral system, and a registry can facilitate the continuity of care.^{30,34} Technology may prove useful in facilitating this.²⁰ Flexibility around roles and scopes of practice among healthcare providers is important in a context of limited resources.²⁷ Volunteers are an important part of the palliative team and the quality of care in rural communities may be affected if there is an insufficient number of volunteers.^{35,36} Since there may not be a full interdisciplinary palliative team in rural areas, alternatives for providing holistic care must be explored.

RPaSS strategically brings together partners for a community-based approach to care. The service has both a stakeholder advisory committee and a clinical team made up of a coordinator, a nurse practitioner, and a physician, as well as individuals who are embedded in the community and have an existing network of relationships. The advisory group meets four times per year to receive updates and provide advice for the service. The clinical team conducts biweekly virtual rounds and coordinates closely with other healthcare providers involved in care. Participants in the study sign a consent form that allows the sharing of information across sectors. The RPaSS is supported by a communication plan that includes both macro (eg, media strategies) and micro (eg, reporting and communication forms) strategies. This plan helps to build connections between the essential partners in palliative care. Care provided by the RPaSS coordinator is contained within a care plan that is left within the registrant's home. All registrants are screened and referred to other community-based volunteer services as appropriate. Hospice societies from the rural communities served through this service are co-investigators on the research project providing important capacity building and knowledge translation strategies.

Family partnerships

Research into family caregiver needs in rural areas^{16,18} has revealed a number of common needs, including timely attention to symptom management, teaching regarding basic care needs and the availability of resources, assistance with negotiating responsibilities for care, and advocacy within the healthcare system. Family caregivers cite the difficulties they experience in obtaining important information and in not knowing the proper questions to ask. They may have difficulty accessing the help required because of resource issues and geographic distance and they may not be aware of the options and services available to them.

Rural social life can have positive and negative effects on family caregivers. The community may rally to assist with instrumental needs; however, family caregivers may experience a loss of privacy. The number of visits from both healthcare providers and concerned neighbors may result in burden for family caregivers without providing the relief they require. Rural caregivers also need support through



their advocacy role. The most helpful support these family caregivers envision is a single person who can provide support, information, and advocacy to help them navigate the system throughout transitions in care. RPaSS provides such a service by registering family caregivers along with patients on the service, which gives them access to the coordinator. Family caregivers receive a resource binder of locally available services and participate in care planning conferences. Clinical practice tools designed to assess caregiver needs, burden, and bereavement are used to guide support and to map outcomes of care (Table 2).

Policies and services that support rural capacity and values

One of the most challenging aspects of rural health service delivery is designing appropriate “rural-friendly” policies. Policies that attempt to standardize approaches across urban and rural contexts often have unintended negative consequences for rural palliative care delivery.²⁴ For example, first available bed policies for residential care may result in relocation to other rural communities for palliative care. Policies regarding the working conditions of personnel such as volunteers, home support workers, and ambulance attendants may mean that these providers are not able to perform the tasks that are most needed (eg, volunteers not being able to contribute to meals or cooking).

In many cases, rural healthcare providers simply find ways to work around these policies. When faced with competing professional and personal interests present in the context of dual rural relationships, relationship interests are more important. However, this often has a subsequent cost to the system and to patients and families. For example, healthcare providers may avoid putting individuals on registered palliative benefits if this means that they have to relocate to designated “palliative beds”. These patients then forgo the benefits and may be cared for in more costly acute care beds. In the face of already limited resources, flexibility in policies for rural healthcare delivery is essential.^{19,27}

Part of the assessment framework for RPaSS ensures that policies that are not rural-friendly are made visible to the community and policy makers. The role of the advisory committee is to carefully consider policies that work against high-quality care and to strategize methods of adapting these policies to rural care while staying true to the original intent of the policy (eg, protection of health of workers and fiscal accountability). The advisory committee includes representatives from the health authority and from the participating city councils so that important decision makers are involved.

Rural-friendly services are also an important part of the rural palliative care capacity. However, individuals may not be aware of which services are available in their community or have the energy or time to seek out these services when confronting a life-limiting illness. For example, rural communities often have volunteer driver and meal programs that serve various populations in the community, but their services may not be widely known. Various options for place of death may be available in the rural community, but family caregivers may not be aware of the options to support an informed decision. High-quality information is available on-line for patients and families, but many do not have the time or expertise to search out and screen these resources.

To facilitate awareness of these services, RPaSS has compiled an inventory of resources located both within the community and on-line to support those living with life-limiting chronic illness. The community coordinator provides education regarding these resources as the need arises. The community coordinator also introduces registrants to My Voice,

Table 2. Outcome measurement and practice tools.

