Development of the Palliative Care Model in the Tri-Facilities area, Nova Scotia

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Executive Summary

The purposes of this project were to 1) learn about the current palliative care model in the Tri-Facilities, 2) identify its stage of development and corresponding opportunities, and 3) evaluate the applicability of a Change Guide prepared in Ontario to enable community palliative care development in Nova Scotia. Information was collected through interviews with those with knowledge about palliative care in the Tri-Facilities, and feedback was received when findings were presented.

The Tri-Facilities refers to a predominantly rural area in Nova Scotia that is comprised of three individual communities that share palliative resources. Application of the Change Guide suggests that the Tri-Facilities' palliative care model is likely in the start-up phase, which is characterized by team building and collaboration. Some challenges associated with the start-up phase include maintaining flexibility as the team develops, providing 24/7 care, and securing referrals from local healthcare providers. Based on identified areas for improvement and community strengths, seven recommendations have been made: 1) Continue to utilize the Change Guide tools, 2) Map the roles, connections, and processes of palliative team members, 3) Clarify, communicate, and support the palliative nurse role, 4) Build capacity through ongoing palliative education, 5) Develop strategies to ensure 24/7 access to palliative care, 6) Optimize technology and other resources to fill gaps, and 7) Measure indicators of the model's success.

The Change Guide proved to be very useful in a Nova Scotian context. Minor adaptations to the tool to incorporate province-specific terms are necessary. Due to rural context, hospital and long-term care facilities were included in this project even though the Change Guide was designed to focus on non-institutionalized care. There were no major issues associated with such an application of the Change Guide. However, future adaptations to encompass rural settings may be necessary. The Change Guide establishes a clear, logical, and tangible framework that can empower communities to further develop their palliative care models.

Introduction

In 2014, Nova Scotia developed an integrated provincial strategy for palliative care. In alignment with this project, the provincial strategy emphasizes the importance of 1) clarifying provincial, health authority, and community service providers' roles and responsibilities to support an integrated approach to palliative care services, 2) developing a change management process for effective roll-out, and 3) establishing integrated care delivery and access to services across settings (Government of Nova Scotia, 2015). Utilization of palliative care programming has been associated with reduced odds of dying in hospital in Nova Scotia (Lavergne, et al., 2015). Timely access to health care and services is often a special concern for rural locations (Tamblyn, 2011; Kelley et al., 2012).

This project focuses on the Tri-Facilities, which is a predominantly rural area located northeast of Halifax, Nova Scotia. It is comprised of three communities that each have a local hospital. The area is part of Nova Scotia Health Authority's Central Zone, and has a history of different levels of access to a palliative physician and/or nurse (Appendix A). Although each of the communities in the Tri-Facilities operates rather independently, palliative care resources are shared. This project was undertaken with the purposes of 1) understanding the current palliative care model operating in the Tri-Facilities, 2) identifying its stage of development and corresponding opportunities, and 3) assessing the applicability of the Change Guide in a Nova Scotian context.

The Change Guide, developed by Dr. Hsien Seow, is a resource that includes key learnings from research on exemplary community-based palliative care teams in Ontario (Palliative Care Innovation, 2015). The Change Guide is intended to be used by communities for reflection, identifying strengths and challenges, and ultimately, for the improvement of their palliative care model. This report is the first application of the Change Guide in Nova Scotia, and adaptations that were deemed appropriate for the change in context were made (Appendix A).

During the fall of 2015, interviewees with experience and knowledge of palliative care in the Tri-Facilities were directly engaged using adapted versions of Tools 1 and 2 of the Change Guide. Tool 1 refers to quality commitments to palliative patients and families, and Tool 2 identifies the palliative care assets that are present in the community (Appendix A). The information gathered from the interviews was compiled and used to inform the discussion of community strengths and recommendations included in this report. Learnings from the interviews were utilized to apply Tool 4 of the Change Guide and analyze the stage of development of the Tri-Facilities' palliative care model.

On December 4th, the findings from this project were presented (Appendix B) to an audience that included interviewees and interested stakeholders (Appendix C). Feedback from the presentation on my application of Tool 4 has been incorporated throughout this report. The information included represents my best understanding from interviews, research, and feedback; it is not necessarily representative of the community's or province's perspective.

Tool 4: Evolution of Palliative Care Models

The Change Guide identifies four major stages of palliative team development: inception, start-up, growth, and mature (Table 1). Each of the stages have associated key opportunities, challenges, milestones, and potential indicators to measure. The purpose is that communities should understand their stage of development in order to establish realistic expectations and generate positive momentum. These stages are similar to the phases identified in the Mary Lou Kelley model of rural palliative care development, which has been validated in its application in rural communities (Kelley et al., 2012; Kelley et al., 2011).

Table 1: Stage of Evolution of Community Palliative Care Models.

Stage of Evolution	What's Happening	Assessment Using Information Collected
Inception	Local champion has a vision for improving palliative care. Begins building necessary infrastructure, resources, and relationships through grassroots efforts.	Palliative care in Tri-Facilities has been operational for many years. Beyond inception stage.
Start-Up	Founding members begin to build team and ways of collaborating. They define and market services offered to patients and providers.	History of different levels of access to palliative doctor. Recent addition of a palliative nurse. Tri-Facilities is in process of developing new ways to collaborate and provide care.
Growth	Stable core team with established relationships works to expand reach.	Tri-Facilities recently added a core team member and change in model of care delivery. Thus, not yet at the growth stage.
Mature	Team is trusted and valued. Seen as hub for knowledge-sharing and expertise.	Palliative care expertise is accessed through Halifax-based team. Tri-Facilities is not yet at mature stage.

The Tri-Facilities is best described as being in the start-up phase. Palliative care has been provided in the Tri-Facilities for many years; thus, the model is beyond the inception stage. However, the recent history of different levels of access to a palliative physician and the appointment of a new palliative nurse represent major changes to the communities' model. As the palliative nurse is new to the role and operating without a formal link to a palliative doctor, new ways of collaborating are in the process of being developed. The services that the palliative nurse can offer are still being defined. For example, it was not clear if there is a specific sub-group of palliative patients, such as those with complex needs, who would be referred to the palliative nurse or if the intention is for all palliative patients in all settings to be seen by her. The ability of the palliative nurse role to work across palliative settings in all three communities is contingent upon local health providers' understanding, acceptance, and utilization of her skillset. These factors are reflective of the start-up phase, which is characterized by building a new team and ways of collaborating. The Tri-Facilities' model is not yet at the growth or mature stage, as the core team is still being established and palliative expertise is generally accessed outside of the communities.

Key Opportunities

There are some opportunities associated with the inception phase that may still be valuable for the Tri-Facilities to consider (Table 2). These refer primarily to creating foundational relationships and building local intelligence of needs, gaps, and assets. Both of these opportunities relate to the recent changes to the model with the new palliative nurse role and no specific palliative physician dedicated to the area. In the past, the Tri-Facilities have utilized local palliative care nurses who did not remain in the position without a formal relationship with a palliative physician (Appendix A). The new hiring of a palliative nurse presents an opportunity to build local intelligence and strategies regarding any needed changes to enable the success of this position.

Table 2: Key Opportunities Associated with Stage of Development.

Stage of Evolution	Key Opportunities	Assessment Using Information Collected
Inception	• Build local intelligence for better understanding of needs, gaps, assets and what will work • Create foundational relationships for a strong core team	• Palliative nurse is in process of building relationships • No specific palliative physician from Central Zone team dedicated to Tri-Facilities area
Start-Up	• Develop effective ways of sharing information • Build rapport with community providers • Build understanding in community of team's role and how providers can be supported • Outreach to upstream partners in community, to encourage timely referrals and collaboration	• Some effective ways of information sharing have been established in community • Many long-standing and positive working relationships • New palliative nurse is building relationships in community • Palliative care nurse, social worker, and OT receive referrals from health providers throughout Tri-Facilities

The start-up phase also has associated key opportunities. The Tri-Facilities has established some effective ways of sharing information without the use of electronic medical records. Each of the three communities utilize interdisciplinary rounds where health providers can discuss and provide updates regarding palliative patients. There are many long-standing and positive working relationships in the Tri-Facilities, which are beneficial for "building community rapport". In regards to receiving referrals, the palliative care nurse, social worker, and occupational therapist (OT) are shared resources within the

three communities and can receive referrals for palliative patients throughout the Tri-Facilities. The degree to which referrals are received is dependent on healthcare providers' understanding of each role's unique skills and contributions.

Key Challenges

Some relevant challenges from the inception phase include building team buy-in and the time required to build relationships (Table 3). These challenges are associated with the recent change to the Tri-Facilities' palliative care team. Obtaining resources and using creative strategies represents another relevant challenge. Although there are many examples of rural resourcefulness in the Tri-Facilities, the usage of a tool like the Change Guide may help in further guiding grassroots efforts and developing innovative strategies.

Table 3: Key Challenges Associated with Stage of Development.

Stage of Evolution	Key Challenges	Assessment Using Information Collected
Inception	• Build team buy-in; can't be top-down • Time and patience to build relationships • Obtain resources or use creative strategies	• Recent change to Tri-Facilities' palliative care team • Using Change Guide might help grassroots
Start-Up	Maintain flexibility as team develops and fills local gaps; Avoid turf wars with local homecare nurses; Manage patient caseload with limited team members; Lack of palliative care trained homecare nurses or physicians; Work towards providing 24/7 care; Get referrals from physicians and hospitals; Secure enough funding to sustain team through start-up	• Homecare nurses are part of palliative care team and work collaboratively • Palliative patients at home are not able to receive 24/7 care in community • Local physicians appear knowledgeable and familiar with providing palliative care
Growth	• Manage travel and serving large regions with limited headcount	• Distance, travel, and rural geography are challenges

Some of the challenges associated with the start-up phase may not be significant barriers for the Tri-Facilities. For example, homecare nurses work collaboratively to provide palliative care and are viewed as part of the palliative care team; thus, issues of turf wars may not be present. Similarly, the Tri-Facilities may not have a significant lack of palliative care knowledge in local family physicians. Family physicians were reported as being familiar with providing palliative care, and only seek palliative expertise as they deem

needed. The ability to provide 24/7 care to palliative patients at home is a challenge that has been identified by the community. Challenges include wait times, 24/7 access to case management, and family supports. These issues have also been identified on the provincial level (Quality End-of-Life Care Coalition of Canada, 2008).

Although the issue of serving large areas is associated with the growth phase in the Change Guide, it is a current challenge for the Tri-Facilities. Distance, geography, and rural context can impact on access to resources. In addition, the palliative care nurse role requires travel across all three communities.

Milestones

The milestones identified by the Change Guide are suggestions of goals for the community to work towards (Table 4). The assembly of a core team with essential roles is in process with the recent appointment of a palliative nurse. In regards to practicing patient-centred care, healthcare providers in the Tri-Facilities have identified a commitment to serving their community and viewing patients as a whole person.

Table 4: Milestones Associated with Stage of Development.

Stage of Evolution	Milestones	Assessment Using Information Collected
Start-Up	• Assemble core team with essential roles, including nurses and physicians • Practice culture of patient-centred mission and vision during decision-making and problem solving • Establish team processes, such as communication tools and methods • Create open ongoing dialogue on pain points and successes	• Communication and collaboration among palliative care providers could be improved • Clear roles and processes could help coordination • Increased use of technology and other communication among providers may have positive impacts • Important to have open communication both within and between teams

The establishment of team processes and communication methods is an important milestone for the Tri-Facilities to achieve, as communication and

collaborating among palliative care providers were identified as areas that could be improved. Due to the distance from Halifax and no specific dedicated palliative physician for the Tri-Facilities, more consistent communication with the Central Zone palliative team is needed and may benefit from improved virtual connections, e.g. via video-conferencing or tele-medicine for both case conferencing and continuing education. Especially with the changes to the palliative care model, a common understanding of each of the roles of all palliative care team members may assist in establishing clear processes and coordinated strategies.

Potential Measures

Recommended measures for the start-up phase include administrative data, indicators related to processes, and indicators related to teamwork (Table 5). The measurement of indicators specific to palliative team functioning and palliative care provision represent current opportunities for the Tri-Facilities. There is one quality coordinator position in the Tri-Facilities which is located at Eastern Shore Memorial Hospital.

Table 5: Potential Measures Associated with Stage of Development.

Stage of Evolution	Potential Measures	Assessment Using Information Collected
Start-Up	• Administrative data: caseload, urgent calls, ED visits, referral sources, place of death • Tracking process progress: document patients' end-of-life preferences, advanced care planning, orphaned patients connected with a doctor • Tracking relationship information: perceptions of "team" collaboration, conflict resolution, power equity, communication, role clarity	• Quality coordinator is located at Eastern Shore • Indicators specific to palliative care provision and team functioning are not currently measured • Data may be available from provincial level for Tri-Facilities

Community Strengths

Throughout this project, many community strengths and assets in the Tri-Facilities were identified. As mentioned previously, healthcare providers in the Tri-Facilities have a strong commitment to serving their communities and viewing patients as a whole person. Rural resourcefulness was also cited as important in overcoming barriers. The lack of anonymity and close bonds associated with rural healthcare are also factors that contribute to high levels of accountability.

The Tri-Facilities also has good foundations that can contribute to increased collaboration and interdisciplinary care. The proximity of different palliative team "home bases" and shared management may allow for increased communication between providers. For example, in Musquodoboit Valley, the hospital, long-term care facility, and family physician offices are located within the same building. This may assist palliative care health providers from different settings to connect with one another. Furthermore, in each of the three communities the homecare nurses are based out of the hospital. The use of interdisciplinary rounds also emphasizes the importance of information sharing across professions and care settings. The integration of the social worker into the palliative care team is another example of a community strength in regards to interdisciplinary care. Lastly, the healthcare providers in the Tri-Facilities often have strong, long-standing, and positive working relationships. This asset is especially relevant to the trust and teamwork required for successful palliative care models (Palliative Care Innovation, 2015).

The Tri-Facilities operate a palliative consult model in which family physicians are the main care decision makers (Appendix A). Their central role and knowledge of palliative care are community strengths. The recent appointment of a full-time local palliative care nurse is another community asset, as her skillsets can be developed and utilized to continue to improve care. Currently, she plays a large role in providing support, navigation, and connecting palliative patients and families to resources.

Recommendations for Tri-Facilities' Palliative Care Model Development

Based on the key learnings from this project and relevant research, recommendations have been made to aid in the continued development of the Tri-Facilities' palliative care model:

- **Continue utilizing the Change Guide tools**

The Change Guide is an easy to use and logical framework that assists in focusing attention on tangible actions to improve palliative care. Its continued use in the Tri-Facilities can have positive impacts on the development of coordinated efforts and innovative strategies. In particular, Tool 3, which was not utilized in this project, should be applied as it relates to communication and collaboration among providers, an identified key area for improvement. A facilitator could be used to guide the usage of the Change Guide in the Tri-Facilities. Facilitators guiding evidence-based palliative care interventions in rural communities have been successful, but consideration should be given to the amount of time required to gain knowledge about a community, explore rural palliative issues, develop strategies, and implement plans (Pesut et al., 2015). Consideration should also be given to the unique nature of the Tri-Facilities as three separate communities that share palliative resources. The pros and cons of utilizing the Change Guide separately in each community or more broadly should be evaluated. Consideration should also be given to the inclusion of the Central Zone palliative care team in this process.

- **Define the palliative care team and map out the associated roles and processes of all team members**

Communication and coordination between providers was identified in the interviews as key areas for improvement. The current palliative care model in the Tri-Facilities requires communication across settings, between communities, and with the Halifax-based Central Zone team. Thus, there must be an established understanding and clear expectations of the different roles in the palliative care model. Firstly, the core palliative care team should be identified. This team may differ between communities and across care settings, but those

responsible for palliative care should be noted. This exercise may be more difficult in rural settings as there is often a generalist approach in which healthcare providers serve multiple roles (Kelley, Sellick, & Linkewich, 2003). However, the exercise can still be completed using broader roles, such as "hospital nurse", if all hospital nurses have similar skillsets and responsibilities for palliative care. The skillsets and responsibilities for each of the roles should be identified. This can assist in determining any duplication of services and remaining gaps.

Most importantly, the processes connecting each of the different roles in the model should be mapped. This exercise can assist in answering questions related to when/who/how other members of the palliative care model can be accessed for support. Because of the recent change in access to Central Zone palliative physicians, the Halifax-based palliative care team should be included in this process to establish clear and agreed upon methods of access and communication. The development of clear and encompassing operational guidelines that identify roles and contributions of all team members is a strategy that has been successfully used to increase collaboration among palliative care teams in other provinces (Quality End-of-Life Care Coalition of Canada, 2008). The creation of process maps for each palliative care setting could prove beneficial for the Tri-Facilities.

- **Clarify, communicate, and support the palliative care nurse role**

As the palliative care nurse is new to her role, there is a need to support this position to allow for its success. Her role, in terms of when/how/by whom she is contacted, her responsibilities, and her current skillsets should be identified in the process described above. As she is referred to palliative patients, the success of her position is dependent upon other healthcare providers' understanding of her role and their relationship with her. Clearly communicating her role and strengths to healthcare providers throughout the Tri-Facilities can assist in building local trust in her capabilities and increasing her referrals.

The palliative care nurse role should also be supported to increase her capacity and palliative care knowledge. The provision of ongoing palliative care education can assist in the continuous development of her skills and

confidence. Her success can also be positively impacted through formal clinical support, as working in isolation is not ideal for any clinician. Because palliative physician expertise is not currently located within the Tri-Facilities, the local palliative nurse should have a formal link to palliative clinicians in Halifax and/or elsewhere. This formal relationship could include regular check-ins, learning opportunities, and consultations regarding patients.

- **Build capacity through ongoing palliative education**

Currently, palliative care expertise is accessed through the Halifax-based Central Zone palliative care team. With the recent creation of one provincial health authority, there may be potential for future collaborations with palliative care teams from other zones. However, skills and knowledge regarding palliative care should be continuously developed in local healthcare providers through educational opportunities. This step is an important component of the development of palliative care models (Palliative Care Innovation, 2015). Consultations with rural healthcare providers have identified a lack of palliative care training as an important barrier to overcome (Kelley, Sellick, & Linkewich, 2003). In addition, the increased capacity for palliative care delivery is a recommendation for family physicians (Canadian Medical Association, 2014).

Strategies utilized by other provinces include the creation of educational materials at the provincial level, funding agencies to provide regular interdisciplinary palliative care education, mentoring programs, annual conferences, refresher days, and videoconferencing (Quality End-of-Life Care Coalition of Canada, 2008). Examples of existing resources that could be provided include Learning Essential Approaches to Palliative Care (LEAP) and the Canadian Hospice Palliative Care Association continuing education opportunities (Pallium Canada, n.d.; Canadian Hospice Palliative Care Association, 2015).