Patient tools	Family tools
McGill quality of life questionnaire ³⁷	Adaptation of the Home caregiver needs survey ³⁸
Edmonton symptom assessment system (revised) ^{39,40}	Family appraisal of caregiving questionnaire for palliative care ⁴¹
	FAMCARE scale ⁴²
	Texas revised inventory of grief ⁴³
Unpublished instruments	
COF-PHLI: palliative spiritual history tool (unpublished work, Pritchard Z.)	COF-PHLI: palliative spiritual history tool (unpublished work, Pritchard Z.)
	Caring at home for someone with life-limiting illness: family decision guide (unpublished work, Robinson C., et al)



an advance care planning package supplied by the British Columbia Ministry of Health. Registrants may choose to discuss their advance care plan with someone other than the RPaSS coordinator, but at minimum, the coordinator educates registrants regarding the necessity of a plan and the resources available to them. Discussion of the preferred place of care, and ultimately death, is facilitated by a decision-making guide that is currently under trial.

Systematic approach to measuring and improving outcomes of care

The close-knit nature of rural relationships can make it difficult to solve quality of care challenges. Families are reluctant to advocate for the care they require because of fears of being labeled a ‘difficult’ family, which may in turn cause healthcare providers to be reluctant to work with them. In rural communities, being labeled a difficult family can have implications for future healthcare encounters. Further, it is challenging for bereaved family members to have the energy or the expertise to know how to recommend improvements in the system. Yet, particularly in a rural community, a difficult death leaves a collective community memory that has far-reaching implications for how citizens view the quality of dying.¹⁶ Therefore, an essential part of rural palliative care improvement is having validated measurements and systematic data collection,^{19,25,30} as well as a knowledge translation plan that allows meaningful engagement of the rural stakeholders.

The RPaSS coordinator systematically collects standardized data as part of the regular visits. Along with a general clinical assessment, this includes patient quality of life, family caregiver needs and burden, and healthcare utilization statistics (Table 2). Family caregivers receive two bereavement visits from the RPaSS coordinator where grief resolution is measured. They also receive a third interview with another member of the research team to measure satisfaction with care provided by the RPaSS coordinator. Tools were trialed for use with a rural population prior to implementation within the project. The satisfaction measure was shown to be particularly challenging for family members to complete. As one family member stated, “Will this be confidential? I am going to need care at some point as well.” Through cognitive interviews, we discovered that there was often a discrepancy between

quantitative measures and qualitative data. Family caregivers would indicate a high degree of satisfaction on the instrument but would then relay stories of care that were highly problematic. We therefore decided to collect both quantitative measures and qualitative interview data as part of the evaluation of the service. This data is discussed within the clinical team of the RPaSS coordinator, nurse practitioner, and physician. Primary care physicians receive regular updates on the care provided by the RPaSS coordinator. To protect the confidentiality of registrants, aggregated data is made available to the advisory committee and forms the basis of discussion regarding the quality of care in the community.

Conclusion

The RPaSS program assessment framework, derived from current evidence of high-quality palliative care in rural areas, identifies essential strategies for assessing and evaluating the quality of the supportive service. This framework builds upon common strengths in rural communities and addresses common challenges in providing rural palliative care services. Such a framework is an important adaptation of quality principles to a rural context. As such, this framework holds unique potential for increasing the likelihood of desired outcomes in the palliative care provision in rural settings. It is important to note that a limitation of the framework is that it seeks to assess only one aspect of rural palliative care related to a supportive service rather than rural palliative care more generally.

In future studies, we will evaluate the use of this framework and conduct psychometric assessment of outcome measures being used as part of the assessment of quality of life, caregiver burden, and healthcare utilization. Although multiple sources were referenced and experts consulted in the development of this framework, it is possible that other relevant assessment criteria may be identified. The use of this assessment framework in other rural settings will help refine the framework and enhance the quality of rural palliative care.

Author Contributions

Conceived and designed the experiments: BP, BH, RS, CAR, JLB, MD. Analyzed the data: BP, MD. Wrote the first draft of the manuscript: BP, MD. Contributed to the writing of the manuscript: BP, BH, RS, CAR, JLB,



MD. Agree with manuscript results and conclusions: BP, BH, RS, CAR, JLB, MD. Jointly developed the structure and arguments for the paper: BP, MD, CAR, JLB. Made critical revisions and approved final version: BP, BH, RS, CAR, JLB, MD. All authors reviewed and approved of the final manuscript.

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Competing Interests

Author(s) disclose no potential conflicts of interest.