- **Develop strategies to ensue 24/7 access to palliative care at home**

The provision of 24/7 care to palliative patients at home is a current challenge for the Tri-Facilities. Two of the communities which operate Collaborative Emergency Centres (which do not admit after 8pm) are developing standing

order policies to allow for palliative patients to be admitted to the hospital during the night. This is an example of community resourcefulness to overcome barriers and provide care for patients.

The palliative paramedic is a provincial initiative that allows for healthcare providers to register palliative patients with EHS, and when they call 911 they can receive emergency palliative care at home from a paramedic (Muise, 2015; Government of Nova Scotia, 2015a). All paramedics across the province have received palliative care training as of the summer of 2015 (M. Harrison, personal communication, December 2, 2015). Interviewees highlighted concerns regarding ready access to this service in rural areas due to the large service areas covered by paramedics, the amount of time required for paramedics to spend with palliative patients at home, and the lack of available paramedics for other emergencies. Program developers are aware of these concerns and are monitoring the use of palliative paramedics in rural communities to identify any needed changes and respond to issues during implementation. A presentation on palliative paramedics was completed in Sheet Harbour, but rural concerns regarding this service may indicate a need for further communication (M. Harrison, personal communication, December 2, 2015). The palliative nurse has recently connected a palliative patient in the Tri-Facilities to this resource, which could have a positive impact on the community's ability to ensure 24/7 care to palliative patients who reside at home.

Other strategies to provide 24/7 care to palliative patients at home could include the coordination and establishment of on-call schedules for willing local family physicians (Palliative Innovation, 2015). The development of collaborative primary care teams in Nova Scotia emphasizes teamwork, which may prove valuable in providing 24/7 care to palliative patients at home (Government of Nova Scotia, 2015b; Colbert, 2015). Access to consistent care at home is an important component of providing palliative patients with the ability to choose the setting in which they would like to die. Recent research in has indicated that only half of adults who die in Nova Scotia do so in their preferred setting (Burge et al., 2015).

- **Optimize technology and other resources to fill gaps**

Technology could assist in improving communication and coordination among care providers. Video conferencing and tele-medicine have been utilized with success in other rural areas (Rygh & Hjortdahl, 2007). Their usage in regards to palliative care should be investigated in the Tri-Facilities as well. In Nova Scotia, Telehealth, a form of videoconferencing technology, is an established resource for delivering healthcare services to patients and connecting among healthcare providers (Health Information Technology Services Nova Scotia, 2010). The use of an online portal for appointment bookings is another recent example of technology utilization in the province (Henderson, 2015). Telecommunication between clinicians, such as through the establishment provincial phone lines, may assist in increasing access to healthcare expertise for patient groups with specific needs (Julian, 2015).

The optimization of existing technologies can have positive impacts for rural communities in Nova Scotia, but IT gaps and deficiencies must also be identified in order to overcome barriers (Health Association of Nova Scotia, 2014). Nova Scotia is currently in the process of developing a provincial electronic health record system, which would allow for more efficient and comprehensive information sharing among healthcare providers (M. Russell, personal communication, October 8, 2015). This could have positive impacts in the future development of the Tri-Facilities' model.

- **Measure indicators of the model's success**

Although the utilization of the Change Guide can assist in determining appropriate palliative care measures, the Tri-Facilities should establish indicators that they feel are valuable and actionable regardless of whether the Change Guide is utilized. Some measures, such as place of death, may already be recorded, but not formally reported as a community palliative care indicator. The Measuring What Matters project in the U.S. established a recommended list of ten quality indicators relating to multiple aspects of palliative care (Dy et al., 2015a). Quality assessment frameworks specific to palliative care models in rural settings have also been developed (Pesut et al., 2013).

Relevant data for the Tri-Facilities palliative care model may exist at the provincial level and should be accessed for further understanding. Because each of the communities operates rather independently, there is value in measuring indicators at the community and also the provincial level, so that unique differences can be determined. The data could then be aggregated to track progress of the broader palliative care model present in the Tri-Facilities. Defining the population of interest, measuring quality data from different sources, and advancing the development of patient and family reported indicators are potential challenges that should be considered when adopting palliative care measures (Dy et al., 2015b).

Project Limitations

There are important limitations to this project that must be acknowledged. Firstly, while the Change Guide was designed to be used at the grass-roots by the community, this initiative was not lead by the Tri-Facilities or a community facilitator. I also do not have palliative care expertise nor experience using the Change Guide. The project was completed as a semester long Directed Project coursework within Dalhousie's Master of Health Administration program. Time available was also a constraint on the work that could be accomplished.

A total of 11 interviews were completed that spanned all three communities in the Tri-Facilities; however, the number and breadth of interviews remain a project limitation. There are important roles that were not interviewed and perspectives that are not represented, such as healthcare providers at the Birches nursing home, personal care workers, the social worker, the occupational therapist, and palliative patients and families. The information gathered from the interviews was also generalized for the Tri-Facilities area, which masks important differences among the three communities. Further limitations relating to the interview process are noted in Appendix A.

This project was also limited to the scope of the Change Guide, which determined the approach, interview questions, and lens for analysis.

Information from the interviews that did not relate the Change Guide were not incorporated into the project, except as background and contextual information. Tools 3 and 5 of the Change Guide were not utilized due to time constraints, which further limits this project. In addition, for the purposes of this project the Change Guide was adapted to primarily be an assessment tool to understand the current state. The original Change Guide tools include questions that are very action-oriented and focused on identifying tangible methods for improvement.

Some of these limitations may have been mitigated in part by the following. The Change Guide is a clear, logical and easy to use framework. In addition, it is Canadian and evidence-based. I am also grateful for the Change Guide's creator, Dr. Hsien Seow's, support throughout the project. The knowledge of my supervisor, Dr. Grace Johnston, who has over 20 years of experience researching palliative care in Nova Scotia is another asset of this project. She attended each of the interviews with me and assisted in guiding this work.

Critique of Change Guide

Tool 1 of the Change Guide (7 Quality Commitments) was highly applicable in this project and required no changes in wording for a Nova Scotian context.

Tool 2 of the Change Guide (Community Palliative Care Assets) required adaptations to include/exclude province-specific language and initiatives. As hospices become available in Nova Scotia, they should be incorporated into Tool 2. Cancer patient navigators are a resource available in Nova Scotia beyond the Central Zone and therefore should also be included in Tool 2. These navigators provide support, education, and navigational assistance to cancer patients and their families (Cancer Care Nova Scotia, 2015). Throughout the interviews, there were discussions about the availability and applicability of different technologies to palliative care. Hence, it is recommended that Tool 2 include technology as a category of community assets. The inclusion of "Other" options at the end of this and other tools in the Change Guide would allow respondents to identify unique assets/quality commitments that are important to their community, but not formally reflected in the tools. Due to continuous

changes in healthcare structures, policies, and processes, the Change Guide will need to be consistently updated to reflect the current environment.

The purpose of the Change Guide is to inform community-based palliative care models. However, if the tool is to be applied in rural communities then the focus may need to be broader and more encompassing. Healthcare providers from hospitals and long-term care facilities were included in the interviews for this project, as they are important components of the communities' palliative care model. In addition, they have close relationships with the family physicians and palliative care nurse who provides care across settings. There were no major difficulties associated with using the Change Guide more broadly. However, future applications in rural settings should consider any needed adaptations.

The Change Guide was very valuable as a framework for in-person interviews. Asking the interviewees to complete the tool and send their responses to an external coordinator would have decreased the depth of responses, prevented the ability to ask clarifying questions, and would have further undermined the intended use of the Change Guide as a grass-roots team building and empowerment tool. Beginning each of the interviews with questions about the community's history was also useful in establishing rapport, context and scope.

Conclusion

The Tri-Facilities is a predominantly rural area in Nova Scotia that has experienced recent change to their palliative care model. Direct engagement with palliative care providers in the each of the communities has identified many community strengths, which could form the foundation of future efforts to develop the palliative model. Family physicians are highly involved in caring for those at the end of life. A local full-time palliative care nurse and social worker are other valuable community assets. The healthcare providers in the community have a strong commitment to overcoming barriers, viewing patients as a whole person, and providing guidance to patients and families. The close proximity of different palliative care settings along with many long-standing positive working relationships are conducive to teamwork and interdisciplinary care.

There is no such thing as a perfect palliative care model, and communities should develop approaches that are unique to their context and strengths. The application of the Change Guide in this project has assisted in determining the Tri-Facilities' current stage of development and potential next steps for continued progress. Although the Change Guide is a resource that was developed in Ontario, its application in this project has indicated that with minor adaptations it can be very useful in a Nova Scotian context.

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APPENDIX A
DESCRIPTION OF PALLIATIVE CARE IN THE TRI-FACILITIES AREA

Caroline McNamee
DALHOUSIE UNIVERSITY November 10, 2015

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Executive Summary

This report is as a description of palliative care in the Tri-Facilities area based on interviews with community members involved in providing palliative care and strategic informants. The interviews used Hsien Seow's Change Guide as a framework.

Tri-Facilities is located northeast of Halifax and is comprised of 3 predominantly rural communities: Musquodoboit Valley, Musquodoboit Harbour, and Sheet Harbour. The Tri-Facilities is part of Central Zone in the Nova Scotia Health Authority, and have accessed a part time palliative physician for a limited time and/or hired a local full-time palliative care nurse. This summer a palliative care nurse was hired to serve the community.

The Tri-Facilities area operates primarily under a family physician consult model, in which primary care physicians are the main decision-makers for care and palliative expertise is consulted as needed. The Central Zone palliative care team provides care to patients from the Tri-Facilities who travel into Halifax or through phone consultations to local family physicians. Palliative patients who reside at home do not have access to comprehensive 24/7 care within their communities, as there is usually no 24/7 family physician coverage and most of the local emergency departments do not admit during the night. Issues regarding communication and coordination among providers were also noted.

Strengths within the community were identified, such as coordinated planning of resources, creative solutions to barriers, provision of guidance and support to patients and families, and a commitment to viewing the patient as a person. Provincial initiatives, such as palliative care paramedics, real-time patient videoconferencing, and the electronic one patient one record system have not yet achieved their potential for improving palliative care in the Tri-Facilities.

Preface

This report is part of a Directed Project coursework for Dalhousie's Master of Health Administration program. Through a residency placement in Toronto this past summer, I had the opportunity to develop an interest in palliative care. As a student in my second year of study, I am excited to continue learning about palliative care through work on this project. My supervisor, Dr. Grace Johnston, guided my work and has spent more than 20 years researching equity in access to palliative care programs in Nova Scotia.

The information included in this report is a reflection of my understanding from readings and interviews. However, I recognize that this situation is complex and that palliative care in the Tri-Facilities has changed over time. In addition, perspectives can vary from person to person. Thus, the information included in this report is an attempt to compile my learnings from the work that I have done and is not a complete documentation of palliative care in the Tri-Facilities area.

Introduction

The Tri-Facilities area in Nova Scotia has been identified as a rural community that may have health service gaps in regards to palliative care. The current provincial palliative care strategic plan, *Integrated Palliative Care: Planning for Action in Nova Scotia*, aims to support access to integrated and quality palliative care in a setting of choice for all Nova Scotians (Government of Nova Scotia, 2014). In order to achieve this vision, the integrated strategy identifies capacity building and system planning based on the needs of respective sites as necessary steps. This report aims to align with the provincial palliative care strategy by documenting the current palliative care model and resources present in the Tri-Facilities area.

The description of the Tri-Facilities' palliative care model in this report is the result of direct engagement with community members involved with the provision of palliative care and strategic informants. A complete list of those who contributed information that aided in the development of this report are included in Appendix A.1. Hsien Seow's Change Guide, based on research into successful palliative care teams in Ontario, serves as a guiding framework for this project (Palliative Care Innovation, 2015). In particular, two tools from the Change Guide were adapted for a Nova Scotian context and used during the interview process (See Appendix A.2). This report will detail what was learned from the interviews, identify important limitations to this work, and discuss the next steps in further analyzing palliative care in the Tri-Facilities through the application of the tools from the Change Guide.

Background & Context

Tri-Facilities is a term that is mainly used internally within the Nova Scotia health system to refer to a group of rural communities located northeast of downtown Halifax. The term primarily refers to three communities that each have a hospital located within the town: Musquodoboit Harbour, Middle Musquodoboit, and Sheet Harbour. However, these hospitals also serve some of the small surrounding communities as well. The three hospitals respectively are Twin Oaks Hospital, Musquodoboit Valley Memorial Hospital, and Eastern Shore Memorial Hospital; each of these hospitals provides palliative care services (Capital District Health Authority, n.d.a). In addition, the three communities that form the Tri-Facilities area have a history of sharing health resources, including those that relate to palliative care.

In April 2015, Nova Scotia centralized the nine district health authorities created in 1997 into one provincial Nova Scotia Health Authority. The NSHA is divided into geographical zones. The Tri-Facilities area is included in the Central Zone with Halifax (Figure 1). To date, the amalgamation of the health authorities changed little in terms of the formal relationship between the Tri-Facilities and the palliative care team based in Halifax.

Prior to the formation of the NSHA, the Central Zone was called Capital Health District Health Authority (CDHA). The palliative care team, based in Halifax, includes: doctors, nurses, social workers, physiotherapists, occupational therapists, music therapists, home care nurses and personal care workers, continuing care coordinators, and volunteers (Capital District Health Authority, n.d.b.). The team provides care, home assessments, and support.

Due to the distance of the Tri-Facilities from Halifax (some parts of the area are 2 hours away by car), the Central Zone palliative care team does not normally provide home consultations in the Tri-Facilities area. The timeline in Appendix A.3 shows that from time to time the Tri-Facilities have had a part time dedicated palliative physician and/or full-time nurse. Currently, the Halifax-based palliative team provides consultations by phone to family physicians in the Tri-Facilities area and provides care to palliative patients from Tri-Facilities who travel into Halifax. The Tri-Facilities have a history of advocating for more support and access to resources regarding palliative care, especially physician services.

The current palliative care nurse was hired in the summer of 2015 and is from the Middle Musquodoboit area. She reports directly to the administrator of Twin Oaks hospital, is not formally connected to the Central Zone palliative care team, and does not directly consult the palliative care physicians located in Halifax.

Increased distance from a palliative care program has been associated with a higher likelihood for hospitalization, which ultimately impacts the patient's ability to choose the setting in which they would like to receive care (Lavergne et al., 2015). Local champions and concerned community members are often important agents of change that have made lasting impacts on palliative care in Canada (Williams et al., 2010).

Findings

The findings discussed below include the predominant answers and major learnings from the NSHA interviews that have been completed to date (Appendix A.1) using the guide in Appendix A.2. Tool 1 asked for the interviewees to rate a series of quality commitments for palliative care in the Tri-Facilities area using a 5-point Likert scale from strongly agree to strongly disagree. Tool 2 asked for the interviewees to describe particular community assets that relate to palliative care.

Tool 1: Quality Commitments to Patients and Families

1. We provide dedicated expertise 24/7 so you never feel alone

The predominant answer to this quality commitment was disagree. This commitment was interpreted in different ways. For example, 24/7 care is technically available to patients in the Tri-Facilities area through telehealth (811) and emergency access to the closest available acute care hospital; however, this does not always equate to palliative care that is available within the community boundaries. Palliative patients who are in hospitals or long-term care facilities within the community have access to 24/7 care. The local family physicians, homecare services, and the palliative care nurse are not able to provide 24/7 coverage to palliative care patients who reside at home. Although the palliative care team based in Halifax is not available to provide direct expertise in the Tri-Facilities area, they are available 24/7 by phone for consultations.

2. We communicate and connect as providers so that you don't have to repeat your story numerous times

The predominant answer to this quality commitment was strongly disagree. Of all of the quality commitments, this commitment was ranked most poorly by the majority of interviewees. Multiple reasons were identified as potential factors that increased the likelihood for patients to repeat their stories. It appears that there may be a culture in healthcare in which each clinician views it as a requirement to obtain their own history of the patient. In addition, patients may want to tell their story to clinicians. Beyond the patient level, as there is no one palliative physician dedicated to the Tri-Facilities area, family physicians may need to repeat information each time a different Halifax-based palliative physician is consulted. Interdisciplinary rounds and the close physical proximity of the hospital, LTC facility, and family physician offices are factors that positively impact communication and collaboration between healthcare providers in the Tri-Facilities. The palliative care and homecare nurses were also identified as having positive communication roles.

3. We respond in a timely and effective manner so you experience minimal discomfort and stress

The predominant answer to this quality commitment was agree. However, the potential for some gaps were noted.

4. ***We attend, proactively, to the wellness of your mind, body and soul so all forms of suffering can be alleviated***

The predominant answer to this quality commitment was agree. The impression was conveyed that there may be potential for more comprehensive proactive support, but that healthcare providers are committed to finding a solution for palliative patients.

5. ***We provide education and guidance so you can prepare for what lies ahead***

The predominant answer to this quality commitment was strongly agree. This quality commitment had the highest ranking from most respondents and the ability to prepare palliative patients and families was identified as a community strength. It was also indicated that the palliative care nurse plays a large role in achieving this quality commitment by spending time talking with the patients and families.

6. ***We support you to resolve personal affairs and realize goals so you can feel fulfilled, and at peace***

The predominant answer to this quality commitment was agree. It was indicated the social worker plays a large role in achieving this quality commitment.

7. ***We serve as advocates so you can achieve the type of care, and death, desired***

The predominant answer to this quality commitment was agree. It was indicated that this indicator could be further improved by removing some of the resistance and barriers to sharing expertise. There is a high level of accountability in rural healthcare because of the strong community bonds and lack of anonymity.

Tool 2: Community Palliative Care Assets & Description of the Model of Care

- **Physician Involvement**

The physician involvement in the Tri-Facilities was primarily described as a consult model. In this model, the primary care physician has the majority of the responsibility for care decision-making. A palliative specialist is consulted for specific expertise. In the Tri-Facilities, the palliative specialist that is consulted by the family physician and provides recommendations is the palliative care nurse based in the community and/or the palliative care physicians that are based in Halifax. Generally, primary care physicians in the Tri-Facilities have experience with providing palliative care, and seek a consultation with a palliative specialist for complex cases.

- **24/7 Physician Availability**

There was not a general consensus by the interviewees in terms of the description of this asset. This is likely due to different interpretations, similar to that for Quality Commitment

1. Physicians are available 24/7 to palliative care patients that are in either a hospital or long-term care facility in the Tri-Facilities area. However, palliative care patients who are residing at home do not have 24/7 access to a physician, unless they travel to an emergency department, as the local family physicians do not have 24/7 coverage.