Disclosures and Ethics

As a requirement of publication the authors have provided signed confirmation of their compliance with ethical and legal obligations including but not limited to compliance with ICMJE authorship and competing interests guidelines, that the article is neither under consideration for publication nor published elsewhere, of their compliance with legal and ethical guidelines concerning human and animal research participants (if applicable), and that permission has been obtained for reproduction of any copyrighted material. This article was subject to blind, independent, expert peer review. The reviewers reported no competing interests.

References

- Randall F, Downie RS. *The Philosophy of Palliative Care: Critique and Reconstruction*. Oxford, England: Oxford University Press; 2006.
- Pastrana T, Radbruch L, Nauck F, et al. Outcome indicators in palliative care—how to assess quality and success. Focus group and nominal group technique in Germany. *Support Care Cancer*. 2010;18(7):859–68.
- Randall F, Downie RS. *Palliative Care Ethics: A Companion to All Specialties*. Oxford, England: Oxford University Press; 1999.
- Dy SM, Aslakson R, Wilson RF, et al. Improving Health Care and Palliative Care for Advanced and Serious Illness. Closing the Quality Gap: Revisiting the State of the Science. Evidence Report No. 208. (Prepared by Johns Hopkins University Evidence-based Practice Center under Contract No. 290-2007-10061-I.) AHRQ Publication No. 12(13)-E014-EF. Rockville, MD: Agency for Healthcare Research and Quality. Oct 2012. <http://www.effectivehealthcare.ahrq.gov/reports/final.cfm>. Accessed May 29, 2013.
- Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage*. 2009;38(1): 145–56.
- American Academy of Hospice and Palliative Medicine, Center to Advocate Palliative Care, Hospice and Palliative Nurses Association, National Hospice and Palliative Care Organization. National consensus project for quality palliative care steering committee. National consensus project for quality palliative care: clinical practice guidelines for quality palliative care, executive summary. *J Palliat Med*. 2004;7(5):611–27.
- Claessen SJ, Francke AL, Belarbi HE, Pasman HR, van der Putten MJ, Deliens L. A new set of quality indicators for palliative care: process and results of the development trajectory. *J Pain Symptom Manage*. 2011;42(2): 169–82.
- Palliative Care Australia. *A Guide to Palliative Care Service Development: A Population Based Approach*. Deakin West, ACT: Palliative Care Australia. 2005. <http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf>. Accessed May 3, 2013.
- Palliative Care Australia. *Standards for Providing Quality Palliative Care for all Australians*. Deakin West, ACT: Palliative Care Australia. 2005. <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow090570.pdf>. Accessed May 3, 2013.
- Australian Government Department of Health and Ageing. Canberra, Australia. 2011. *Guidelines for a Palliative Approach for Aged Care in the Community Setting—Best Practice Guidelines for the Australian Context*. [http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/\\$File/COMPAC%20Vol%202%20RTF%20accessible%20WEB.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/$File/COMPAC%20Vol%202%20RTF%20accessible%20WEB.pdf). Accessed May 3, 2013.
- Schenck AP, Rokoske FS, Durham DD, Cagle JG, Hanson LC. The PEACE Project: identification of quality measures for hospice and palliative care. *J Palliat Med*. 2010;13(12):1451–9.
- Rajmakers N, Galushko M, Domeisen F, et al. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. *J Palliat Med*. 2012;15(3):308–16.
- Robinson CA, Pesut B, Bottorff JL, Mowrey A, Broughton S, Fyles G. Rural palliative care: a comprehensive review. *J Palliat Med*. 2009;12(3): 253–8.
- Pesut B, Robinson CA, Bottorff JL, Fyles G, Broughton S. On the road again: patient perspectives on commuting for care. *Palliat Support Care*. 2010;8(2):187–95.
- Wilson DM, Fillion L, Thomas R, Justice C, Bhardwaj PP, Veillette A. The “good” rural death: a report of an ethnographic study in Alberta, Canada. *J Palliat Care*. 2009;25(1):21–9.
- Pesut B, Bottorff JL, Robinson CA. Be known, be available, be mutual: a qualitative ethical analysis of social values in rural palliative care. *BMC Med Ethics*. 2011;12:19.
- Robinson CA, Pesut B, Bottorff JL. Issues in rural palliative care: views from the countryside. *J Rural Health*. 2010;26:78–84.
- Robinson CA, Pesut B, Bottorff JL. Supporting rural family palliative caregivers. *J Fam Nurs*. 2012;18(4):467–90.
- Goodridge D, Duggleby W. Using a quality framework to assess rural palliative care. *J Palliat Care*. 2010;26(3):141–50.
- National Rural Health Association. *Providing Hospice and Palliative Care in Rural and Frontier Areas*. Kansas City, MO. 2005. <http://www.nhpc.org/resources-rural-providers/rural-toolkit>. Accessed July 12, 2012.
- Kelley ML. Developing rural communities' capacity for palliative care: a conceptual model. *J Palliat Care*. 2007;23(3):143–53.
- Kelley ML, Williams A, DeMiglio L, Mettam H. Developing rural palliative care: validating a conceptual model. *Rural Remote Health*. 2011;11(2):1717.
- Habjan S, Kortess-Miller K, Kelley ML, Sullivan H, Pisco L. Building capacity in rural health services: the effect of continuing education. In: Kulig JC, Williams AM, editors. *Health in Rural Canada*. Vancouver, BC: UBC Press; 2012.
- Pesut B, Beswick F, Robinson CA, Bottorff JL. Philosophizing social justice in rural palliative care: Hayek's moral stone? *Nurs Philos*. 2012;13(1):46–55.
- Canadian Hospice Palliative Care Association. *Applying a Model to Guide Hospice Palliative Care: An Essential Companion Toolkit for Planners, Policy Makers, Caregivers, Educators, Managers, Administrators and Researchers. To be used in conjunction with A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. Ottawa, ON: Canadian Hospice Palliative Care Association. 2005. http://www.chpca.net/media/7458/Applying_a-Model-to-Guide-Hospice-Palliative-Care-Toolkit.pdf. Accessed July 12, 2012.
- British Columbia Ministry of Health. *A Provincial Framework for End-of-Life Care*. Victoria, BC: Ministry of Health. May 2006. <http://www.health.gov.bc.ca/library/publications/year/2006/framework.pdf>. Accessed July 12, 2012.