The hospitals located in Middle Musquodoboit and Musquodoboit Harbour each operate a collaborative emergency centre (CEC) staffed by a nurse and paramedic. The CEC at Musquodoboit Valley Memorial Hospital is closed from 8pm to 8am, but is open 24/7 at Twin Oaks. Thus, if a palliative patient calls 911 during the night, they will likely be transported out of the Tri-Facilities area and to the nearest hospital with an open emergency department that can admit patients:: in Truro for Musquodoboit Valley and in Dartmouth for Twin Oaks patients. Due to the distance to other centres, Sheet Harbour operates a 24/7 emergency department. In this sense, physicians are available 24/7 through the use of emergency services, but they are not necessarily accessible within the patient's community. The palliative care physicians based in Halifax are available 24/7 for consultations via the phone, but not for direct visits with patients in their homes.

- **Clear Focus**

The main term that was used to describe this asset was somewhat clear. Healthcare providers have a clear focus in terms of wanting to pursue what is best for the patient. However, there could be more clarity regarding the coordination of palliative care services between different providers.

- **Funding**

There were multiple terms that were used to describe the funding of the palliative care services present in the Tri-Facilities area. The Nova Scotia Health Authority and Department of Health and Wellness fund the palliative nurse position, as well as palliative medication. There is also funding through the hospitals due to dedicated palliative care beds and services provided. In addition, palliative patients receive care through home care services and in long-term care facilities. Unlike other areas in NSHA where VON provides homecare nursing, at each of the hospitals in the Tri-Facilities, the home care nurses are employed through the hospital. Personal care workers providing home care are contracted through Northwood and We Care. Lastly, there has been community fundraising for palliative care services for individual patients and through local charitable agencies.

- **Home Base for Team**

There was not one single term that was used to describe the home base of the palliative care team in the Tri-Facilities area. Palliative patients can receive care from multiple providers and in multiple settings. Thus, there can be multiple home bases, including hospital, home care, and long-term care facilities. The palliative team that is providing services to the patient is not static and will likely change depending on the patient's setting.

The palliative care nurse is an exception to this as she travels to see all palliative patients in the Tri-Facilities that are referred to her regardless of their setting. The palliative nurse has a main office at Twin Oaks Hospital, so this could be considered her primary home base.

At Musquodoboit Valley Memorial Hospital, the hospital, long-term care facility, and a primary physician office are located within the same building. At Eastern Shore, the hospital and long term care care facilities are adjacent. In both Musquodoboit Valley and Eastern Shore, the long term care facilities report to the same management as the hospital. Thus, there is a centralized home base for many of the palliative care services that patients will receive regardless of which "team" is providing that care.

Twin Oaks Hospital and the adjacent long-term care facility do not report to the same management. Birchview Nursing Home reports instead to a continuing care manager. This fall, a primary care clinic has been relocated to be within the Twin Oaks Hospital.

There is a virtual component to the communication amongst palliative care providers, especially due to the distance consultations with the palliative care resources in Halifax. Also, providers of palliative care in the community enable communication across care settings through interdisciplinary patient rounds, phone, and in-person contact. However, internet-based electronic communications are not typically used.

- **Palliative Support**

Psycho-social services and spiritual/religious support were the two main palliative support resources that were identified in the interviews. The three communities share one social worker, and 2 occupational therapists who also provide some palliative support. Bereavement services can be accessed in Halifax. In some cases, volunteers played a large role in providing palliative support through education, bereavement, and community fundraising. However, this was not prevalent throughout the Tri-Facilities and the dominant finding was that volunteers are not a large source of palliative support.

- **Geography**

Interviewees were asked to describe the geography and service area of the Tri-Facilities in their own words. It was primarily described as a rural community that is centered around the location of 3 hospitals. However, Twin Oaks Hospital has a catchment area that is a blend of both rural and suburban due to being on the cusp of a growing development in Porter's Lake and Lake Echo. The Tri-Facilities area follows county lines and comprises Halifax County East (Figure 2). The three communities cover a relatively wide geographic spread and border different urban centres. Musquodoboit Harbour is located relatively close to Halifax/Dartmouth while Middle Musquodoboit is located closer to Truro. Sheet Harbour is furthest from all other centres and is approximately equidistant to Halifax/Dartmouth, Antigonish, Pictou, and Truro.

Nurse Role

Each of the following nurse roles were identified as being available in the Tri-Facilities community: nurse practitioner, continuing care assessment, homecare nurse, palliative care nurse, and hospital nurse. The nurse practitioner's ability to prescribe medication was noted as an asset some, but not all interviewers. Nurse practitioners mainly provide other primary care, not palliative care.

- **24/7 Nursing Availability**

Most interviewees indicated that nurses were somewhat available 24/7. Nurses are available 24/7 in either a hospital or long-term care facility, but are not available 24/7 for palliative patients who reside at home unless they were to be transported to a hospital. The hospital are developing standing order policies to enable after-hours hospital admissions for palliative patients.

- **Palliative Paramedic Availability**

All of the interviewees indicated that the palliative paramedic was a service that was not utilized in the Tri-Facilities area. The palliative paramedic is a relatively new service in Nova Scotia that allows for palliative care patients to call 911 and receive symptom and pain management at home from paramedics trained in providing palliative care (Muise, 2015; Government of Nova Scotia, 2015b). The service was intended to be available to patients across the province in late June regardless of their geographic location, but interviewees were not aware of this program's utilization in the Tri-Facilities. Before being able to access the service, healthcare providers must identify "special patients" in the community and register them with Emergency Health Services (Government of Nova Scotia, 2015b). Due to the large coverage area of paramedics serving the Tri-Facilities, there is some doubt about the application of palliative paramedics in rural communities, especially because providing emergency palliative care in the home may require a significant amount of time spent. Although in theory this service could be valuable in the Tri-Facilities, there would need to be appropriate protocols established to allow for quick access to care for both palliative patients and other emergencies. A number of those interviewed mentioned a current lack of timely paramedic responses for urgent conditions due to relocating their local paramedics to provide coverage elsewhere. Given this lack of confidence in timely access to paramedic support, there was a reluctance to incorporate the new palliative paramedic for 24/7 support.

Limitations

There are multiple limitations to this work that are important to acknowledge. Firstly, the description of palliative care in the Tri-Facilities that is included in this report is an interpretation of the information that was gathered through interviews. Although best efforts were made to accurately compile the information from the interviews, this report

represents a best attempt at understanding and may contain errors due to misinterpretations. In addition, none of the interviews were recorded, which may have increased the likelihood for information to be lost.

Another important limitation to this work is the number of people who were interviewed. Nine NSHA contacts were interviewed who have direct experience with the palliative care services in the community, and two Department of Health and Wellness contacts were interviewed as strategic informants. The small number of people who were interviewed significantly limits the amount and breadth of information that was able to be collected. In addition, the type of people who were interviewed may also represent a bias in the reported findings. For example, only one family physician was interviewed. Personnel from the long-term care facility in Musquodoboit Harbour were not interviewed. Palliative patients and families are another important group who are not represented in this report.

This report is also limited by the generalization of interview responses. By focusing on the predominant interview answers, there may be important insights that are not reported due to other interviewees not sharing the same opinion. Generalizing the findings for the Tri-Facilities area as a whole does not allow for an in-depth understanding of palliative care in each of the individual communities, which masks important differences between them.

Lastly, this work is limited to the conceptual framework outlined in Hsien Seow's Change Guide. The adapted tools from the Change Guide determined the interview questions that were asked and the findings that were reported. Additional information that was learned through the interviews is not included in this report other than to provide background and contextual information.

Next Steps

Since this report may contain inaccuracies, an important step was to share it with those who were interviewed for feedback and factual corrections.
Learnings from this project will be shared in a presentation on December 4th, 2015. The presentation will take place at Cancer Care Nova Scotia-=, Room 544 at 12:00pm. Distance connection to the presentation is planned, so that those who cannot be physically present can still attend. Those invited to attend the presentation include the academic supervisor, all who contributed to the project, and selected guests. The presentation will include a description of the model of palliative care present in the Tri-Facilities area, a discussion of community strengths and recommendations based on the Change Guide framework, and a critique of the Change Guide's applicability in a Nova Scotian context. The purposes of the presentation are to 1) update all interviewees and interested parties on my findings from the project, and 2) provide further opportunity for discussion and input.

There will be a final paper that will include an analysis of palliative care in the Tri-Facilities area guided by Hsien Seow's Change Guide and the application of Tool 4

(Palliative Care Innovation, 2015). This tool builds upon the information gathered regarding palliative care in the Tri-Facilities to identify the community's stage of progression towards a robust palliative care model. A palliative care model that is fluid, integrated, and adaptable will likely be more successful in responding to the varied needs of different palliative patients (Lunney et al., 2003). The final paper will also include further depth in literature cited and critique the use of the Change Guide framework in a Nova Scotian context. This final paper will be available January.

Conclusion

The Tri-Facilities refers to a rural area northeast of Halifax that is primarily comprised of 3 distinct communities that have had a history of collaboration and sharing resources. Although the Tri-Facilities is part of Central Zone, they have been unable to receive ongoing direct services from the Central Zone palliative care specialists because of their rural location. Currently, the 3 communities in the Tri-Facilities share a recently appointed palliative care nurse who travels to palliative patients in any setting. In order to receive palliative care physician expertise from the team based in Halifax, family physicians in the Tri-Facilities area must consult with them via distance connection.

Palliative care in the Tri-Facilities area operates primarily under a consult model in which the primary care physician remains as the main decision-maker for a patient's care and a palliative specialist provides specific expertise or recommendations. The 24/7 availability of both nurses and physicians in the community is not an issue for patients in a hospital or long-term care facility, but can be problematic for palliative patients who reside at home. Collaborative emergency centres located in two of the communities provide some after-hours care, but may not be able to admit patients into the local hospital during the night.

Some palliative care assets that are available in the community include home bases for different palliative care providers, a dedicated palliative care nurse role, and social work and other support. Assets that could be improved upon are the establishment of a clear focus, coordinated efforts, and an understanding of the different roles and resources involved with palliative care in the community. Connection to the palliative paramedic program might represent a very useful asset for this predominantly rural community. However, appropriate protocols and confidence in timely access will need to be established to ensure its success in a rural area.

Technology and virtual connection may represent an underused resource in the area. Virtual consultation for patients is accessible across NSHA, but appears to be rarely used to date for palliative patients. Also, the Nova Scotia Electronic Health Record (SHARE) and the One Patient One Record Initiative are examples of provincial efforts to increase efficiency and access to information across the health system (Government of Nova Scotia, 2015c; M. Russell, personal communication, October 8, 2015). Work is currently underway to design a process to scale up wider implementation, so that across the province patients and healthcare providers can access one electronic health record per patient (M. Russell, personal communication, October 8, 2015). However, fee-for-

service reimbursement appears to be delaying expansion (Stuart Cameron, CBC Radio Morning Interview, November 16, 2015). These future developments could have a positive impact on the palliative care in the Tri-Facilities.

In regards to the pursuit of high quality, the Tri-Facilities area has many strengths within the community, such as the guidance, support, and compassion that are provided to patients. There is also a sense that patients are viewed as a whole person within the community instead of being characterized solely by their condition and symptoms. Areas in which there could be improvement primarily relate to access, communication and coordination amongst care providers.

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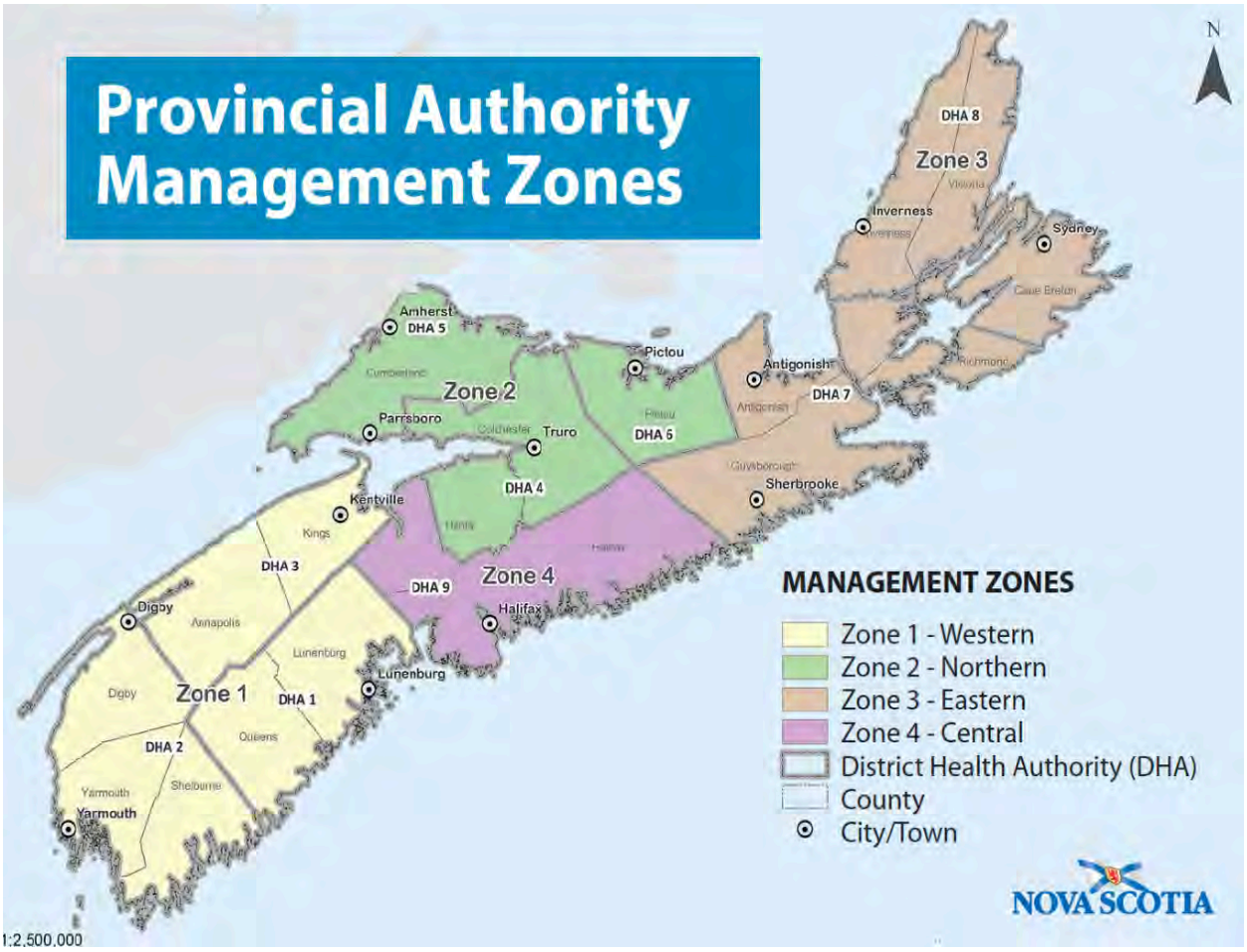


Figure 1: Map of zones within Nova Scotia Health Authority (Government of Nova Scotia, 2015a). Tri-Facilities is located within Central Zone, which is indicated as Zone 4 in purple.

Figure 2: Map of Tri-Facilities area (Basemap: Google Maps, 2015).
Halifax County is indicated in this map by the red borders. Adaptations were made to the basemap to indicate the location of the three hospitals in the Tri-Facilities by placing blue circles over each of the communities. Based on information collected in the interviews, the black dashed line was added to the map to represent an estimate of the western boundary of the Tri-Facilities' catchment area. Areas within Halifax County that lie east of the black dashed line are considered to be part of the Tri-Facilities area.

Appendix A.1: List of Interviewees

Name	Title	Date Interviewed
Dr. Jeff Dempster	Central Zone palliative care physician	September 17th
Diana Graham	Health Services Manager at Musquodoboit Valley Memorial Hospital	September 11th
Helena Cole	Clinical Supervisor at Musquodoboit Valley Memorial Hospital	September 11th
Wanda Hubley	Clinical Lead, Home Care Nursing at Musquodoboit Valley Memorial Hospital	September 11th
Marilyn Cipak	Health Services Manager at Twin Oaks Hospital	September 24th
Martina Cejpova	Palliative Care Nurse for Tri-Facilities	September 24th
Cheryl Tschupruk	Provincial Palliative Care Coordinator	October 8th
Mary Russell	Project Director at Department of Health and Wellness	October 8th
Sandra Hatch	Quality Care Coordinator at Eastern Shore Memorial Hospital & Harbourview Lodge	October 22nd
Cathy Logan	Clinical Supervisor at Eastern Shore Memorial Hospital & Harbourview Lodge	October 22nd
Dr. Lisa Bonang	Family physician at Twin Oaks Hospital	November 6th

Appendix A.2: Adapted Change Guide Tools

Tool 1: Quality Commitments to Patients and Families

Use the scale below to describe the quality commitments for palliative care in the Tri-Facilities community

Quality Commitments	Scale					Comments
1. We provide dedicated expertise 24/7 so you never feel alone	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
2. We communicate and connect as providers so that you don't have to repeat your story numerous times	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
3. We respond in a timely and effective manner so you experience minimal discomfort and stress	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
4. We attend, proactively, to the wellness of your mind, body and soul so all forms of suffering can be alleviated	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
5. We provide education and guidance so you can prepare for what lies ahead	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
6. We support you to resolve personal affairs and realize goals so you can feel fulfilled, and at peace	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
7. We serve as advocates so you can achieve the type of care, and death, desired	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
8. Other						

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide*. Pages 3-4. Hamilton, ON. Accessed from: http://www.palliativecareinnovation.com/workbook/The%20Workbook%20-%20PCI - Minor edits were made for clarity in this project

Tool 2: Models of care

What words most accurately describe each of these palliative care assets in your Tri-Facilities community?

Asset	Description				
Physician Involvement[1]	Consult		Shared	Substitution	
24/7 Physician Availability	Not available	Rarely Available	Available every once in awhile	Somewhat Available	Available 24/7
Clear Focus	Not at all clear	Not very clear	Neutral	Somewhat clear	Very clear
Funding	Community fundraising	Hospital	Home Care	Long-term Care Facility	Other[2]
Home Base for Team	Hospital	Virtual	Home Care	Long-term Care Facility	Other[2]
Palliative Support	Bereavement services	Psycho-social services	Spiritual/ religious support	Volunteers	Other[2]
Geography	Please comment[2]:				
Nurse Role	Nurse Practitioner	Continuing Care Assessment	Homecare nurse	Palliative Care nurse	Other[2]
24/7 Nursing Availability	Not available	Rarely Available	Available every once in awhile	Somewhat Available	Available 24/7
Palliative paramedic	Not available	Rarely Available	Available every once in awhile	Somewhat Available	Available 24/7

1. The next page provides a description of these models.
2. As needed, please explain your answers above

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook*. Pages 5-6. Hamilton, ON. Accessed from: http://www.palliativecareinnovation.com/workbook/The%20Workbook%20-%20PCI/. Edits were made to adapt for the Nova Scotia context.