27. MacLean MJ, Kelley ML. Palliative care in rural Canada. *Rural Soc Work*. 2001;6(3):63–73.
28. Castleden H, Crooks VA, Schuurman N, Hanlon N. “It’s not necessarily the distance on the map ...”: using place as an analytic tool to elucidate geographic issues central to rural palliative care. *Health Place*. 2010;16(2):284–90.
29. National Gold Standards Framework Centre. The Gold Standards Framework. 2012; <http://www.goldstandardsframework.org.uk/>. Accessed April 2, 2012.
30. Canadian Hospice Palliative Care Association. *The Pan-Canadian Gold Standard for Palliative Home Care: Towards Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home*. Ottawa, ON: Canadian Hospice Palliative Care Association. December 2006. http://www.chpca.net/media/7652/Gold_Standards_Palliative_Home_Care.pdf. Accessed July 12, 2012.
31. Wilson DM, Birch S, Sheps S, Thomas R, Justice C, MacLeod R. Researching a best-practice end-of-life care model for Canada. *Can J Aging*. 2008;27(4):319–30.
32. Rosenberg JP, Canning DF. Palliative care by nurses in rural and remote practice. *Aust J Rural Health*. 2004;12(4):166–71.
33. Crooks VA, Castleden H, Schuurman N, Hanlon N. Visioning for secondary palliative care service hubs in rural communities: a qualitative case study from British Columbia’s interior. *BMC Palliat Care*. 2009;8:15.
34. Hall P, Weaver L, Handfield-Jones R, Bouvette M. Developing leadership in rural interprofessional palliative care teams. *J Interprof Care*. 2008;22(S1):73–9.
35. McKee M, Kelley ML, Guirguis-Younger M. So no one dies alone: a study of hospice volunteering with rural seniors. *J Palliat Care*. 2007;23(3):163–72.
36. McKee M, Kelley ML, Guirguis-Younger M, MacLean M, Nadin S. It takes a whole community: the contribution of rural hospice volunteers to whole-person palliative care. *J Palliat Care*. 2010;26(2):103–11.
37. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliat Med*. 1995;9(3):207–19.
38. Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vézina L. Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med*. 2006;9(4):912–21.
39. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*. 1991;7(2):6–9.
40. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multicenter study comparing two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *J Pain Symptom Manage*. 2011;41(2):456–68.
41. Cooper B, Kinsella GJ, Picton C. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psychooncology*. 2006;15(7):613–22.
42. Kristjanson LJ. Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. *Soc Sci Med (1982)*. 1993;36(5):693–701.
43. Faschingbauer TR, Zisook S, DeVaul R. The Texas Revised Inventory of Grief. In: Zisook S, editor. *Biopsychosocial Aspects of Bereavement*. Washington, DC: American Psychiatric Press, Inc.; 1987:109–24.