Primary Care (Family) Physician model

1. **Consultation:** The family physician has full responsibility for care-related decision making. The palliative care specialist[1] focuses on one, or only some, problems, makes recommendations, may make some repeat visits, may write some prescriptions – until the situation is stabilized; at which time the palliative care specialist is no longer involved in the patient's care.

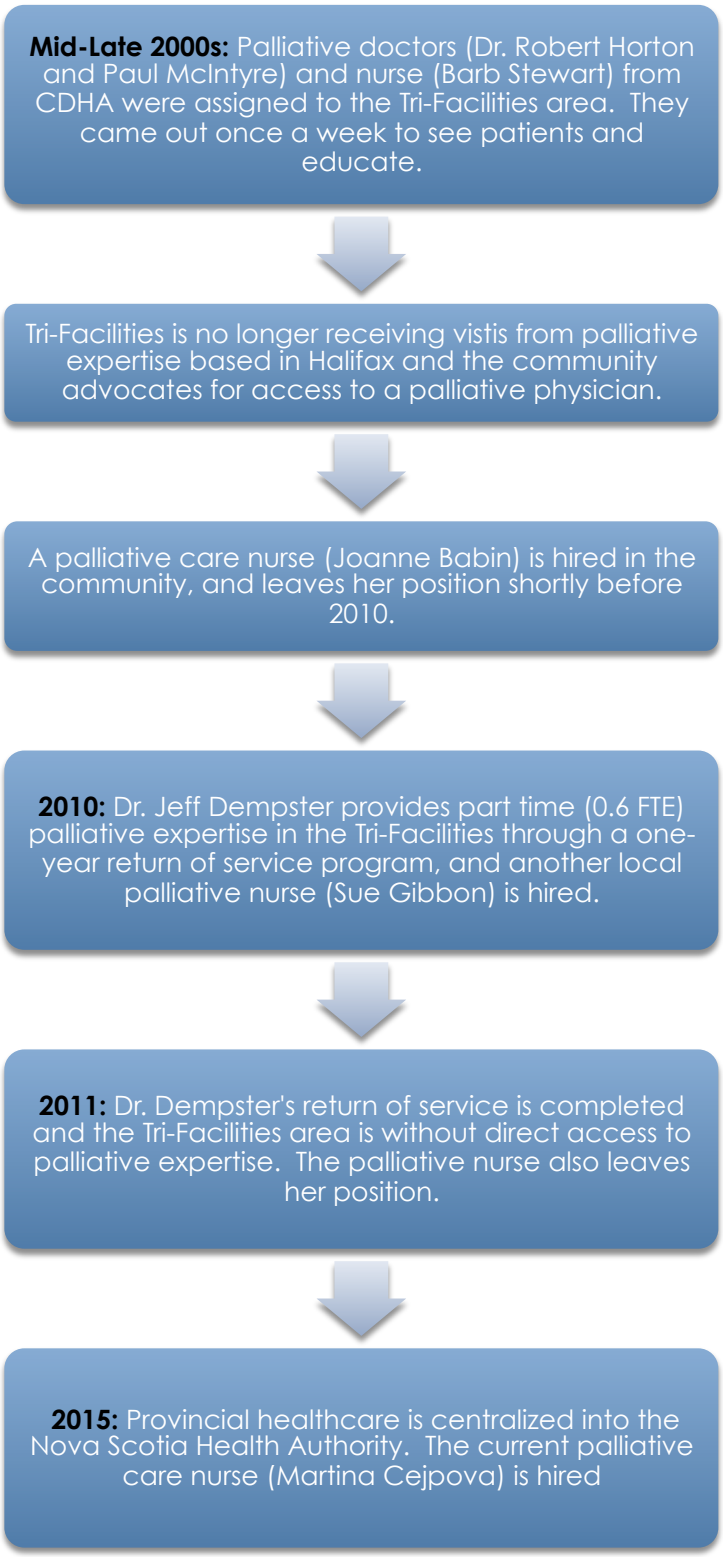
2. **Shared Care:** Decision-making responsibility is shared between the family physician and the palliative care specialist. The specialist focuses on all palliative care needs and continues prescribing related prescriptions on an as-needed basis. The specialist also continues to make regular patients visits- possibly with the family physician.

3. **Substitution:** The family physician becomes peripheral and is no longer involved in the patient's care. The palliative care specialist has full decision-making responsibility and takes on all aspects of care- not just palliative issues. The specialist is also responsible for all follow-up orders, prescriptions and regular, ongoing patient visits.

1. The palliative care specialist can be either a nurse or a physician.

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide*. Page 28. Hamilton, ON. Accessed from: http://www.palliativecareinnovation.com/change-guide/Change%20Guide%20-%20PCI/. Minor edits were made for clarity in this project.

Appendix A.3: History of Specialized Palliative Care Consultation in the Tri-Facilities



APPENDIX B

Palliative Care in the Tri-Facilities

Caroline McNamee
Master of Health Administration, Dalhousie University
December 4, 2015

Introduction and Approach

- MHA student at Dalhousie University
- Interest in learning more about palliative care
- Engaged with community members and those with knowledge about palliative care in Tri-Facilities

Goals:

1) To learn about current palliative care model in Tri-Facilities,
2) To assess feasibility of using Change Guide in Nova Scotia

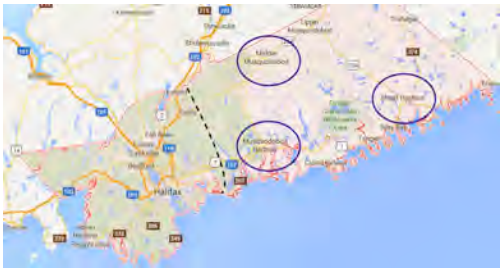
- Represents my understanding of current state

Change Guide and Workbook

- Developed by Dr. Hsien Seow and based on research in Ontario
- How do you build a successful palliative care model in the community?
- Provides tools for reflection, formulating strategies, and identifying strengths and challenges
- Re-inventing the wheel is unnecessary

PALLIATIVE CARE INNOVATION

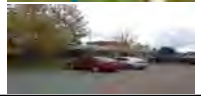
Where is Tri-Facilities?



Context

- History of physician/nurse palliative services
- HANS Reports
- Provincial Integrated Palliative Care Strategy
- District Health Authority amalgamation
- Recent appointment of palliative nurse





Tool 1: Quality Commitments to Patients and Families

Quality Commitments	What are we doing now?	What are the challenges?	What else can we do?
1. We provide dedicated expertise 24/7 so you never feel alone			
2. We communicate and connect as providers so that you don't have to repeat your story numerous times			
3. We respond in a timely and effective manner so you experience minimal discomfort and stress			
4. We attend, proactively, to the wellness of your mind, body and soul so all forms of suffering can be alleviated			
5. We provide education and guidance so you can prepare for what lies ahead			
6. We support you to resolve personal affairs and realize goals so you can feel fulfilled, and at peace			
7. We serve as advocates so you can achieve the type of care, and death, desired			

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 3-4. Hamilton, ON. Minor edits were made in this project.

Tool 1: Quality Commitments to Patients and Families

Use scale below to describe quality commitments for palliative care in Tri-Facilities community

Quality Commitments	Scale				
1. We provide dedicated expertise 24/7 so you never feel alone	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2. We communicate and connect as providers so that you don't have to repeat your story numerous times	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
3. We respond in a timely and effective manner so you experience minimal discomfort and stress	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4. We attend, proactively, to the wellness of your mind, body and soul so all forms of suffering can be alleviated	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
5. We provide education and guidance so you can prepare for what lies ahead	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
6. We support you to resolve personal affairs and realize goals so you can feel fulfilled, and at peace	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
7. We serve as advocates so you can achieve the type of care, and death, desired	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8. Other					

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 3-4. Hamilton, ON. Minor edits were made for clarity in this project.

2015-12-04 Caroline McNamee - Palliative Care in Tri-Facilities

Tool 2: Community Palliative Care Assets

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Page 5. Hamilton, ON.

2015-12-04 Caroline McNamee - Palliative Care in Tri-Facilities

Tool 2: Community Palliative Care Assets

What words most accurately describe each of these palliative care assets in your Tri-Facilities community?

Asset	Description				
Nurse Role	Nurse practitioner	Continuing care assessment	Homecare nurse	Palliative care nurse	Other
24/7 Nursing Availability	Not available	Rarely available	Available every once in awhile	Somewhat available	Available 24/7
24/7 Physician Availability	Not available	Rarely available	Available every once in awhile	Somewhat available	Available 24/7
Physician Involvement	Consult		Shared		Substitution
Clear Focus	Not at all clear	Not very clear	Neutral	Somewhat clear	Very clear
Funding	Community fundraising	Hospital	Home care	Long-term care facility	Other
Home Base for Team	Hospital	Virtual	Home care	Long-term care facility	Other
Palliative Support	Bereavement services	Psycho-social services	Spiritual/religious support	Volunteers	Other
Geography	Please comment:				
Palliative Paramedic	Not available	Rarely Available	Available every once in awhile	Somewhat Available	Available 24/7

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Page 6. Hamilton, ON. Minor edits were made for clarity in this project.

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Key Learnings

- Tri-Facilities share palliative resources, but each community operates independently
- Family physicians have an important role in community palliative care model
- There is a commitment to preparing patients, providing guidance, and helping them achieve their personal goals
- Palliative nurse plays an important role in providing information, navigation, support, and connection to resources for patients and families
- 24/7 care is not available for palliative patients at home
- Communication and coordination between providers could be improved

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Tool 3: Factors Make Team a Success

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Page 8. Hamilton, ON.

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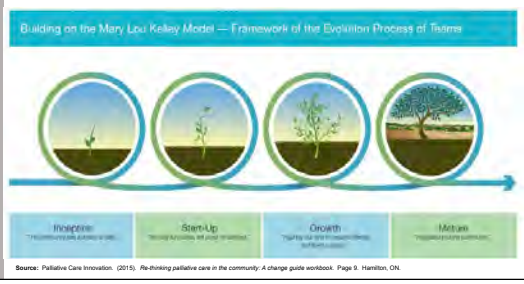
Tool 4: Evolution of Teams



Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Page 9. Hamilton, ON.

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Tool 4: Stage of Development

Stage of Evolution	What's Happening	Assessment Using Information Collected
Inception	Local champion has a vision for improving palliative care. Begins building necessary infrastructure, resources, and relationships through grassroots efforts.	Palliative care in Tri-Facilities has been operational for many years. Beyond inception stage.
Start-Up	Founding members begin to build team and ways of collaborating. They define and market services offered to patients and providers.	History of different levels of access to palliative doctor. Recent addition of a palliative nurse. Tri-Facilities is in process of developing new ways to collaborate and provide care.
Growth	Stable core team with established relationships works to expand reach.	Tri-Facilities recently added a core team member and change in model of care delivery. Thus, not yet at the growth stage.
Mature	Team is trusted and valued. Seen as hub for knowledge-sharing and expertise.	Palliative care expertise is accessed through Halifax-based team. Tri-Facilities is not yet at mature stage.

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 10-11. Hamilton, ON. Minor edits were made in this project.

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Tool 4: Key Opportunities

Stage of Evolution	Key Opportunities	Assessment Using Information Collected
Inception	• Build local intelligence for better understanding of needs, gaps, assets and what will work • Create foundational relationships for a strong core team	• Palliative nurse is in process of building relationships • No specific palliative physician from Central Zone team dedicated to Tri-Facilities area
Start-Up	• Develop effective ways of sharing information • Build rapport with community providers • Build understanding in community of team's role and how providers can be supported • Outreach to upstream partners in community, to encourage timely referrals and collaboration	• Some effective ways of information sharing have been established in community • Many long-standing and positive working relationships • New palliative nurse is building relationships in community • Palliative care nurse, social worker, and OT receive referrals from health providers throughout Tri-Facilities

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 10-11. Hamilton, ON. Minor edits were made in this project.

2015-12-01 Caroline McNamee - Palliative Care in Tri-Facilities

Tool 4: Key Challenges

Stage of Evolution	Key Challenges	Assessment Using Information Collected
Inception	• Build team buy-in; can't be top-down • Time and patience to build relationships • Obtain resources or use creative strategies	• Recent change to Tri-Facilities' palliative care team • Using Change Guide might help grassroots
Start-Up	Maintain flexibility as team develops and fills local gaps; Avoid turf wars with local homecare nurses; Manage patient caseload with limited team members; Lack of palliative care trained homecare nurses or physicians; Work towards providing 24/7 care; Get referrals from physicians and hospitals; Secure enough funding to sustain team through start-up	• Homecare nurses are part of palliative care team and work collaboratively • Palliative patients at home are not able to receive 24/7 care in community • Local physicians are knowledgeable and familiar with providing palliative care
Growth	• Manage travel and serving large regions with limited headcount	• Distance, travel, and rural geography are challenges

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 10-11. Hamilton, ON. Minor edits were made in this project.

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Tool 4: Milestones

Stage of Evolution	Milestones	Assessment Using Information Collected
Start-Up	• Assemble core team with essential roles, including nurses and physicians • Practice culture of patient-centred mission and vision during decision-making and problem solving • Establish team processes, such as communication tools and methods • Create open ongoing dialogue on pain points and successes	• Communication and collaboration among palliative care providers could be improved • Clear roles and processes could help coordination • Increased use of technology and other communication among providers may have positive impacts • Important to have open communication both within and between teams

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 10-11. Hamilton, ON. Minor edits were made in this project.

2015-12-01 Caroline McNamee - Palliative Care in Tri-Facilities

Tool 4: Potential Measures

Stage of Evolution	Potential Measures	Assessment Using Information Collected
Start-Up	• Administrative data: caseload, urgent calls, ED visits, referral sources, place of death • Tracking process progress: document patients' end-of-life preferences, advanced care planning, orphaned patients connected with a doctor • Tracking relationship information: perceptions of "team" collaboration, conflict resolution, power equity, communication, role clarity	• Quality coordinator is located at Eastern Shore • Indicators specific to palliative care provision and team functioning are not currently measured • Data may be available from provincial level for Tri-Facilities

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook.* Pages 10-11. Hamilton, ON. Minor edits were made in this project.

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Community Strengths

- Commitment to viewing patient as a whole person
- Strong role of family physicians
- Full-time palliative nurse
- Resourcefulness to overcome barriers
- Proximity of different palliative team "home bases" and shared management
- Social worker is well integrated
- Interdisciplinary rounds
- Often strong, long-standing, positive working relationships

2015-12-01 Caroline McNamee - Palliative Care in Tri-Facilities

An Example of Community Strength

Palliative care garden built by volunteers at Eastern Shore Memorial Hospital in Sheet Harbour

Community Recommendations

- Utilize Change Guide tools
- Map out roles, connections, and processes of all palliative care team members (including Central Zone team)
- Clarify, communicate, and support palliative care nurse role
- Build capacity by ongoing palliative education to local health providers
- Develop strategies to ensure 24/7 access to palliative care at home
- Investigate applicability of palliative paramedic in rural areas
- Optimize technology and other resources to fill gaps
- Measure indicators of model's success

Critique of Change Guide's Application in Nova Scotia

Tool 1

- Highly applicable and required few changes

Tool 2

- Province-specific language needed to be changed and province specific initiatives were included/excluded
- Hospices may need to be included in the future
- Technology should be included as a category for community assets

Overall

- Value of in-person interviews and beginning with questions regarding community's history
- Provide "Other" options at end of each tool so respondents can add unique assets/quality commitments important to their community

Project Limitations and Strengths

Limitations

- Initiative was not lead by community or facilitator
- Expertise in delivery of palliative care and in using the Change Guide was limited
- Time
- Number and breadth of interviews
- Tools 3 and 5 were not utilized
- Scope of Change Guide

Strengths

- Clear, logical framework that is easy to use
- Evidence-based and current
- Canadian
- Support from Hsien Seow
- Knowledge and experience of supervisor

Conclusions

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook*. Page 9. Hamilton, ON.

- No such thing as a perfect palliative care model
- Teamwork, coordination, and communication are key
- Tri-Facilities have many strengths, which can aid in further development of their model
- Change Guide, with minor adaptations, can be useful and applicable in Nova Scotia

Acknowledgments

- All interviewees and contributors to this project
- Dr. Grace Johnston
- Cheryl Tschupruk
- Cancer Care Nova Scotia
- Dr. Hsien Seow
- All of you for listening and contributing today

Questions and Comments

Remember … DON'T WAIT FOR:
1. For system level indicators. The driver of change should be patient needs and quality commitments. …
2. For perfect model. …
3. For perfect tools. Communication and relationships will always be more important.
4. For new resources. Use what you have, differently.
5. For perfect plan … strive to continually improve.
6. For perfect standardized pathway.
7. For the electronic medical record. … Technology will never replace old-fashioned face-to-face or telephone communications
8. For palliative care expert to arrive. We are all responsible for basic palliative care knowledge.
9. For the champion to emerge…. Many champions are needed.
10. For someone else, such as policymakers, to eliminate the barriers ….

Source: Palliative Care Innovation. (2015). *Re-thinking palliative care in the community: A change guide workbook*. Page 15. Hamilton, ON.

Appendix C: December 4th, 2015 Presentation Attendees

Mode of attendance, names, and positions
In Person
Marianne Arab, Manager, Supportive Care, Cancer Care Nova Scotia (CCNS)
Martina Cejpova, Palliative Care Nurse, Tri-Facilities, Central Zone, Nova Scotia Health Authority (NSHA)
Tricia Cochrane, Vice President Integrated Health Services, Primary Health Care and Population Health, NSHA
Michelle Harrison, Project Manager, CPAC Paramedics Providing Palliative Care at Home Project, CCNS
Leslie Hill, Patient Engagement Coordinator, CCNS
Grace Johnston, Professor, School of Health Administration, Dalhousie University, and Epidemiologist, CCNS
Meg McCallum, Manager, Education, CCNS
Paul McIntyre, Head, Palliative Medicine, Central Zone, NSHA
Cynthia Stilwell, Community Occupational Therapy, Central Zone
Cheryl Tschupruk, Palliative Care Coordinator, Nova Scotia Department of Health and Wellness (DHW), and CCNS
Hilary Woodside, Advance Care Planning Project Coordinator, CCNS
Karen Woodworth, Patient Navigator, Head and Neck Cancers, Central Zone, NSHA
Via Distance Technology
Shannon Ryan Carson, Health Care Manager, Primary Care, Tri-Facilities, Central Zone, NSHA
Diana Graham, Health Services Manager, Musquodoboit Valley Memorial Hospital, Central Zone, NSHA
Jill Petrella, Coordinator, Quality and Cancer Site Teams, CCNS
Susan Philpott, Senior Policy Analyst, Primary Health Care, DHW
Hsien Seow, Associate Professor, Department of Oncology, McMaster University, Hamilton, Ontario
Vickie Sullivan, Operations Executive Director - Central Zone, NSHA